# FACTORS INFLUENCING QUALITY OF LIFE AMONG PEOPLE LIVING WITH HUMAN IMMUNODEFICIENCY VIRUS (PLHIV) IN COASTAL SOUTH INDIA

Abstract:

# **Background:**

Anti Retro-viral Therapy (ART) has increased life expectancy of HIV/AIDS patients, but the quality of life (QOL) still remains the same.

## Methodology:

In this cross-sectional study, 356 PLHIV were interviewed to assess their QOL using WHOQOL- HIV Bref questionnaire. The association between QOL with socio-demographic, clinical and co-habitation status of the participants was tested using ANOVA and student t-test, and P value <0.05 was considered statistically significant.

#### **Results:**

Physical domain of QOL showed maximum score of 16.4, while a minimum score of 12.2, was seen in social relationship domain. Participants with higher Socio Economic Status (SES) and self-motivated to take ART had shown better scores across all the domains of QOL (P<0.05).

## **Conclusion:**

In our study, Quality Of Life was high among males, younger patients, married participants, higher socio economic status, longer duration of ART, self-motivation to take ART, absence of opportunistic infection and with higher CD4 count.

Index Terms— Human Immunodeficiency Virus, People Living with Human Immunodeficiency Virus, Quality of Life, Anti Retro-viral Therapy, WHOQOL-HIV BREF.

# I. INTRODUCTION

With the introduction of Highly Active Anti-retroviral Therapy (HAART) and scaling up of its availability, life expectancy of the infected persons has increased. <sup>[1]</sup> In the HAART era infected individual might live a longer life; however they might not have lived well satisfied life. So determining quality of life is considered to be essential to identify the overall wellbeing of people living with HIV.

As there is no cure for HIV infection and non-availability of vaccines for its prevention, the infected person has to follow ART regimen life-long, which had led to PLHIV facing increasing health-

related challenges pertaining to the disease, managing medication, side effects due to medication & ageing. Hence it is important to determine the factors contributing to better Quality of Life (QOL) among People Living with HIV (PLHIV). Studies have shown an inverse relationship between quality of life and factors like HIV infection stages, unemployment, perceived health status, stress & medication adverse effects due to ART <sup>[2]</sup> and depression is in turn associated with social-support & self-esteem, <sup>[3,4]</sup> factors affecting QOL might be inter-linked to many heath related factors. So Quality of life (QOL) has become an important indicator for implementing HIV health-related intervention.

World Health Organization (WHO) has defined quality of life as 'individual's perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns'. [5] As QOL shows wide variations depending on different socio-demographic and clinical characteristic of the individuals, [6,7,8] 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. In this study we have assessed the QOL and factors influencing it among the PLHIV in Coastal South India.

# II. METHODOLOGY

Background information of the study area:

Mangalore city is the administrative headquarters of the Dakshina Kannada District, and the fourth largest city in the State. Mangalore city spans an area of  $200~\rm km^2$  and has a population of 4.9 lakhs with 94.03% literacy rate. [9] The prevalence of HIV has been showing a declining trend in Dakshina Kannada District during the past four year, however, the HIV prevalence rate of 0.75% is higher than State prevalence of 0.52%. [10]

Study settings and design:

In this cross-sectional study 356 PLHIV attending Infectious Disease Department of a tertiary care hospital in Mangalore, Karnataka were interviewed and QOL was assessed during the period of April 2014 to December 2014.

Sample size calculation:

Sample size was calculated considering the expected proportion of adherence to ART among PLHIV as 63.7%, [11] convenient sampling method was used for recruitment of participants.

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Ethics approval:

The protocol was approved by the Institutional Ethics Committee (IEC) at Kasturba Medical College, Mangaluru (Manipal University) prior to the commencement of the study.

Study population:

PLHIV aged 18 years and above, who were on ART were included in the study. PLHIV were approached and explained about the objectives of the study in local language (Kannada) and written informed consent was obtained from the PLHIV who were willing to participate in the study.

Data collection:

The data was collected by face-to-face interview. Patient's confidentiality was maintained by interviewing them in separate room. The average duration of interview was about 30 minutes. Baseline characteristics of the study participants were collected using pretested semi-structured questionnaire which included socio-demographic and clinical characteristics (gender, age, marital status, ART availability, duration of ART, distance travelled, motivation to take ART, opportunistic infections, CD4 count, mode of transmission and co-habitation status) & socio-economic status was assessed using modified Kuppuswamy scale, [12] which includes education, occupation and income of the participants.

Quality of life was assessed using World Health Organization Quality of Life (WHOQOL) HIV-Bref instrument. [13] WHOQOL-HIV BREF questionnaire includes 31 items distributed into six domains namely, physical (4 items), psychological (5 items), level of independence (4 items), social relationship (4 items), environment (8 items) and spirituality (4 items), 2 items about overall general health. The respondents answered each question using a 5 point Likert scale. Scores of negatively directed questions were reversed to make scores higher. Higher scores generally indicate better QOL. Average scores of all items in each domains was multiplied by four to convert domains scores to the range of 4 to 20, to make it comparable with scoring pattern of WHOQOL-100.

Data analysis:

The collected data was entered and analyzed using SPSS version 16.0. The association between quality of life domain scores with socio-demographic, clinical characteristics and co-habitation status of the participants was analyzed using one way ANOVA (analysis of variables) and student-t test. P <0.05 was considered to be statistically significant.

# III. RESULTS

Socio-demographic and clinical characteristics:

Out of 356 participants in the study, (62.9%, n=224) were males, Majority of them (41.3%, n=147) were aged between 41-50 years and 65.7% (n=234) were married. Majority of them (44.1%, n=157) had been receiving ART for more than 3 years and 48.6% (n=173) of the participants belonged to middle/lower middle class of socio economic status.

Opportunistic infections were present among 6.2% (n=22) participants. CD<sub>4</sub> count ranged from 201-600 cells/mm<sup>3</sup> among 59.6% (n=212) and 53.4% (n=190) of the participants co-habitated with their spouse and children. The socio-demographic and clinical characteristics of the participants are shown in Table -1.

Quality of Life Scores:

The mean (SD) of transformed scores ranging from 4-20 across the six domains of QOL are shown in Table -2. Physical domain of QOL showed maximum score of 16.4 (2.2) and social relationships domain showed the minimum score of 12.2 (1.7) among our study participants.

Association between QOL scores with socio-demographic and clinical characteristics:

Association between quality of life domain scores with sociodemographic and clinical characteristics of the participants are shown in Table - 3. We observed that participants with higher Socio Economic Status (SES) had higher domain scores in all the six domains of QOL and this association was found to be statistically significant. (P<0.05). Participants who were self-motivated to take ART also have showed higher domain score across all the six domains of QOL with statistically significant association. (P<0.05)

A statistically significant association (P<0.05) was observed with the marital status and age of the participants in Physical, Psychological, Level of independence & Social relationships domains of QOL and participants who are married had shown higher QOL domain scores compared to those who are unmarried and widowed.

PLHIV having opportunistic infections had lower domain scores and statistically significant (P<0.05) association was found with respect to Physical, Psychological, Level of independence and Environmental domains of QOL. CD4 count of the participants showed significant association in all the domains except social relationship & environmental domains of QOL. Participants with higher CD4 counts had shown higher QOL domain scores.

Participants who were receiving ART for longer duration (>36 months) were having higher scores in all the domains of QOL with statistically significant association (*P*<0.05) in Physical, Psychological, Level of independence & environmental domains of QOL. With respect to gender, males have shown higher scores compared to females across all the domains and there is a significant association with psychological & level of independence domains of QOL.

Association between the quality of life with co-habitation status:

In relation to the patient's co-habitation status, participants living with spouse and participants living with spouse and children were having higher QOL domain scores in all the domains. Whereas, participants living with their children had shown lower scores in all domains of QOL compared to those who are not living with their children and statistically significance association was found in Physical, Psychological and Level of independence domains of QOL.

Associations between the quality of life with co-habitation status of the participants are shown in Table -4.

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## IV. DISCUSSION

Mean QOL domains score was maximum for physical domain followed by level of independence, psychological, environmental & spirituality domain of QOL. Social relationship domain showed the minimum score.

Physical, psychological & level of independence domains of QOL have shown a significant difference between gender, males were having better QOL scores compared to females. These findings are consistent with other study findings, [14,15,16] however some studies have also shown no significant difference with respect to gender. [17,18] Higher QOL scores in our study among males could be due to better social environment and job opportunity than females, which helps to deal with HIV disease and cope with treatment.

Marital status was significantly associated with physical, psychological, level of independence & social relationship domains of QOL. PLHIV who are married showed better QOL mean scores compared to widowers. Similar findings are observed in other studies.<sup>[19,20]</sup> Physical, emotional & psychological support of a spouse is more important as compared to support from rest of the family, this could be a reason for better QOL scores of married subject in our study.

It was observed that participants with higher Socio Economic Status (SES) showed better QOL domain scores. Majority of the participants (49.3%) belongs to middle/lower middle class of SES and a significant difference was observed in all the six domains of QOL across all the SES. These findings can be explained by high literacy rate and better awareness about HIV disease in Costal South India. Educated patients have a better understanding about the disease, treatment availability, prevention & spread of HIV infection. They will also be able to comprehend instructions regarding ART and possible side effects and adhere to the treatment better with a better understanding of the whole treatment process. This will in turn lead to better coping attitudes towards disease and improved QOL. Similarly occupation & income also leads to better health and better QOL. In our study, many of the participants were engaged in unskilled work, craft & trade related, fisheries, transport and driving, etc. these activities helps them earn money for their livelihood & keep them healthy both physically and mentally, which in turn is responsible for better QOL. Other study finding also suggests higher SES with better QOL. [21,22,23,24,25]

Our study demonstrated that PLHIV who have received ART for longer duration have a significant difference in physical, psychological & level of independence domains of OOL. Patients who are on ART for more than 36 months have shown better QOL mean scores than patients receiving ART for lesser duration in our study. These findings could be due to side effects and other discomfort at the initiation of ART. Patients may take some time to get adjusted for the particular dosage regimen and also pill burden could be other problem if patient is suffering from any opportunistic infection. Similar results were found in different studies where it was found that patients who understand and follow the dosage schedules of ART including dietary restriction and maintenance of good health, higher scores in domains of QOL have observed over period. [26,27,28,29] Better QOL domain scores were achieved among PLHIV receiving ART for longer duration in other study findings. [30,31,32] On contrast, shorter duration of ART and patients who have not followed the ART regimen were observed with lower QOL scores. [33,34,35]

In our study, PLHIV who are self-motivated to take ART showed better QOL scores in all six domains of QOL than those who take medication on compulsion. These findings suggest patient's dedication & obedience towards their treatment, health and understanding of importance of adherence to ART. Only 6.2% of the participants had opportunistic infections with lower QOL scores in all the domains compared to participants with the absence of opportunistic infection.

Significant difference was observed between CD4 count of the participants and physical, psychological, level of independence and spirituality domains of QOL. These findings are similar with other studies. [36,15,18,19,23,27,31] This could be explained based on patient's knowledge regarding the adherence to ART and improvement in CD4 count. As CD4 count is regularly monitored in our settings, improvement in CD4 counts might encourage participant with betterment of immunity and built in confidence within them to take good care of their health and which provides better QOL, which resembles with other study findings. [20]

Patient's co-habitation status also has affected QOL domain score in our study. As in our study majority of the participants were married (65.7%), participant's living with spouse has shown higher QOL scores with significance difference in psychological, level of independence, social relationship and spirituality domains of QOL. This could be due to the reason that, living with spouse is often helpful financially and also provides social security & safety. Participants living with only children also had shown significance difference in all domains except environmental and spirituality domains of QOL. Patients who are not living with their children had shown better QOL domain mean scores, this explains avoidance of disclosure of HIV status to their children and worries about the spread of HIV infection through blood or also could be due to the fact that they cannot live longer as others with their children. Participants living with their spouse and children had shown significance difference in Physical, social relationship & environmental domains mean scores of QOL. This might be due to good family bonding & better social environment among PLHIV. In contrast, participants living with others & living alone have not shown any significance difference in QOL domains. Mean domain scores among them were higher in those who are living with other & living alone. These findings may be due to stigma & discrimination faced by PLHIV from the society & family members, and also shows patients who are unmarried tend to live alone or with other person.

However, as the study participant's recruitment was done by convenient sampling method among PLHIV attending Infectious Disease Department of a tertiary care hospital, therefore study results might not represent the general population.

In conclusion, the Quality Of Life domain scores are high among males, younger age, participants who are married, participants with higher socio economic status, longer duration of ART, participants who are self-motivation to take ART, absence of opportunistic infection and with higher  $CD_4$  count.

Participants living with spouse & living with spouse and children had shown higher QOL domain scores compared to participants living alone, living with others. Participants living with their children also had shown lower QOL domain scores.

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Table-1: Socio-demographic and clinical characteristics of the participants: (n=356)

Characteristics	Number (%)
<b>Gender</b> Male Female	224 (62.9) 132 (37.1)
Age (years) 18-30 31-40 41-50 >50	023 (06.5) 118 (33.1) 147 (41.3) 068 (19.1)
<b>Marital status</b> Married Unmarried Widowed	234 (65.7) 047 (13.2) 075 (21.1)
Socio Economic Scale Upper Upper middle Middle/Lower middle Lower/Upper lower Lower	0 040 (11.2) 173 (48.6) 139 (39.0) 004 (01.1)
Duration of ART (in months) <12 13-36 >37	076 (21.3) 123 (34.6) 157 (44.1)

Motivation to take ART Self-motivated Compulsion	274 (77.0) 082 (23.0)
Opportunistic infections Present Absent	022 (06.2) 334 (93.8)
CD <sub>4</sub> (cells/mm³) ≤ 200 201-600 >601	024 (06.7) 212 (59.6) 120 (33.7)

Co-habitation status*	
Living alone	014 (03.9)
Living with parents	105 (29.5)
Living with spouse	033 (09.3)
Living with children	042 (11.8)
Living with spouse & children	190 (53.4)
Living with others	075 (21.1)

\* Multiple responses

Table – 2: Transformed scores of the six domains of QOL (n= 356)

QOL domains	Transformed score Mean (SD)
Physical	16.4 (2.1)
Psychological	12.4 (1.9)
Level of independence	13.6 (2.2)
Social relationships	12.1 (1.7)
Environmental	12.4 (1.9)
Spirituality	12.5 (2.2)

Table – 3: Association between the quality of life and socio-demographic and clinical characteristics of the participants: (n= 356)

	WHOQOL-HIV BREF DOMAINS					
CHARACTERISTICS	Physical Mean (SD)	Psychologi cal Mean (SD)	Level of independ ence Mean (SD)	Social relationshi p Mean (SD)	Environm ental Mean (SD)	Spirituality Mean (SD)

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GENDER						
Male	16.6 (2.2)	12.7 (3.0)	13.9 (2.1)	12.2 (1.7)	12.4 (2.2)	12.7 (2.3)
Female	16.2 (2.0)	12.0 (2.0)	13.1 (2.2)	12.1 (1.7)	12.2 (1.3)	12.2 (2.1)
P value*	P=0.095	P=0.005	P<0.001	P=0.471	P=0.356	P=0.156
AGE						
18-30	17.5 (1.4)	13.2 (2.5)	14.2 (2.1)	13.0 (1.9)	12.7 (1.8)	12.9 (3.0)
31-40	16.9 (1.9)	12.6 (1.8)	13.8 (2.0)	12.3 (1.7)	12.5 (1.9)	12.5 (2.2)
41-50	16.0 (2.1)	12.3 (1.9)	13.6 (2.4)	12.0 (1.5)	12.3 (1.7)	12.6 (2.2)
>50	15.3 (2.3)	12.0 (2.3)	13.0 (2.2)	11.9 (1.9)	12.0 (2.7)	12.2 (2.1)
P value**	P=0.001	P=0.007	P=0.007	P=0.004	P=0.085	P=0.263
MARITAL STATUS						
Married	16.6 (2.0)	12.6 (2.0)	13.7 (2.0)	12.4 (1.6)	12.5 (2.0)	12.5 (2.3)
Unmarried	16.7 (2.1)	12.7 (2.2)	14.0 (2.2)	11.9 (1.9)	12.0 (2.4)	12.8 (2.4)
Widowed	15.6 (2.2)	11.9 (1.6)	12.8 (2.6)	11.5 (1.4)	12.1 (1.4)	12.2 (1.8)
P value**	P=0.003	P=0.007	P=0.008	P=0.001	P=0.146	P=0.341
SES						
Upper middle	17.3 (1.9)	13.4 (2.2)	14.5 (1.9)	12.7 (1.8)	13.5 (1.5)	13.4 (2.2)
Middle/lower middle	16.5 (2.2)	12.4 (2.0)	13.6 (2.3)	12.2 (1.6)	12.4 (2.3)	12.4 (2.2)
Lower/upper lower	16.0 (2.1)	12.2 (1.9)	13.2 (2.1)	11.9 (1.6)	12.0 (1.4)	12.2 (2.2)
Lower	16.5 (0.6)	12.0 (1.8)	12.2 (0.5)	10.7 (0.5)	11.2 (0.1)	12.5 (1.1)
P value**	P=0.002	P=0.002	P=0.001	P=0.003	P=0.001	P=0.017

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Duration of ART						
<12	15.7 (2.2)	11.6 (1.6)	12.7 (1.6)	12.0 (1.4)	12.0 (1.4)	12.1 (1.9)
13-36	16.5 (1.8)	12.5 (2.0)	13.5 (2.1)	12.1 (1.8)	12.3 (2.6)	12.5 (2.4)
>37	16.6 (2.2)	12.7 (2.0)	14.0 (2.4)	12.3 (1.7)	12.5 (1.5)	12.7 (2.2)
P value**	P=0.005	P=0.001	P=0.001	P=0.197	P=0.043	P=0.076
Motivation to take ART						
Self-motivated	16.8 (1.8)	12.7 (2.0)	13.9 (2.0)	12.3 (1.6)	12.6 (1.9)	12.7 (2.2)
Compulsion	14.9 (2.3)	11.3 (1.6)	12.5 (2.5)	11.6 (1.7)	11.4 (1.9)	11.6 (2.0)
P value*	P=0.001	P=0.001	P=0.003	P=0.001	P=0.001	P=0.001
Opportunistic infections						
Present	14.1 (2.4)	11.0 (1.2)	11.6 (1.5)	11.5 (1.3)	11.4 (1.3)	12.2 (1.9)
Absent	16.6 (2.1)	12.5 (2.0)	13.7 (2.2)	12.2 (1.7)	12.4 (2.0)	12.5 (2.2)

P value*	P=0.001	P=0.001	P=0.001	P=0.059	P=0.018	P=0.636
CD <sub>4</sub> Count						
<200	15.0 (2.3)	11.2 (1.6)	12.4 (1.7)	11.6 (1.2)	11.7 (1.1)	11.7 (1.4)
201-600	16.4 (2.2)	12.3 (2.0)	13.6 (2.4)	12.2 (1.6)	12.3 (2.0)	12.4 (2.2)
>600	16.6 (1.8)	12.8 (1.8)	13.7 (1.9)	12.2 (1.7)	12.5 (2.0)	12.8 (2.3)
P value**	P=0.014	P=0.001	P=0.043	P=0.239	P=0.056	P=0.017

<sup>\*</sup> Student t-test \*\* ANOVA test

Table – 4: Association between the quality of life and co-habitation status of the participants: (n= 356)

	WHOQOL-HIV BREF DOMAINS					
CO-HABITATION STATUS	Physical Mean (SD)	Psychologi cal Mean (SD)	Level of independ ence Mean (SD)	Social relationshi p Mean (SD)	Environm ental Mean (SD)	Spirituality Mean (SD)
Living alone			` '	,		
Yes	16.3 (2.8)	12.2 (1.8)	13.7 (2.2)	11.3 (1.8)	11.4 (3.5)	11.9 (2.4)
No	16.4 (2.1)	12.4 (2.0)	13.6 (2.2)	12.2 (1.6)	12.4 (1.8)	12.5 (2.2)
P value*	P=0.787	P=0.751	P=0.872	P=0.053	P=0.052	P=0.269
Living with spouse						
Yes	16.7 (2.2)	13.3 (2.2)	14.3 (2.0)	12.9 (1.4)	12.6 (1.3)	13.5 (2.2)
No	16.4 (2.1)	12.3 (1.9)	13.5 (2.2)	12.0 (1.6)	12.3 (2.0)	12.4 (2.2)
P value*	P=0.423	P=0.008	P=0.040	P=0.006	P=0.393	P=0.004
Living with children						
Yes	15.5 (2.0)	11.6 (1.4)	12.9 (3.1)	11.7 (1.4)	12.1 (1.4)	12.0 (1.1)
No	16.5 (2.1)	12.5 (2.0)	13.7 (2.1)	12.2 (1.7)	12.4 (2.0)	12.5 (2.2)
P value*	P=0.006	P=0.005	P=0.032	P=0.071	P=0.362	P=0.178
Living with spouse & children						
Yes	16.6 (2.0)	12.5 (1.9)	13.7 (1.1)	12.4 (1.6)	12.6 (2.0)	12.4 (2.3)
No	16.1 (2.2)	12.3 (2.0)	13.4 (2.4)	11.8 (1.6)	12.1 (1.8)	12.5 (2.1)
P value*	P=0.027	P=0.204	P=0.375	P=0.001	P=0.017	P=0.622
Living with others						
Yes	16.3 (2.2)	12.2 (2.1)	13.3 (2.3)	11.9 (1.8)	11.1 (1.5)	12.6 (2.3)
No	16.4 (2.1)	12.5 (1.1)	13.6 (2.2)	12.2 (1.6)	12.4 (2.0)	12.5 (2.2)
P value*	P=0.628	P=0.329	P=0.262	P=0.132	P=0.063	P=0.679

<sup>\*</sup> Student t-test