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Assessment Of Quality of Life Among PLHIV Attending the FIART Clinic of Bankura Sammilani Medical College, West Bengal

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ABSTRACT

Introduction: People Living with HIV (PLHIV) are facing increasing challenges pertaining to the disease as life expectancy is gradually rising. This study was conducted to assess the quality of life (QOL) in various domains among PLHIV and to find out its' associated factors.

Methods: A descriptive, cross-sectional study was conducted in Facility Integrated Antiretroviral Therapy (FIART) clinic of Bankura Sammilani Medical College & Hospital (BSMCH) among 99 PLHIV from 01/07/2019 to 30/06/2020. Data were collected by interviewing PLHIV aged within 18-60 years using pre-designed, pre-tested, and semi-structured questionnaire incorporating WHO Quality of Life for HIV (WHOQOL-HIV) - BREF version to assess the QOL of the study subjects in various domains.

Results: 44% participants rated their QOL as good, 79% satisfied with their health. Among all other domains, QOL score (median- 17.0, IQR- 4) was found highest in physical domain, while it was lowest (median- 14.0, IQR- 2) in spiritual domain. Overall QOL was significantly higher in males, rural residents, joint family and higher socio-economic class. Multiple linear regression revealed statistically significant relation of overall QOL with residence, family type and socio-economic status.

Conclusion: Psychological and spiritual well-being of PLHIVs is an area of concern and requires clinical attention.

Keywords: HIV/AIDS, Quality of life; PLHIV; WHOQOL-HIV BREF

INTRODUCTION

Human immunodeficiency virus infection and acquired immune deficiency syndrome (HIV/AIDS) is a chronic disease of immune system caused by infection with human immune deficiency virus (HIV). It gradually weakens immune system by destroying the CD4 T- lymphocytes (CD4 cells) leaving the body vulnerable to life-threatening opportunistic infection and malignancies. Around 38.0 million people were living with HIV (PLHIV) worldwide.[1] India has the third largest HIV epidemic in the world having 0.22% HIV prevalence among the adults in 2017 whereas West Bengal having prevalence of 0.21%.[2]

With initiation of anti-retroviral treatment (ART), HIV patients achieve excellent improvement of their clinical course but a PLHIV has to come up with a range of HIV-related symptoms like the infection itself, co-morbid illnesses, or iatrogenic effects from HIV-related medications.[3-4] Many of the HIV patients struggle with numerous social problems such as stigma, discrimination, poverty, depression, substance abuse, and cultural beliefs, which can affect their QOL.[5] Hence, HIV/AIDS infection compromises the QOL in PLHIV and it has become an important indicator for implementing HIV health-related intervention.[6]

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QOL is defined by the World Health Organization (WHO) as "the condition of life resulting from the combination of the effects of the complete range of factors such as those determining health, happiness (including comfort in the physical environment and a satisfying occupation), education, social and intellectual attainments, freedom of action, justice and freedom of expression."[7]

With the introduction of highly active antiretroviral therapy (HAART) and scaling up of its availability, life expectancy of the infected persons has increased.[8] In the HAART era, infected individuals might live a longer life; however, they might not lead a well-satisfied life as the infected person has to follow ART regimen lifelong. This might lead to PLHIV facing increasing health-related challenges pertaining to the disease, managing medication, side effects due to medication and aging. Hence, it is important to determine the factors contributing to better QOL among PLHIV.

As QOL shows wide variations depending on different socio-demographic and clinical characteristic of the individuals,[9-11] measuring QOL and determining factors affecting QOL will help us in understanding, which domains of the QOL are commonly affected and will also provide regional data for planning intervention strategies to improve the QOL among PLHIV.

There was dearth of studies in this context in West Bengal specially in Bankura, regarding QOL of PLHIV, though it is vulnerable to infiltrate from neighbouring districts, states like Bihar and Jharkhand.[12-14] With this background, the present study was conducted to assess the QOL of PLHIV patients attending Bankura Sammilani Medical College (BSMCH) FIART centre in Bankura, West Bengal in respect of physical, psychological, level of independence, social, environmental and spiritual domains and to find out associated factors with their QOL.

MATERIALS AND METHODS

This institution-based, descriptive, cross-sectional study was conducted at facility integrated antiretroviral therapy (FIART) clinic of BSMCH (Centre Code- WB/BKR/01) from 1st July 2019 to 30th June 2020 among all registered PLHIV aged between 18 - 60 years receiving ART with minimum duration of HIV diagnosis of 6 months. Patients having serious complications of the disease (e.g., severe pneumonia, Hepatitis B) and with other serious co-morbid conditions (e.g., cancer, uncontrolled diabetes, renal failure) were excluded from the study.

As no data on prevalence of poor QOL of PLHIV were found in context of Bankura, so cconsidering 50% prevalence of poor QOL of PLHIV in Bankura, 95% confidence interval (CI) and 10% absolute error, sample size was calculated to be 96. Applying finite population correction [Finite population size = 856 registered adult PLHIV (as stood on 2 September 2018] revised sample size came out to be 90. Assuming 10% non-response rate the final sample size was 99.

The study subjects were selected by systematic random sampling among all the registered PLHIV patients attending FIART clinic. Data were collected with the help of a pre-designed, pre-tested semi-structured interviewer administered questionnaire (in Bengali language) containing WHO Quality of Life for HIV (WHOQOL-HIV) BREF Version, 2002 as well as patient's medical records (if required) bi-weekly for six months (total 48 days), until the desired sample size was achieved.[15] Approximately, two to three study participants were interviewed per day. Since the total registered PLHIV was 856 and the desired sample size was 99, hence the sampling interval came out to be 9 [$\frac{856}{99}$= 8.64]. First participant was selected following a simple random sampling technique using random number table from the FIART clinic register. Then from every 9th PLHIV had been included in the study with prior communication over phone and appointment was taken individually for interview. If any selected participants were ineligible as per exclusion criteria, then very next registered PLHIV were included as study subjects.

WHOQOL-HIV BREF Version, 2002 contains six domains namely Physical health (4 items), Psychological health (5 items), Level of independence (4 items), Social relationship (4 items), Environment (8 items) and Spirituality/Religion/Personal beliefs (4 items). First two questions evaluated overall QOL. Individual items were rated on a 5point Likert scale where 1 indicates low, negative perceptions and 5 indicates high, positive perceptions. Some facets (pain and discomfort, negative feelings, dependence on medication, death and dying) were not scaled in a positive direction, meaning that for these facets higher scores did not denote higher QOL. The scale was validated for language as well as content (CVI- 0.94, CVR-0.89) with Cronbach's alpha value 0.703.

Calculation of Domain Scores

Box 1 – Method of calculation of domain score

Computation of domain scores
Domain 1 = (Q3 + Q4 + Q14 + Q21)/4 * 4
Domain 2 = (Q6 + Q11 + Q15 + Q24 + Q31)/5 *4
Domain 3 = (Q5 + Q22 + Q23 + Q20)/4 * 4
Domain 4 = (Q27 +Q26 + Q25 + Q17)/4*4
Domain 5 = (Q12 + Q13 + Q16 + Q18 + Q19 + Q28 + Q29 + Q30)/8 *4
Domain6 = (Q7 + Q8 + Q9+ Q10)/4 *4
(These equations calculate the domain scores. All scores are multiplied by 4 so as to be directly comparable with scores derived from the WHOQOL-100)
Overall QOL = (Q1 + Q2)/2 * 4 [16]

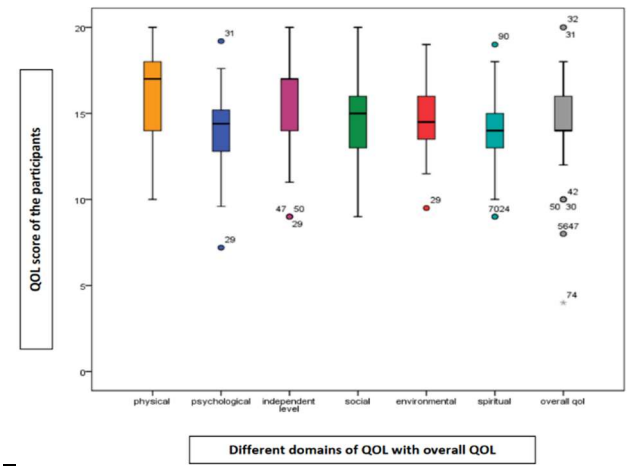
After explaining the purpose of the study and prior written informed consent data were collected in a

private room maintaining their dignity, privacy and comfort consent with face-to-face interview. The average duration of the interview was about 40 minutes. At the end of data collection each participant were thanked for their cooperation. Ethical Clearance was obtained from the Institutional Ethics Committee of Bankura Sammilani Medical College and Hospital, Bankura.

Data were codified and entered in MS Excel Spread Sheet. Data were presented in the form of table and diagram and mean, median, proportion, inter-quartile range and standard deviation were calculated for describing the data. Normality of the data set was tested by Shapiro-Wilk's normality test as well as various plots like histogram, P-P plot etc. Scores of overall QOL & other continuous data did not follow normal distribution. For bivariate analysis Mann Whitney U, Kruskal Wallis, Spearman's correlation was applied wherever required. p value of <0.05 was considered as significant with 95% confidence interval for drawing statistical inference regarding relationship among variables. Variables, which had p values <0.1 in bivariate analysis, were considered for multiple linear regression analysis to find out strength of association of different variables with QOL of the participants. Software package IBM SPSS 22.0 trial version was used for data analysis.[17]

RESULTS

The overall age of participants was 36.1±8.9 years (mean ± SD) with median of 35 years; range was 19-56 years. Most of the participants (69.7 %) belonged to 21-40 years age group. In this age group, females were predominant (83.3%).



Domains	Mean SD	Median	Score Range
Physical	16.0 ± 2.7	17.0	10.0-20.0
Psychological	13.9 ± 2.1	14.4	7.20-19.20
Independence	15.8 ± 2.4	17.0	9.0- 20.0
Social	14.4 ± 2.4	15.0	9.0- 20.0
Environmental	14.7 ± 1.7	14.5	9.5- 19.0
Spiritual	14.1 ± 2.0	14.0	9.0- 19.0
Overall	14.6 ± 2.5	14.0	4.0- 20.0

Figure 1: Box whisker plot showing IQR of QOL of the participants in respect of different domains of QOL

Table 1: Distribution of participants according to socio-demographic variables and overall QOL (N=99)

Variables	Overall QOL Mean rank	p (2-tailed)
Age (years)	-	0.514
Gender		
Male	55.66	0.033*
Female	48.99	
Religion		
Hindu	51.1	0.05
Muslim	23.88	
Caste		
General	50	0.663
Scheduled Caste	47.52	
Scheduled Tribe	49.1	
Other backward classes	66	
Residence		
Rural	52.1	0.030*
Urban	33.18	
Education level		
Illiterate	51.11	0.822
Primary	49.51	
Secondary	47.03	
HS & above	58.57	
Occupation		
Homemaker	42.37	0.293
Laborer	50.07	
Business and service	56.48	
Commercial sex worker	71	
Type of family		
Nuclear	55.82	0.013*
Joint	42.1	
Socio-economic status		
Class I, II, III	58.63	0.038*
Class IV, V	46.25	
Marital status		
Married	52.82	0.109
Others	43.19	
Cohabitation		
Alone	41.18	0.255
Family	51.1	
Addiction		
Present	52.33	0.312
Absent	46.71	
Distance from home to hospital	-	0.834
Duration since diagnosis of HIV		0.952
Duration of ART	3.53 ± 2.7 (mean ± SD)	0.547

Majority of the participants were Hindu (95.9 %), belonged to General Caste (66.7%), lower SES class (37.4%), joint family (57.6%), residing in rural area (88.9 %). 14.1% participants were illiterate, while more than half of the participants (63.6 %) had primary level of education.

Majority of the female participants was homemaker (64.6 %) while most of the male participants were laborer (27.6%). More than two-thirds (70.7%) of the participants were married, living with their family (83.8%). 44% of participants rated their QOL as good, while the majority (79%) satisfied with their health.

Among all the domains, QOL score was found highest (median- 17.0, IQR- 4) in physical domain, while it

was lowest (median- 14.0, IQR- 2) in spiritual domain. (Fig no. 1)

Overall QOL was significantly higher ($p<0.05$) in participants, who were males, residing in rural area, belonging to joint family and higher socioeconomic class. [Table 1]

Linearity for residual values cross-checked by p-p plot, scatter plot and were found normally distributed. Durbin-Johnson value was 1.622 (<2= positive autocorrelation). Multiple linear regression revealed statistically significant Positive relation of overall QOL with residence, type of family and socioeconomic status but not with male gender. [Table 2]

Table 2: Multiple linear regression between overall quality of life of the participants and its predictors (N=99)

Model	Unstandardized Coefficients		Standardized Coefficients			95.0% C.I for B	Collinearity Statistics	
	B	Std. Error	Beta	t	p value		Tolerance	VIF
(Constant)	12.727	0.719		17.696	0	11.30- 14.16		
Residence	2.114	0.763	0.271	2.771	0.007	0.60- 3.63	1	1
(Constant)	11.845	0.78		15.184	0	10.29-13.39		
Residence	2.32	0.746	0.297	3.109	0.002	0.84- 3.80	0.988	1.012
Type of family	1.213	0.475	0.244	2.555	0.012	0.27- 2.16	0.988	1.012
(Constant)	11.126	0.829		13.426	0	9.48- 12.77		
Residence	2.655	0.746	0.34	3.558	0.001	1.17- 4.14	0.949	1.054
Type of family	1.343	0.469	0.271	2.867	0.005	0.41- 2.27	0.973	1.028
Socioeconomic status	1.145	0.51	0.215	2.247	0.027	0.13- 2.16	0.95	1.052

a. Dependent Variable: overall QOL

DISCUSSION

This study had revealed that overall age of participants was 36.11±8.9 years (mean±SD) with median of 35 years; range was 19-56 years. Most of the participants (69.7 %) belonged to 21-40 years age group in which females were predominant (83.3%). This finding is comparable with the findings of the study by Khakha DC *et al*, Marashi T *et al* and Dasgupta P *et al.*[18-20]

In this study, 43.4% of the participants rated their QOL neither poor nor good, 6.1% rated their QOL poor, while 44.4% rated it as good. Majority of the participants (68.7% much, 11.1% very much) were satisfied with their health while few (5%) were dissatisfied. This was contrary to the finding of Sarkar T *et al* had found that only 19.1 % were satisfied with their health but 36.6% were dissatisfied.[21] This might be due to the difference in study setting.

In this study, highest score of QOL was obtained in physical domain; this suggests that the patients had relatively better quality of health services and good accessibility to them. Similar findings were reported in various studies.[20, 22-25]

Spiritual domain had lowest score of QOL in this study, as worrying about future, dying and death was a prime concern in majority of the participants. Some of them were bothered about people blaming them for having HIV infection. This was on the contrary to findings to several studies. [26-29]

Followed by spiritual domain, psychological domain was, however, badly affected indicating poor self-esteem, social contacts, and sexual activity. QOL in Psychological domain scored lowest in study done by Marashi T *et al.*, Dasgupta P *et al* whereas scored highest in Khakha DC *et al*, Sarkar T *et al*, Yadav S.[18-21,30]

The mean score of Overall QOL was 14.60 ± 2.46 (Mean± SD) with a median of 14.0, range was 4-20. It was significantly associated with all the domains and similar findings were also reported by Gupta SK *et al.*[28]

In this study, overall QOL was significantly associated with male gender, rural residence, joint family and high socioeconomic class. This finding is consistent in various studies 20, 23-26, 28, 30-33) Low levels of literacy among females, unemployment, financial dependency, and social binding can be the contributory factors for lower scores on QOL domains by females.[20,23-26,28,30-33] On the contrary, study by Dasgupta P *et al*, Sarkar T *et al* reported lower SES has better QOL.[20-21]

This study had shown that overall QOL was higher in the Hindu religion, married individual, higher education level and person with addiction although it failed to reach statistical significance. Similar study by Dasgupta p *et al*. reported that the Muslim had poor QOL compared to The Hindu.[20] Various studies had also shown that good QOL is found higher in married and with higher level of education.[20,25,28] It might be due to more positive attitude toward the disease with the increasing awareness level.

Overall QOL was positively correlated with duration since HIV diagnosis and duration of ART. Early diagnosis of HIV with prompt ART can decrease chances of HIV related complication, improve overall survival and thereby improve QOL. A Brazilian study reported participant having long duration of ART with good adherence had better QOL.[34]

Addiction helps in numbing emotional stress related to HIV infection. QOL also high in those who travel by bus to reach FIART center. Overall QOL was positively correlated with monthly cost of transport.

Current study revealed that overall QOL was negatively correlated with age of the participants which corroborates with various studies.[20,35] The lowest scores for QOL younger might be due to lack of education and duration of disease. On the other hand, Sarkar T *et al* reported young PLHIV (less than 40 years) has better QOL.[21]

This study also revealed a negative correlation between overall QOL with distance from home to hospital and patient's age during diagnosis of HIV. Patients who were coming from interior part of the district with poor transport accessibility had poor QOL compared to those coming from places nearer to the hospital with better transport facilities. However, evidence could not be provided due to very limited resources in this account. As previously discussed, young age has negative correlation with QOL, so those PLHIV who were diagnosed at a young age had poorer QOL.

The present study had some limitations like recall bias regarding duration of addiction during interview. There was a possibility of conscious falsification of some sensitive information by the participants as well.

CONCLUSION

QOL among PLHIV and its' determinants assessment is very much needed besides adherence of treatment. Especially, spiritual, psychological, environmental domain of QOL must be prioritized during attendance to ART center. Counselling regarding HIV-related stigma and psychotherapy for PLHIV is of paramount importance and need of the hour.

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