

ORIGINAL ARTICLE

Quality of life of people living with HIV/AIDS before and after receiving antiretroviral therapy

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Abstract

Background- HIV/AIDS is a chronic illness. Besides having serious morbidities, opportunistic infections, it also adversely affects quality of life of People Living with HIV/AIDS (QOL- PLHIV). Early and prompt initiation of antiretroviral therapy (ART) might improve quality of life of PLHIV in various domains like psychological, physical, environment level of independence, social relationship and spirituality/religion/personal beliefs. **Material and methods-** The study was conducted at a medical institute of North India. Patients attending ART centre of the institute for the treatment of HIV/AIDS were interviewed on WHOQOL-HIV questionnaire. **Aim and objectives-** To assess and compare quality of life of people living with HIV/AIDS at initiation and after 6 months of receiving antiretroviral therapy. **Result-** QOL-PLHIV was improved in various domains when assessed after six months of receiving ART. For physical domain mean score increased from 12.83 to 13.85, for psychological domain from 12.54 to 14.31, for level of independence from 12.95 to 13.21, for social relationship from 12.46 to 14.15, for environment domain from 11.98 to 13.15 and for spirituality/religion/personal belief mean score increased from 11.41 to 11.96. Respective standard deviation was decreased when compared from before initiation of ART to six months after receiving ART. **Conclusion –** Quality of life of people living with HIV/AIDS was improved significantly after receiving ART.

Keywords

WHOQOL-HIV; Antiretroviral therapy (ART); People living with HIV/ AIDS (PLHIV); Quality of life domains.

Introduction

The acquired immune-deficiency syndrome (AIDS) is a fatal illness caused by human immune-deficiency virus which breaks down the body's immune system and leaves the victim vulnerable to lot of life-threatening opportunistic infections, neurological disorder, or unusual malignancies.(1) Living with HIV/AIDS not only hampers physical health but also mental and social well-being. It is not only the virus that cause disease, but also a social and historical event that impacts how others react towards PLHIV.(2)Unless a cure is found or life prolonging therapy can be made wisely available, majority of people living

with HIV/AIDS will suffer with the diseases, with serious impact on quality of life.(3)

HIV continues to be a major global public health issue, having claimed 36.3 million [27.2–47.8 million] lives so far. There were an estimated 37.7 million [30.2–45.1 million] people living with HIV at the end of 2020. Total of 0.68 million [0.48–1.0 million] people died from HIV-related causes and 1.5 million [1.0–2.0 million] people acquired HIV in year 2020.(4) In India there were estimated 2.34 million [1.79 million – 3.09 million] PLHIV in 2019.(5)

The development of medicines for HIV/AIDS has led to significant increase in the life expectancy and quality of life for people living with HIV/AIDS. The average number

of years a PLHIV lives after treatment started with combination ART is estimated to be 20-35 years.(6) This tends to transform HIV to chronic disease.(7) Chronic traits of a disease increase demand for care, treatment, and support for PLHIV. In order to fulfill demand for care and treatment, family, friends, and the community can be major sources of support.(8)

World Health Organization has defined quality of life that it is an individual's perception what position in life they have in context to their culture and value systems. It is also related to their expectations, their goals in life, their standards as well as concerns.(9) WHO describes quality of life under six domains. These are the psychological, physical, environment, level of independence, social relationship and spirituality/religion/personal beliefs.(10) Various studies have been carried out both globally as well as in India on the quality of life. (11-15) However there are limited studies conducted that compares the quality of life before initiation and after receiving ART for a period of time. Therefore, the present study was planned and conducted to assess QOL-PLHIV and how quality of life of PLHIV is affected by ART besides increase in life expectancy.

Aims & Objectives

To assess and compare quality of life of people living with HIV/AIDS before initiation and six months after receiving antiretroviral therapy.

Material & Methods

The Study was conducted in ART centre of a medical institution in North India. Ethical approval for the study was obtained from Institute ethical committee. The study was conducted for a period of 2 years. One field worker was trained to collect the data. Every new patient, more than 18 years of age, attending ART centre for starting ART was enrolled in study. Patients who have taken ART previously or taking ART at any other centre or those who did not gave their consent to participate in the study were excluded. All the patients enrolled in a year during period of data collection were included in the study.

Patients were informed about study and ensured about their confidentiality in the study. Written informed consent was obtained from all the patients. Hindi version of Quality of Life instrument by World Health Organization (WHOQOL-HIV) was used. (10) Permission to use WHOQOL-HIV was obtained from World Health Organization. All enrolled patients were followed up after 6-7 month of initial interview.

Tool for the study- WHOQOL-HIV was used as data collection tool. Information regarding socio-demographic profile of study subjects such as age, sex, religion, marital status, socioeconomic status, education, occupation was also obtained. The full version of WHOQOL-HIV includes 120 questions related to various aspects of quality of life. It comprises of 6 domains and 29 facet scores. It also includes one general facet score that measures general

health and overall quality of life. Out of all facet scores, five are specific to HIV/AIDS.

A five-point Likert scale was used for each item. In the scale one denotes low and negative perception and high, positive perception is indicated by five. So each domain scores range between 4 and 20. Scores of domains and facet are scaled in a positive direction. This means higher quality of life is denoted by higher scores. Some facets are not scaled in a positive direction. These are negative feelings, pain and discomfort, death and dying, dependence on medication. For these facets higher quality of life is not denoted by higher scores. Recoding of these facets was done (1 as 5, 2 as 4, 3 as 3, 4 as 2 and 5 as 1). After recoding, better quality of life is reflected by higher scores. Contribution of each facet is equal to the domain score. Within the domain, mean of the facet scores were computed. Thus, final domain scores were calculated.

Statistical analysis- The results are presented in frequencies, percentage and mean score of QOL. Student t- test was used for testing of means. Analysis of Variance (ANOVA) was used for testing of variance for more than two groups. Repeated measure of ANOVA was used for pre observation and post observation of the study. p value of less than 0.05 was considered significant with 5% level of significance. All the analysis was carried on Microsoft Excel and R software.

Results

Total 123 HIV/AIDS patients were enrolled in study. In follow up study when patients have completed six months of ART, 23 participants were either transferred out or died or lost to follow up or did not taken drug on the scheduled date. So that total of 100 patients were sustained in the study. The study population had male: female ratio of 75:25 and Hindu: Muslim ratio of 80:20 and this ratio was maintained at initiation and after 6 months of therapy.

In [table 1](#), ANOVA and t-test was used for significance testing. As per marital status, married persons had better quality of life with 12.95 mean score value for physical domain and 12.64 mean score for psychological domain in comparison to unmarried persons with a mean score of 12.73 and 12.42 respectively. In contrast unmarried persons had better quality of life in rest of the domains.

As per educational status, persons with high school and intermediate had better quality of life in physical, level of independence and environmental domains with mean score of quality of life being 13.32, 13.29 and 13.54 respectively in comparison to others. Better quality of life for psychological domain was seen in illiterate persons with mean score of 12.70, for social relationship in graduation and above (mean score 13.02) and for spirituality in persons with education upto upper secondary (mean score 11.70).

As per profession, others (home maker, students) had better quality of life in physical, psychological and level of

independence with mean score of 13.54, 12.87 and 13.39 respectively. For social relationship and environment domain unskilled had better quality of life in comparison to others with mean score of 12.61 and 12.18 respectively. Unemployed persons had best quality of life in comparison to others for spirituality domain with mean score 12.39.

In [table 2](#), married persons had better quality of life in level of independence, social relationship and environment with mean score of 13.24, 14.20 and 13.24 respectively. In contrast unmarried persons had better quality of life in physical and psychological domains with mean score 14.24 and 14.45 respectively. For spirituality widow/divorcee/separated had more score (mean score 12.17) in comparison to others.

As per educational status, illiterate persons have better quality of life in physical and spiritual domain with mean score 14.62 and 12.61 respectively. Graduation and above have better quality of life in psychological, social relationship and environment domain with mean score 14.49, 14.32 and 13.59 respectively. Upper secondary had better quality of life in level of independence with mean score 13.38.

As per profession, clerks/professional have better quality of life in physical and spiritual domain with mean score 13.91 and 12.54. Unemployed persons had better quality of life in psychological and social relationship domain with mean score of 14.51 and 14.39. Skilled /unskilled persons had better quality of life in environment domain with mean score 13.30.

We used repeated measure of ANOVA on QOL score of sociodemographic profile to assess the impact of ART before initiation and after six months of receiving ART. Repeated measure of ANOVA was applied on all six domains of quality of life. After analysis of repeated measure of ANOVA, it was observed that some characteristics have significant changes in quality of life mean score. For gender, quality of life was significantly improved in environment domain after receiving ART as shown by increased mean score. For religion, physical, physiological and environment domain, for caste, physiological and social relationship domains, for marital status physiological domain had significantly improved quality of life as mean scores are increased. For literacy, physiological and spirituality domain and for profession physiological, social relationship and environment domains had significant change in quality of life as shown by increased mean score. For type of family, no significant change was seen in any domain.

Quality of life of HIV/AIDS patients was compared for all six domains. Two-sample independent t-test was used for testing of mean between before starting ART and six months after receiving ART.

[Table 3](#) and [figure 1](#) shows quality of life in all domains was improved after 6 months of Antiretroviral therapy. The improvement was significant for all domains except level

of independence and spirituality/religion/personal beliefs. Psychological domains had highly significant improvement in quality of life followed by improvement in the domain social relationships, environment domain, physical domain and improvement in domain spirituality/religion/personal belief.

Discussion

A study conducted by Motilewa O. et al. (2015)(11) in HIV clinic, South Nigeria on 161 people living with HIV/AIDS showed that health related quality of life of respondent were significantly different at the overall quality of life and in all domains except the spirituality domains. After 4 months in care the pre- HAART respondents had better quality of life in all the domains except the environmental domain, however significant changes were only observed in respect to psychological, social and spirituality domains. Whereas another study on people living with HIV/AIDS in Brazil found that the perception of quality of life for psychological domain (15.32±2.51), and social relationships domain (15.50±2.80) were superior. However, quality of life regarding domains: physical (14.68±3.28), level of independence (13.86±2.87), environment (14.40±2.12) and spirituality (14.09±3.88) was intermediate. (Cunha G. et al. (2015)(12)

One such study carried out in South India by Abraham S. et al. (2014)(13) on 100 PLHIV found that the highest mean quality of life (QOL) score was for physical domain (18.3±3) and lowest score was for social domain (5±2). QOL score for psychological and environment domains were 12.02±2.46 and 15.08±3.22 respectively. This reveals that PLHIV face social consequences more than physical ailments.

In a study carried out by Samson P.E. et al. (2013)(14) on 123 PLHIV in Cross River Nigeria found that overall QOL mean score in three domains (psychological health, social relation and environment) were similar that is 13.3, 13.8, and 13.7 respectively. It was also noted that physical health score was 14.3, highest in all domains.

Charles B. et al. (2012)(15) conducted their study on 400 PLHIV in South India and WHO BREF scale was applied to measure QOL. This study reported poor QOL among 34% participants. QOL markedly affected in social domain (poor QOL 51.2%) as compared to other domains such as physical (42.5%), psychological (40%) and environmental (34%)

In our study, we found highest QOL score in level of independence domain 12.95 ± 2.31 followed by physical domain 12.83 ± 2.57, psychological domain 12.54 ± 1.73, social relationship 12.46 ± 2.11, environment domain 11.98 ± 2.10 and lowest QOL mean score for spirituality/religion/personal belief as 11.41 ± 2.40 before initiation of ART. When assessed after six months of taking ART, the QOL score was highest in psychological domain 14.31±1.33 followed by, social relationship 14.15 ± 1.38, physical 13.85±2.16, level of independence 13.21 ± 1.32,

environment 13.15 ±1.02 and lowest mean score for spirituality/religion/personal belief 11.96 ± 2.06.

Conclusion

Quality of life in different domains had larger variation between different sociodemographic classes. Overall quality of life in each domain improved while reducing variations across different sociodemographic classes after 6-7 months of ART initiation

Recommendation

ART should be initiated in HIV positive patients as early as possible as the current study found that there is improvement in mean score of quality of life across various domains after receiving ART. This also means that the population that is still left out and has not access to HIV treatment should be focused and treated with ART so that they may have better quality of life.

Limitation of the study

This study was a single centre study conducted at a medical institute, so this may not be representative of marginalized population in remote areas that still do not have access to treatment of HIV/AIDS. So, the study can not be generalized to all HIV patients.

Relevance of the study

This study gives representation of quality of life of PLHIV. This gives the opportunity to make relevant policies to improve the quality of PLHIV.

Authors Contribution

PK, SDK, AKS: Study design, data collection and compilation, drafting of manuscript. AP, SD: statistical analysis and interpretation of data. All authors equally contributed for finalization of manuscript with intellectual content.

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Tables

TABLE 1: RELATIONSHIP OF QUALITY OF LIFE WITH SOCIODEMOGRAPHIC PROFILE (AT INITIATION OF ART)

Domains	Physical	Psychological	Level of independence	Social relationship	Environment	Spirituality
	$\bar{x} \pm \sigma$	$\bar{x} \pm \sigma$	$\bar{x} \pm \sigma$	$\bar{x} \pm \sigma$	$\bar{x} \pm \sigma$	$\bar{x} \pm \sigma$
Sex						
Male	12.70±2.47	12.47 ± 1.75	12.93±2.32	12.57 ±2.09	12.1±2.15	11.42±2.49
Female	13.24 ± 2.88	12.77 ±1.68	13±2.33	12.07 ±2.14	11.58±1.92	11.37±2.10
p- Value	>0.05	>0.05	>0.05	>0.05	>0.05	>0.05
Religion						
Hindu	12.82 ± 2.61	12.57 ±1.76	13.06±2.42	12.45 ±2.17	12.03±2.21	11.31±2.38

Domains	Physical	Psychological	Level of independence	Social relationship	Environment	Spirituality
Muslim	12.89 \pm 2.46	12.43 \pm 1.64	12.48 \pm 1.80	12.46 \pm 1.88	11.78 \pm 1.61	11.83 \pm 2.48
p- Value	>0.05	>0.05	>0.05	>0.05	>0.05	>0.05
Caste						
General	13.04 \pm 2.69	12.56 \pm 1.72	13.28 \pm 2.41	12.64 \pm 2.27	12.31 \pm 2.08	11.94 \pm 2.50
OBC	12.41 \pm 2.22	12.61 \pm 1.77	12.43 \pm 2.17	12.45 \pm 1.87	11.94 \pm 1.97	10.82 \pm 2.28
SC & ST	13.27 \pm 3.04	12.24 \pm 1.75	13.17 \pm 2.22	11.72 \pm 2.06	10.76 \pm 2.24	11.05 \pm 1.91
p- Value	<0.0001	>0.05	<0.01	<0.0001	<0.0001	<0.0001
Marital status						
Married	12.95 \pm 2.68	12.64 \pm 1.75	12.92 \pm 2.34	12.37 \pm 2.14	11.94 \pm 2.15	11.23 \pm 2.29
Unmarried	12.73 \pm 1.96	12.42 \pm 1.49	13.43 \pm 1.95	13.08 \pm 1.65	12.34 \pm 1.88	12.3 \pm 2.75
Widow/Divorcee/Separated	10.56 \pm 2.25	10.90 \pm 2.05	10.88 \pm 2.95	11.00 \pm 3.01	10.94 \pm 2.13	10.56 \pm 2.16
p- Value	<0.0001	<0.0001	<0.0001	<0.0001	<0.0001	<0.0001
Type of Family						
Nuclear	12.74 \pm 2.49	12.54 \pm 1.55	12.8 \pm 2.14	12.29 \pm 2	11.75 \pm 1.97	11.61 \pm 2.46
Joint	13.10 \pm 2.85	12.55 \pm 2.22	13.40 \pm 2.78	12.97 \pm 2.37	12.68 \pm 2.36	10.78 \pm 2.09
p- Value	>0.05	>0.05	>0.05	>0.05	>0.05	>0.05
Education						
Illiterate	12.68 \pm 2.53	12.7 \pm 1.76	12.6 \pm 2.12	12.15 \pm 2.07	11.29 \pm 1.81	11.36 \pm 2.33
Upper Secondary	12.95 \pm 2.54	12.41 \pm 1.70	13.13 \pm 2.32	12.36 \pm 1.79	11.88 \pm 1.66	11.70 \pm 2.62
High School & Intermediate	13.32 \pm 2.05	12.57 \pm 1.93	13.29 \pm 1.52	13.00 \pm 2.03	13.54 \pm 2.55	11.25 \pm 2.16
Graduation and Above	12.65 \pm 2.95	12.57 \pm 1.78	12.99 \pm 2.82	13.02 \pm 2.79	12.88 \pm 2.83	10.85 \pm 2.00
p- Value	<0.0001	<0.0001	<0.0001	<0.0001	<0.0001	<0.0001
Profession						
Unemployed	12.94 \pm 1.46	12.36 \pm 2.06	12.56 \pm 2.09	12.47 \pm 1.42	11.88 \pm 1.72	12.39 \pm 4.12
Unskilled/Skilled	13.00 \pm 2.67	12.66 \pm 1.62	13.26 \pm 1.93	12.61 \pm 1.80	12.18 \pm 1.94	11.32 \pm 2.33
Clerk/Professional	12.40 \pm 2.64	12.35 \pm 1.84	12.63 \pm 2.53	12.33 \pm 2.38	11.93 \pm 2.35	11.25 \pm 2.33
Home Maker/Students	13.54 \pm 2.54	12.87 \pm 1.53	13.39 \pm 2.37	12.52 \pm 2.16	11.83 \pm 1.95	11.54 \pm 1.83
p- Value	<0.0001	<0.0001	<0.0001	<0.0001	<0.0001	<0.0001

\bar{x} = Mean σ = Standard deviation

TABLE 2: RELATIONSHIP OF QUALITY OF LIFE WITH SOCIODEMOGRAPHIC PROFILE (AFTER SIX MONTHS OF RECEIVING ART)

Domains	Physical	Psychological	Level of independence	Social relationship	Environment	Spirituality
	$\bar{x} \pm \sigma$	$\bar{x} \pm \sigma$	$\bar{x} \pm \sigma$	$\bar{x} \pm \sigma$	$\bar{x} \pm \sigma$	$\bar{x} \pm \sigma$
Sex						
Male	13.98 \pm 2.29	14.35 \pm 1.34	13.19 \pm 1.24	14.14 \pm 1.27	13.19 \pm 1.01	12.19 \pm 2.11
Female	13.48 \pm 1.71	14.22 \pm 1.32	13.28 \pm 1.57	14.16 \pm 1.68	13.01 \pm 1.06	11.31 \pm 1.79
p- Value	>0.05	>0.05	>0.05	>0.05	>0.05	>0.05
Religion						
Hindu	13.86 \pm 2.11	14.27 \pm 1.35	13.18 \pm 1.36	14.21 \pm 1.4	13.17 \pm 1.07	11.78 \pm 1.84
Muslim	13.81 \pm 2.41	14.47 \pm 1.26	13.31 \pm 1.21	13.93 \pm 1.31	13.04 \pm 0.81	12.62 \pm 2.71
p- Value	>0.05	>0.05	>0.05	>0.05	>0.05	>0.05
Caste						
General	13.77 \pm 2.39	14.42 \pm 1.22	13.19 \pm 1.3	14.04 \pm 1.34	13.18 \pm 0.87	12.12 \pm 2.24

Domains	Physical	Psychological	Level of independence	Social relationship	Environment	Spirituality
OBC	13.88±2.02	14.11±1.59	13.19±1.13	14.44±1.44	13.16±1.23	11.83±1.99
SC & ST	14.10±1.60	14.48±0.90	13.33±1.95	13.73±1.35	12.93±1.03	11.67±1.48
p- Value	>0.05	>0.05	>0.05	>0.05	>0.05	>0.05
Marriage						
Married	13.76±2.22	14.28±1.37	13.24±1.4	14.20±1.45	13.24±1.01	11.96±2.21
Unmarried	14.24±1.71	14.45±1.14	13.15±1.06	13.93±1.18	12.75±1.06	11.9±1.42
Widow/Divorcee/Sepa rated	14.08±3.39	14.40±1.56	12.75±0.25	14.00±0.66	12.75±0.66	12.17±1.01
p-value	>0.05	<0.0001	<0.0001	<0.01	<0.0001	<0.0001
Type of Family						
Nuclear	14.01±2.31	14.37±1.36	13.28±1.42	14.09±1.44	13.11±1.03	12.22±2.19
Joint	13.42±1.66	14.17±1.27	13.02±1.02	14.31±1.22	13.24±1.01	11.24±1.48
p-value	>0.05	>0.05	>0.05	>0.05	>0.05	>0.05
Education						
Illiterate	14.62± 2.39	14.43±1.63	13.06±1.15	14.28±1.62	12.97±1.06	12.61±2.52
Upper Secondary	13.57± 2.13	14.25±1.34	13.38±1.50	14.13±1.27	13.12±1.09	11.60±1.84
High School & Intermediate	12.75± 1.66	13.70±0.65	12.54±0.73	13.17±0.96	12.75±0.52	11.75±1.92
Graduation and Above	13.72 ±1.75	14.49±0.92	13.24±1.24	14.32±1.34	13.59±0.78	11.88±1.73
p-value	<0.0001	<0.0001	<0.0001	<0.0001	<0.0001	<0.0001
Profession						
Unemployed	13.79 ±1.67	14.51±1.03	13.42±1.55	14.39±1.46	13.09±1.04	11.55±1.93
Unskilled/Skilled	13.87± 2.17	14.22±1.39	13.18±1.34	14.00±1.41	13.30±1.01	11.53±2.04
Clerk/ Professional	13.91± 2.49	14.26±1.49	13.07±1.16	14.10±1.33	13.09±1.04	12.54±2.09
Others	12.50± NA	13.60±NA	14.25±NA	13.50±NA	12.38±NA	12.00±NA
p-value	<0.0001	<0.0001	<0.0001	<0.0001	<0.0001	<0.0001

\bar{x} = Mean σ = Standard deviation

TABLE 3: QUALITY OF LIFE IN VARIOUS DOMAINS AT INITIATION AND AFTER SIX MONTHS OF RECEIVING ART

Domains	At initiation of ART Mean (95% CI)	After six months of receiving ART Mean (95% CI)	Mean difference (95%CI)
Physical domain	12.83 (12.38-13.29)	13.85(13.43-14.28)	1.02 (0.40-1.65)
Psychological	12.54 (12.24-12.85)	14.31(14.05-14.58)	1.77 (1.37-2.18)
Level of independence	12.95 (12.54-13.36)	13.21 (12.95-13.47)	0.26 (-0.23-0.75)
Social relationship	12.46 (12.08-12.83)	14.15 (13.88-14.42)	1.69 (1.23-2.16)
Environment	11.98 (11.61-12.35)	13.15 (12.95-13.35)	1.17 (0.74-1.59)
Spirituality / religion / personal beliefs)	11.41 (10.99- 11.83)	11.96 (11.55-12.36)	0.55 (-0.04-1.14)

Figures

FIGURE 1: COMPARISON OF MEANS AND 95% CONFIDENCE INTERVALS OF QUALITY OF LIFE DOMAIN SCORES AT INITIATION VERSUS AFTER SIX MONTHS OF RECEIVING ART

