Quality of Life of People Living with HIV and AIDS on Art from a Tertiary Hospital in North Kerala

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Abstract

Quality of life (QoL) refers to how well we live. Some people say the quality of life is about wealth and owning things, while others may define it in terms of physical, mental, and emotional well-being. A cross-sectional study on the quality of life of people living with HIV and AIDS attending ART-Clinic Calicut, a tertiary care unit in North Kerala where patients can check their CD4 count and get antiretroviral treatment free of cost. The study was conducted from over a period of 6 months with the help of two sets of questionnaires, part 1 to interview the subject on Socio-demography, Family details, Personal habits, Risk behavior, Disease-related details and part 2 for assessing quality of life by WHOQoL-HIV instrument. The sample size was calculated to be 310. The current study shows a good overall quality of life. The study shows a better score for the physical domain, psychological domain, independence domain, social relationship domain, and Environment domain but a lower score for spirituality/ religion/ personal belief domain. Social support given to PLHA was found to be an independent determinant that significantly improves Overall QoL and all its domains. The absence of HIV infection among children significantly improves all domains of QoL. The absence of opportunistic infection significantly improves all domains except the Physical domain which shows improvement but is not significant. All factors that improve Overall QoL were found to be improving all six domains of QoL.

Keywords: Quality of life, QoL, People living with HIV and AIDS, PLHA.

Introduction

Quality of life (QoL) refers to how well we live, i.e., the general well-being of people and societies. It is the standard of happiness, comfort, and health that a person or group of people experience. It is an inherently ambiguous and subjective term. Some people say the quality of life is about wealth and owning things, while others may define it in terms of physical, mental, and emotional well-being.

India has around 2.27 million adults living with HIV/AIDS who face several challenges in life. Stigma, discrimination, and psychosocial issues are prevalent. People living with HIV/AIDS (PLHA) must cope with a range of HIV-related symptoms (related to infection, comorbidities, or iatrogenic effects from HIV-related medications) for extended periods. A plethora of morbidities due to a crippling immune system reduces the quality of life. The advent of highly active antiretroviral treatment has changed this deadly disease to a chronic manageable illness, with the focus shifting from fighting the virus to ensuring a good QOL.

The development of antiretroviral drugs has significantly changed the perception of HIV/AIDS from a very fatal to a chronic and potentially manageable disease, and the availability and administration of antiretroviral therapy (ART) has significantly reduced mortality and morbidity associated with HIV and AIDS. With a newly emerging ageing HIV population comes a complex set of health-

related challenges that need to be considered and addressed. People ageing with HIV have many of the same health-related problems as the general population, including comorbidities and polypharmacy. But they are also at higher risk of experiencing other chronic illnesses such as cardiovascular disease, hypertension, Type-2 diabetes, and chronic kidney disease than those who do not have HIV. With this comes the need to take life-long treatment for their HIV, often consisting of multiple components for as many as 40 years or more. A host of issues, such as depression, anxiety, financial stress, and experiences of, or apprehension about, HIV-related discrimination, prevent many people living with HIV from relegating their HIV to the periphery of daily life. This can have a detrimental impact on their emotional wellbeing and health-related quality of life, day in day out.

Quality of life is an important component in the evaluation of the well-being of people living with HIV/AIDS (PLHIV). There is a relationship between ART and the quality of life of people living with HIV and AIDS, and several studies have reported a strong positive association between ART and improved quality of life in different domains among people living with HIV and AIDS in both developed and developing countries. However, a few studies have reported on the negative effects of ART, which directly or indirectly related to the quality of life and longevity of HIV-infected persons.

This study was aimed at evaluating the QoL of PLHIV attending the antiretroviral clinics in a tertiary care hospital in North Kerala. The study also looks into the association of selected socio-demographic factors, personal habits, and disease-related variables on the quality of life.

Methodology

A cross-sectional study was done on the quality of life of people living with HIV and AIDS attending ART-Clinic Calicut, a tertiary care unit in North Kerala where patients can check their CD4 count and get antiretroviral treatment free of cost. The study was conducted from over a period of 6 months with the help of two sets of questionnaires, part 1 to interview the subject on Socio-demography, Family details, Personal habits, Risk behavior, Disease-related details and part 2 to assess quality of life by WHOQoL-HIV instrument. The study included HIV-positive patients aged 18 years and above registered on ART for ≥ 6 months and checking CD_4 from ART clinic, and willing to participate in this study. Seriously ill subjects and those with psychiatric illness who could not be interviewed and are not in a state of providing information were excluded.

Sample Size

The sample size was calculated to be 310, using the formula $n = 4SD^2 / d^2$; where SD: 0.88, the standard deviation of the mean score (3.2) for overall quality of life in a similar study; and d: degree of precision. Based on an international study by O'Connell done in six culturally diverse sites, including two from India, using the WHO QoL-HIV questionnaire [1].

Sampling Method

Study subjects were selected from the ART register by simple random sampling, done with the help of computer-generated random numbers. Those who were dead were excluded. Out of 1221 eligible subjects 310 were selected. The selected study subjects were interviewed when they came to monitor their CD4 count.

Study Tool

The data was collected by using a semi-structured questionnaire.

Part I: Semi-structured questionnaire for subject interview by the investigator. It consists of questions for collecting data pertaining to the following characteristics, which include Socio-demographic characteristics, Personal and risk behavior, and medical details. Clinical details and CD_4 count were obtained from records.

Part II: WHOQOL-100, a 100 items quality of life assessment by WHO is too lengthy to be applicable in research where the quality of life is one of the many variables of interest. The abbreviated version with 26 items is more acceptable by subjects, especially those with illness.

Quality of life data was collected by WHO QoL-HIV instrument, which was field tested by WHO QoL HIV group in six centres across the world, including two centres in India. This instrument contains 29 facets, each with four items, which are subsumed in six domains and a general facet that measures the overall QoL. Items are rated on a 5- point Likert interval scale where 1 indicates low, negative perception and 5 indicates high positive perception. Facet scores are the mean of the four items in each facet. Domain scores are obtained by adding the facet means in the respective domain dividing by the number of facets in that domain and multiplying by 4. The domain scores range from 4 to 20. The worst possible QoL is 4 and best possible QoL is 20. The overall QoL facet score, which is the mean of four items measuring the quality of life and general health perceptions, ranges from 1 to 5. Score 1 represents the worst possible score and 5 the best possible score. The WHOQoL-HIV instrument was translated into the local language Malayalam, back-translated, and reviewed by a panel of three Clinicians, 5 drop-in centre coordinators, and six Medical Social Workers. This was initially piloted in 30 subjects. All domains were significantly correlated between each other and with overall QoL. Cronbach alpha was 0.92 for the six domains and overall QoL.

Quality of Life Domains

Physical domain - Includes pain, energy, sleep, and symptoms of PLWHA.

Psychological domain - Include positive/negative feelings, thinking, memory, and self-esteem.

Level of Independence domain- Includes wok capacity, activities of daily living and dependence on medication.

Social relationship domain- Includes personal relationships, social inclusion/support, and sexual activity.

Environment domain- Includes physical safety, home/physical environment, financial resource, and opportunities.

*Spirituality/Religion and Personal Beliefs (*SRPB)- Includes feelings of blame about his/her HIV status, concerns about future and worries about death.

Overall quality of life- Includes general quality of life and health perceptions.

Data Collection

This was done using the pretested semi-structured questionnaire for subject interview by the investigator and later by the pretested translated WHO QoL-HIV instrument which was administered to the subject and asked them to fill in their perception in the last two weeks. The subjects were interviewed in a room with good privacy. Unprobed, non-judgmental attitude and non-responsive body language was followed to minimize bias. About 3 to 4 subjects were interviewed per day. Clinical details, including CD_4 count values, were obtained from medical records.

Data Analysis

The data collected was coded and entered in an MS excel sheet and analyzed with SPSS statistical software. P value at ≤ 0.05 was considered significant.

Calculation of QoL Scores

QoL scores were calculated for each domain and for overall quality of life.

Domain- 1 (Physical)	=	{Facets (Pain + Energy + Sleep + Symptoms) / 4} $\times$ 4
Domain-II (Psychological)	=	{Facets (Positive feel + Cognitive + Esteem + Body +Neg. feel) / 5} $\times$ 4

Domain-III (Level of independence)	=	{Facets (Mobility + Activities of daily living +Dependence + Work) / 4} ×4
Domain-IV (Social relationships)	=	{Facets (Relationship + Support + Sex + Inclusion) / 4} × 4
Domain-V (Environment)	=	{Facets (Safety + Home + Finance + Care + Information + Leisure + Environment + Transport) / 8} × 4
Domain-VI (Spirituality/Religion/ Personal Beliefs)	=	{Facets (Forgive + Future + Death + Spirituality, Belief) / 4} × 4
Overall QoL	=	**The mean of four items measuring the quality of life and general health perceptions**

Mean QoL scores were taken. To understand the factors affecting overall QoL, participants were categorized into 2 groups based on mean score of the facet measuring overall quality of life and general health perceptions. Those with overall QoL score > 3 were rated as having good QoL and ≤ 3 as poor QoL. Statistical comparison was done by using chi-square test for categorical variables and t-test/ANOVA for continuous variables. To understand the factors affecting QoL domains, a multiple linear regression was done. Risk assessed by using odds ratio and level of significance was estimated with 95% confidence interval and p-value.

Ethical Concerns

The study protocol was approved by the Institutional Ethic Committee of Govt. Medical college, Calicut. Informed written consent was taken from the nodal officer of the ART clinic. Informed written consent was taken from the drop-in centre (Prathyasha) coordinator, Calicut. Informed written consent was taken from all study participants. Data from subjects were collected with adequate privacy. No invasive procedure was done. All information collected was kept strictly confidential.

Results & Discussion

Out of 1221 eligible subjects 310 were selected by simple random sampling, and 285 participated in the study. The overall response rate was 91.94%.

Characteristics of the Study Population

Out of 285 subjects, 205(71.9%) were males and 80(28.1%) were females. NFHS-3 data says that the prevalence of HIV in males is 0.36%, which is more than that in females 0.22%.[2] The mean age of the study population was 41.8 ± 7.5 yrs (23-73yrs). The mean age of males was 43 ± 7.3 yrs (23-73yrs), and females was 38 ± 6.7yrs (26-60yrs). Females had a significantly lower age compared to males and are often infected at an earlier age (t=5.3, df=283, p <0.001*). UN report (2001) says that Women are often infected at an earlier age than men [3]. Out of the 285 subjects, 164(80%) males and 78(97.5%) of females belong to the age group of 18-50 years. Most of the study subjects, 114(40%), belong to age group of 31-40 years. In the study, 54 (67.5%) females were less than 40 years of age as compared to 78(38%) males in this category (X^2 value = 20.07, df=1, p ≤ 0.001). Females had a higher risk of infection below 40 years of age as compared to males (OR= 3.38, CI= 1.89-6.06). NFHS-3 data shows that the maximum HIV prevalence is in the age group 30-40 years (0.46%) [4].

Table 1. Age-sex distribution of study population

Age group	Males (%) n=205	Females (%) n=80	Total (%) n=285
18-30	8 (3.9%)	10 (12.5 %)	18 (6.3%)
31-40	70 (34.1%)	44 (55 %)	114 (40%)
41-50	86 (42%)	24(30%)	110 (38.6%)
51-60	37(18%)	2 (2.5%)	39 (13.7%)
Above 60	4 (2%)	0 (0%)	4 (1.4%)

About 34 (11.9%) of subjects shifted their residence after diagnosis of HIV. Reasons for change of residence were that they didn't want others to know about their infection, and some said that they were asked to vacate their house.

A study done by NACO (2006) in six highly prevalent states reported a 12% shifted their residence after revealing their HIV status, and the major reasons were social stigma and unemployment [5].

Table 2. Distribution of Study Population based on Educational Status

Educational status	Male (%) n=205	Female (%) n=80	Total (%) n=285
Illiterate/ Just Literate	10(4.9%)	4(5.1%)	14(5%)
1-4 standard	23(11.2%)	9(11.3%)	32(11.2%)
5-7 standard	54(26.3%)	14(17.5%)	68(23.9%)
8-10 standard	101(49.3%)	36(45%)	137(48.1%)
Pre degree–Degree	17(8.3%)	14(17.5%)	31(10.9%)
Postgraduate and professional	0(0%)	3(3.8%)	3(1.1%)

Majority of study population, 271(95.1%), were educated with 137(48.1%) attending high school and 34(11.9%) being college educated. The literacy rate among male and female study populations was 96.1% and 96.3%, respectively, which is comparable to Kerala's status. In Kerala, the literacy rate for males is 96%, and that for females is 92% (census 2011) [6].

Table 3. Distribution of Study Population by Occupation and Gender

Occupation	Male (%) n=205	Female (%) n=80	Total (%) n=285
Not employed	22(10.7%)	13(16.2%)	35(12.3%)
Housewife	-	29(36.2%)	29(10.2%)
Manual laborer	25(12.2%)	7(8.7%)	32(11.2%)
Unskilled worker	8(3.9%)	7(8.7%)	15(5.3%)
Semiskilled worker	35(17.1%)	5(6.3%)	40(14%)
Skilled worker	87(42.4%)	9(11.3%)	96(33.7%)
Clerical / Office job	11(5.4%)	5(6.3%)	16(5.6%)
Business/Shop owner	14(6.8%)	0(0%)	14(4.9%)
Professional	2(1%)	4(5%)	6(2.1%)
Pension	1(0.5%)	1(1.3%)	2(0.7%)

About 22 (10.7%) of males were unemployed. 29 (36.2%) of females were housewives, and the work participation of females was found to be high. Among employed subjects, 96(33.7%) were skilled workers, and among skilled workers (47), 49% were drivers. Those in office jobs, business, and professionals were a small group in study 36 (12.6%). Probably they may be availing services from the private sector. Work participation of females, according to the Kerala census (2001), is 14.5% [7]. The report

of KSACS on behavioral surveillance survey shows that clients of female sex workers include drivers (21%), skilled workers (20%), unskilled workers(18%), business/trade (17%), clerical(10%), manual labourer (7%) and executive/supervisory(2%) [8].

Most study subjects belong to nuclear family 164 (80.4%) and 41(19.7%) belong to the joint family. The mean number of members in the family was 4.6 ± 2.2 (Range = 1 to 14) NFHS-3 data shows that 60.5% of the Kerala population belongs to the nuclear family and 39.5% belongs to the joint family [2].

Table 4. Marital Status and Gender

Living arrangement	Male (%) n= 205	Female (%) n=80	Total (%) n=285
Unmarried	25(12.2%)	0(0%)	25(8.8%)
Married living together	163(79.5%)	34(42.5%)	197(69.1%)
Separated / Divorced	15(7.3%)	8(10%)	23(8.1%)
Widowed/er	2(1%)	**38(47.5%)**	40(14%)

The study included 80 female subjects, and all were married. Among married study subjects, 38(47.5%) females and 2(1%) males lost their legal partner, and the risk was 80.52 (range: 17.9 to 503.37) times higher in females. A study done by NACO in six highly prevalent states reported that 36.1% of females were widowed, and 7.4% were separated or divorced [9]. HIV-related social stigma leads to unemployment and loss of income among PLHA [9]. The socio-economic status of study subjects based on Modified Kuppuswamy's classification is given in Table 5.

The majority of study subjects, 202(70.9%), belong to lower and upper lower groups of social class. Patients with high socio-economic status may be taking treatment from private hospitals.

The living arrangement of study subjects with respect to HIV-infected persons in the family are given in Table 6.

Table 5. Socioeconomic Status of Study Population

Socio-Economic status	Number of subjects n=285	Percentage (100%)
I - Upper class	1	0.4%
II – Upper middle	8	2.8%
III- Lower middle	74	26%
IV- Upper lower	195	68.4%
V- Lower lower	7	2.5%

Table 6. Distribution of HIV in the Family and Living Arrangement

HIV in the family	Living arrangement n=285			
	Unmarried n=25	Married living together n=197	Separated/Divorced n=23	Widowed/er n=40
Only self-affected	25(100%)	78(39.6%)	13(56.5%)	
Partner also affected		107(54.3%)	8(34.8%)	36(90%)
Children with both parents affected		12(6.1%)	2(8.7%)	4(10%)

Out of 260 married subjects 18(6.9%) were separated and 5(1.9%) were divorced. Among married females, 38(47.5%) were widowed. Considering married subjects, the chance of separation was higher when only one partner was infected, 13(56.5%), as compared to both partners infected, 10(43.5%), but this was not significant (OR=1.98, CI= 0.77-5.17).

In a focus group discussion in Pune (2001), it was noted that the ultimate impact of a husband getting the disease first is that the wife will become a widow, and if the husband becomes infected, the wife will support him, but if the wife alone is infected or if the husband has other partners it will end up in separation [10].

Personal Habits and High-Risk Behaviors

22(10.7%) of males were current smokers, while 52.2% of males were ever smokers. According to a Global adult tobacco survey by WHO, the prevalence of smoking among adult males in Kerala is 27.9% [11].

22(10.7%) of males were currently using alcohol while 118(57.6%) reports ever use of alcohol. NFHS-3 data for Kerala shows that the prevalence of alcohol use among males is 45% [2].

5(2.4%) of males used illicit drugs but gave up the habit after starting ART. Among them, 4(2%) people gave the history of injecting drug use. NACO annual report (2010-'11) shows that in India, 1.6% of HIV infection is transmitted by contaminated needles used for injecting illicit drugs [12], and KSACS sentinel surveillance data reports that among high-risk groups, the HIV prevalence is 7.85% in intravenous drug users [13].

172(86%) of males gave prior sexual contact with female sex workers. 24(8.4%) showed homosexual behavior. 4(2%) gave the history of Intravenous drug use and needle sharing. All gave up their high-risk behavior after starting ART. None of the females reported any risky behavior.

KSACS sentinel surveillance data[13] reports that among high-risk groups, the HIV prevalence is 0.87% in female sex workers, 0.96% in men having sex with men and 7.85% in intravenous drug users. KSACS HIV sensitization data report [14] that among different modes of HIV transmission, 85.71% are through the sexual route, 1.81% by contaminated needles used for injecting illicit drugs, 1.72% by blood and blood products, 4.5% by the parent to child transmission and 6.26% unidentified [13].

Age at Diagnosis of HIV

The mean age at diagnosis in males of 39.9 ± 7.6 years (21-66) is higher than that of females, 34.5 ± 7.3 years (19-59), but this difference is not significant (t=1.12, df=283, p=0.26). Most of the females are tested after the male partners become positive. Moreover, antenatal screening for HIV is a part of the AIDS control programme. All these probably lead to an early age of detection for females in this group. UN report (2001) says that Women are often infected and detected at an earlier age than men [3].

The mean period since diagnosis of infection was 3.7 ± 2.6, (Range 1-15) years for females, which were higher compared to males, 3.3 ± 2.3, (Range 1-15) years but this difference is not significant (t=1.1, df=283, p=0.26). In our study, the infection was diagnosed among females at a younger age compared to males and 40(50%) of them reported that their husband died due to the infection. This explains the increased duration since diagnosis among females. Starting antiretroviral treatment in the early stage of infection boosts the immune system and reduces the risks of HIV-related death and disease [14].

Time period since diagnosis to initiation of ART ranges from 1 month to 10 years. In the study males started treatment earlier 173(76.2%) compared to females and this difference is significant ((X^2=10.13, df=1, p=0.002*) and the odds ratio being 2.6(CI= 1.37-4.96). This may be because, in males, the diagnosis was delayed compared to females, in which case the immune status may be low, leading to the early start of ART.

The mean period of ART was 3.9 ± 2.4, (Range- 0.6 to 14.4) years for males, which were higher compared to females, 2.8 ± 1.9,

(Range- 0.6 to 8.7) years, but this difference is not significant (t=0.96, df=283, p=0.34).

The late diagnosis followed by early treatment among males on contrary to females maybe the reason for their long treatment duration.

Default in ART

18(6.3%) defaulted ART drugs of which 13(72.2%) were males and 5(27.8%) were females. The mean duration of default was 9.2 ± 3.9 months. The reasons for default are given in Table 7.

Table 7. Reasons for Default in Treatment with Mean Duration and Gender

Reasons for default	Male (%) n=13	Female (%) n=5	Total (%)
Lack of time	5(38.4%)	0(0%)	5(27.8%)
Side effects to ART drugs	2(15.4%)	3(60%)	5(27.8%)
Hospitalization for other disease	3(23.1%)	0(0%)	3(16.6%)
Others- feeling better, didn't bother,etc.	3(23.1%)	2(40%)	5(27.8%)

Among the subjects, 267(93.7%) consumed drugs regularly, probably because they were counseled on the need for regular consumption of ART. ART centres will provide counseling for antiretroviral drug preparedness, and adherence counseling will be given at each monthly visit explaining the importance of regular drug intake.

Table 8. Distribution of Study Population based on CD4 Count and Gender

CD4 count	Male n=205(%)	Female n=80(%)	Total 285(100%)
≤ 200	19(9.3%)	2(2.5%)	21(7.4%)
201- ≤500	108(52.7%)	35(43.8%)	143(50.2%)
501- ≤1000	74(36%)	37(46.2%)	111(38.9%)
>1000	4(2%)	6(7.5%)	10(3.5%)

CD4 Count of Study Subjects

The mean CD_4 count of females, 573 ± 287(Range: 30-1780), was found to be higher than males 461 ± 229 (Range: 46-1325), and this difference is found to be significant (t=3.4, df=283, **P = 0.001***). In females, the infection may be detected early as soon as their partner becomes positive and may start the ART early probably explains their improved CD4 status.

CD_4 levels in relation to the severity of immune suppression given by WHO[121] (2005) is that there is no significant immune suppression if CD_4 >500/mm3, mild immune suppression if CD_4 between 350 − 499/mm3, advanced immune suppression if CD_4 between 200 −349/mm3 and severe immune suppression if CD_4 <200/mm.

Among study subjects, only 15(5.3%) reported some form of opportunistic infections in a 3-month period. This may be due to the antiretroviral treatment. The majority, 12(4.2%), suffered from Tuberculosis. CMV was reported by a person with CD4 less than 200. Other infections include Herpes1(0.4%) and Candidiasis (0.4%). No opportunistic infection was reported for those with CD4 count 1000 or more, showing improved immune status. TB is the most common opportunistic infection among people living with HIV/AIDS in India.[15] HIV-infected persons have approximately an 8 times greater risk of TB than persons without HIV infection [15].

Quality of Life (Qol)

The quality of life of persons living with HIV/AIDS was assessed using WHOQoL-HIV scale. It contains 29 facets which is subsumed as 6 domains, and 1 facet which measures the overall quality of life.

Facet scores and overall QoL range from 1 to 5 and domain scores, which is the average of facet score multiplied by 4, range from 4 to 20. *Domain scores more than 12 and overall QoL score more than 3 are considered as improved score.*

Indicators of Quality of Life

The scores for different aspects of the quality of life of study subjects are given below in Table 9.

Table 9. Quality of Life of PLHA

Indicators of QoL	Mean Score	SD of Score
Domain-I (Physical)	14.56	2.2
Domain-II (Psychological)	14.12	2.2
Domain-III (Level of independence)	14.52	2.04
Domain-IV (Social relationship)	13.16	2.1
Domain-V (Environment)	13.44	2.12
Domain-VI (Spirituality, Religion and Personal belief)	11.6	2.7
Overall QoL	**3.32**	**0.75**

In our study, spirituality, religion and personal belief domain, which includes the feeling of blame about his/her HIV status, concerns about the future, and worries about death shows a poorer score. The physical domain, level of independence domain, psychological domain, Environment domain, and social relationship domain showed highest scores in order.

Overall QoL

The current study shows a good overall quality of life and general health perception score of **3.32 ± 0.75**. This is comparable to study done by O'Connell at six culturally diverse sites (Australia, Brazil, Bangalore & Delhi from India, Thailand, and Zimbabwe) (3.2 ± 0.88) and the study done by Venter in South Africa (3.36 + 0.77) [1, 27]. The overall quality of life and general health perception score in studies done at Manipur and Estonia are found to be showing poorer scores as compared to our study [17, 19].

Physical Domain

The current study shows a better physical domain score of **14.56 ± 2.2** which includes pain, energy, sleep, and symptoms of PLWHA. This score is comparable to a study done at Brazil. Studies were done at Bangalore [21],

Ethiopia [25], and Nigeria [26] show a higher score than our study. Studies done at Puducherrry [16], Varanasi [23], Manipur [17], Bangladesh [20], Ethiopia [25], and South Africa [18] are showing a lower but comparable score to our study. Another study done at Varanasi by Yogit raj etal in persons showing AIDS-related symptoms shows the lowest score of 7.87 ± 1.83 for the physical domain [22].

Psychological Domain

The current study shows a better psychological domain score of **14.12 ± 2.2** which includes positive/negative feelings, thinking, memory and self-esteem. This score is comparable to studies done at Varanasi [23], Estonia [19], Brazil [24], and South Africa [18]. Studies were done at Bangalore [21], Ethiopia [25], and Nigeria [26] show a higher score than our study. Studies were done at Puducherry [16], Manipur [17], and Bangladesh [20] are showing a lower but comparable score to our study. Another study done at Varanasi by [22] in persons showing AIDS-related symptoms shows the lowest score of 8.5 ± 1.54 for the psychological domain.

Table 10. Comparison of Domain Scores in Different Studies

Author	Overall QoL	Physical domain	Psychological domain	Level of independence	Social relations	Environment domain	Spirituality/ personal belief domain
	Mean score (SD)	Mean score (SD)	Mean score (SD)	Mean score (SD)	Mean score (SD)	Mean score (SD)	Mean score (SD)
Current study (Kerala)	*3.32 (0.75)*	*14.56 (2.2)*	*14.12(2.2)*	*14.52 (2.04)*	*13.16 (2.1)*	*13.44 (2.12)*	*11.6 (2.7)*
T.Mahalakshmi et al (Puducherry, India; 2011) [16]	3.38 (0.68)	13 (4.5)	12.7 (4)	14.7 (4.1)	13.6 (3.7)	14.5 (3.1)	12.7 (2.5)
Lamkang et al (Manipur, India; 2009) [17]	2.89 (0.69)	12.44 (0.83)	12.72 (0.67)	12.28 (0.79)	11.84 (0.81)	11.56 (0.68)	-
Karl Peltzer et al (South Africa; 2008) [18]	2.8 (1)	13.2 (3.2)	13.9 (2.8)	12.6 (3.1)	14 (2.8)	12.2 (2.2)	14.4 (3.5)
Kristi ruutel etal (Estonia, 2009) [19]	2.9 (0.84)	13.3 (3.2)	13.7 (2.3)	14.5 (3.2)	13.9 (2.6)	12.3 (2.1)	12.8 (2.9)
Imam et al (Bangladesh; 2011) [20]	3.14 (0.93)	12.41 (3.03)	11.63 (2.62)	12.21 (2.28)	12.98 (2.4)	11.8 (1.77)	13.37 (3.21)
P.S Chandra et al (Bangalore; 2009) [21]	-	15.88 (2.2)	15.35 (1.73)	16.49 (2.1)	13.14 (2.29)	14.77 (1.42)	13.9 (2.43)
Yogit raj et al (Varanasi; 2008) [22]	-	7.87 (1.8)	8.5 (1.5)	8.57 (1.59)	9.17 (2.59)	8.78 (1.5)	6.93 (1.26)
Manoj Kumar et al (Varanasi; 2009) [23]	-	13.32 (1.93)	14.48 (2.26)	-	13.52 (4.34)	13.96 (3.03)	-
Elisabete Cristina et al (Brazil; 2007) [24]	-	14.6 (2.8)	14.9 (2.8)	-	14.2 (3.6)	13.5 (2.3)	-
Amare Deribew et al (Ethiopia; 2009) [25]	-	15.04 (304)	15.6 (2.85)	13.34 (3.2)	12.9 (3.2)	11.99 (2.9)	17.17 (3.35)
A.AFatiregun et al (Nigeria; 2009) [26]		15.2 (2.5)	15 (2.8)	14.2 (1.9)	13.2 (2.5)	13.1 (1.9)	15.7 (3.4)

Level of Independence

The current study shows a better level of independence domain score of **14.52 ± 2.04,** which includes work capacity, activities of daily living, and dependence on medication. This score is comparable to studies done at Puducherry [16], Estonia [19], and Nigeria [26]. Study done at Bangalore shows a higher score than our study. Studies done at Manipur [17], Bangladesh [20], Ethiopia [25] and South Africa [18] are showing lower but comparable scores to our study. Another study done at Varanasi by Yogit [22] in persons showing AIDS-related symptoms shows the lowest score of 8.57 ± 1.59 for the level of independence domain.

Social Relationship Domain

The current study shows a better social relationship domain score of **13.16 ± 2.1** which includes personal relationships, social inclusion/support and sexual activity. This score is comparable to studies done at Puducherry [16], Bangalore [21], Varanasi [23], Bangladesh [20], Ethiopia [25] and Nigeria [26]. Studies done at Estonia, Brazil and South Africa shows a higher score than our study while Manipur shows a low score. Study done at Varanasi by Yogit raj etal [22] in persons showing AIDS related symptoms shows lowest score of 9.17 ± 2.59 for Social relationship domain.

Environment Domain

The current study shows a better Environment domain score of **13.44 ± 2.12** which includes physical safety, home/physical environment, financial resource, and opportunities. This score is comparable to studies done at Varanasi by Manoj Kumar [23], Brazil [24], and Nigeria [26]. Studies done at Puducherry [16] and Bangalore [21] show a higher but comparable score than our study. Studies done at Manipur [17], Bangladesh [20], Estonia [19], Ethiopia [25], and South Africa [18] show a lower but comparable score to our study. A study done at Varanasi by Yogit raj [22] in persons showing AIDS-related symptoms shows the lowest score of 8.78 ± 1.5 for the level of independence domain.

Spirituality, Religion and Personal Belief Domain

The current study shows a lower score for spirituality/ religion/ personal belief domain of **11.6 ± 2.7,** which includes the feeling of blame about his/her HIV status, concerns about the future and worries about death. Studies were done at Ethiopia [25], Nigeria [26], South Africa [18], Puducherry [16], Bangalore [21], and Estonia [19] shows higher scores than our study. A study done at Varanasi by Yogit raj etal [22] in persons showing AIDS-related symptoms shows the lowest score of 6.93 ± 1.26 for spirituality/ religion/ personal belief.

Factors Affecting Quality of Life

For understanding the factors affecting QoL participants were categorized into 2 groups based on mean score of the facet measuring overall quality of life and general health perceptions. *Those with overall QoL > 3 were rated as good QoL and ≤ 3 as poor QoL.*

Table 12. Factors Affecting Quality of Life

		Overall QoL score		Odds ratio	95% CI
		≤3 n (%)	>3 n (%)		
Age	≤40 years (n=132)	**62(47%)**	70(53%)	1.37	0.86-2.2
	>40 years (n=153)	**60(39.2%)**	93(60.8%)		
Gender	Male (n=205)	**124(60.5%)**	81(39.5%)	1.61	0.93-2.8
	Female(n=80)	**39(48.8%)**	41(51.3%)		
Place of residence	Urban(n=46)	**21(45.7%)**	25(54.3%)	1.15	0.58-2.26

	Rural(n=239)	**101(42.3%)**	138(57.7%)		
Change of residence	Yes(n=251)	**108(43%)**	143(57%)	1.08	0.52-2.23
	No(n=34)	**14(41.2%)**	20(58.8%)		
Educational status	≤7th standard(n=114)	**49(43%)**	65(57%)	1.01	0.63-1.63
	>7th standard(n=171)	**73(42.7%)**	98(57.3%)		
Occupational status	Unemployed(n=62)	**35(56.5%)**	27(43.5%)	**2.03**	**1.15-3.58**
	Employed(n=223)	**87(39%)**	136(61%)		
Family type	Nuclear family (n=229)	**95(41.5%)**	134(58.5%)	1.32	0.73-2.38
	Joint family (n=56)	**27(48.2%)**	29(51.8%)		
Family income	≤ 4000 (n=166)	**72(43.4%)**	94(56.6%)	1.06	0.64-1.75
	>4000 (n=119)	**50(42%)**	69(58%)		
Socio-economic status	Lower(n=202)	**91(45%)**	111(55%)	1.38	0.81-2.32
	Upper, Middle(n=83)	**31(37.3%)**	52(62.7%)		
Living arrangement	Separated/ Widowed/ Divorced (n=63)	**39(61.9%)**	24(38.1%)	**2.7**	**1.45-5.06**
	Married living together(n=197)	**74(37.6%)**	123(62.4%)		
HIV in family	Parents and Children infected(n=18)	**9(50%)**	9(50%)	1.08	0.67-1.7
	Single / Both partners infected (n=267)	**113(42.3%)**	154(57.7%)		
Peer group social support	Present(n=73)	**28(38.4%)**	45(61.6%)	1.28	0.72-2.29
	Absent(n=212)	**94(44.3%)**	118(55.7%)		
Addictive behavior (Smoking, Alcohol, IDU, Drugs)	Never user (n=119)	**58(48.7%)**	61(51.3%)	1.52	0.94-2.44
	Current/Ever user (n=166)	**64(38.6%)**	102(61.4%)		
Clinical staging	Stage 2&above(n=83)	**38(45.8%)**	45(54.2%)	1.19	0.69-2.05
	Stage 1(n=202)	**84(41.6%)**	118(58.4%)		
Duration of ART	≥ 3 years(n=128)	**60(46.9%)**	68(53.1%)	1.35	0.82-2.23
	< 3 years(n=157)	**62(39.5%)**	95(60.5%)		
CD4 count	≤ 200(n=21)	**15(71.4%)**	6(28.6%)	**3.67**	**1.38-9.76**
	>200(n=264)	**107(40.5%)**	157(59.5%)		
Opportunistic infection	Present(n=16)	**10(62.5%)**	6(37.5%)	2.34	0.75-7.47
	Absent(n=269)	**112(41.6%)**	157(58.4%)		

62(47%) of study subjects at or below 40 years and 60(39.2%) above 40 years had poor overall quality of life scores. Those at or younger than 40 years are showing poor quality of life, but this difference is not statistically significant (OR=1.37, CI=0.86-2.2). [16] in her study had also reported that as age increases social relationship determinant of quality of life improves (B value=0.19, P=<0.001), O' [1] reported that older patients(>30yrs) had lower negative feelings and had better QoL and [28] reported that women younger patients (<35 yrs) were associated with a lower QoL. However, a study done in Estonia by [19] reported that those of younger age of less than 30 years (45%) showed a good quality of life than ≥30 years (28.7%).

124(60.5%) of the male study subjects and 39(48.8%) of females were showing good overall quality of life score. Males are showing better overall quality of life but is not statistically significant. (OR: 1.61, CI: 0.93-2.8)

Study done in Ethiopia by [29] reported a better QoL for males. Study done by [21] in Bangalore had reported that males had better Environmental aspect of quality of life) while females had better Spirituality, Religion and Personal belief aspect of quality of life. [24] study showed a significantly better Environmental and Psychological quality of life score for males than females. In contrast to the above a study done in Estonia by [19] and a study done in Bangladesh by [20] reported that females had 21(45.7%) from urban area and 101(42.3%) of the study subjects from rural area had poor overall quality of life score. Those belonging to urban area had a poorer overall quality of life score, but the difference is not statistically significant (OR=1.15, CI= 0.58-2.26). In contrast according to study done in Varanasi by [23] and in Bangladesh by [20] showed that those belonging to Urban areas had significantly higher QoL scores compared to those from Rural area.

108(43%) of the subjects who changed their residence after being diagnosed with HIV/AIDS and 14(41.2%) who had not shifted had an overall poor quality of life but not significantly different (X^2= 0.42, df=1, P=0.84). A study done by NACO in six high prevalent states reported that the major reasons for change of residence after diagnosing HIV infection were social stigma and Unemployment [9].

49 (43%) of subjects with primary or lower education and 73(42.7%) high school and above education had poor quality of life. In this study the Level of education was not significantly associated with quality of life (OR= 1.01, CI= 0.63-1.63). Studies done at Puducherry [16], Varanasi study [23] and Estonian study [19] had reported that educational status of study subjects was not associated with quality of life. However, [30] study showed a significantly improved quality of life in the psychological domain for subjects with higher educational status.

In this study 35(56.5%) of unemployed and 87(39%) employed had poor overall quality of life (X^2=6.03, df=1, **P=0.014*).** The Unemployed had a significantly high risk for poor overall quality of life compared to employed. (OR= 2.03, CI= 1.15-3.58). Other studies also report similar findings. Study done in Estonia [19] and a Bangladesh study by [20] reported a good QoL score among those who were employed compared to unemployed. [30] study done in New Delhi showed a good QoL scores in Physical and Environmental domains for those who were employed.

In the study 95(41.5%) of those belonging to nuclear family and 27(48.2%) of those from joint family had poor overall quality of life but this difference is not statistically significant (OR=1.32, CI=0.73-2.38). Care and support for PLHA may be more in nuclear families. As HIV infection possess social stigma chance of discrimination may be more if other families living with them realize their infection. In the study done by [25] in Ethiopia reported that family support improves QoL of PLHA. According to studies done by [4] in several international centres and Subramanian et al[5] reported that social stigma decreases QoL.

91(45%) of those from lower socio-economic status and 31(37.3%) of those from middle/upper socio-economic status had low overall quality of life. Those with low socio-economic status had poor overall quality of life but not statistically significant (OR=1.38, CI=0.81-2.32). A study done at South Africa, [18] Puducherry study [16], study by Imam et al in Bangladesh [20] found that good socioeconomic status is a significant predictor of overall QoL.

39(61.9%) of those separated/widowed/divorced and 74 (37.6%) married living together had poor overall quality of life (X^2 value=11.51, df=1, P= 0.001*). Those who are separated/ widowed/ divorced have a significantly poor overall quality of life compared to married living together (OR=2.7, CI= 1.45-5.06).

Similar results were reported from Estonian [19], Varanasi [23], Chennai [5] and Lebanon

[31] studies which showed a significantly good QoL score among those married living together.

9(50%) of those in which both parents and children infected and 113(42.3%) only single or both parents infected had poor overall quality of life but not significant. (OR=1.08, CI=0.67-1.7). [30] study done in New Delhi and in China [32] reported that patients with family support had better QoL scores.

94(44.3%) of study subjects with no social support from peer group and 28(38.4%) with social support had poor overall quality of life. The odds of having a QoL score above 3 was 1.28 times higher in those with social support (CI= 0.72 - 2.29). Mean QoL score for those with social support was higher, 3.7(±0.78) compared to 3.2(±0.69) for those with no social support and this difference is significant. (t= 4.7, df=114, **P= <0.001***). Studies done at Puducherry [16], China by [32], Taiwan by [33], Ethiopia by [27] and Venezuela by [34] reported that better social support and peer counseling had significant positive influence on quality of life. 64(38.6%) of those who showed addictive behavior current/Past and 58(48.7%) of those with no addictive behavior had a poor overall quality of life but this difference is not statistically significant (X^2 value: 2.94, df: 1, P 0.091). Improved scores among current users may have been subjective as addictive substances will elevate mood and ever user may have subjective feeling of being better after stopping substance use. [35] Estonian [19] and [36] studies done in USA reports lower QoL scores for those who used recreational drugs and intra venous illicit drugs. 38(45.8%) of clinical stage 2 and above and 84(41.6%) of those in stage 1 had poor overall quality of life. Those subjects with clinical stage 2 and above had poor overall quality of life compared to those in stage 1 but not significant (OR= 1.19, CI= 0.69-2.05) [16] reported that early stage of the infection has significant positive influence on all domains of QoL. [19] study reported that those in the AIDS category had poor QoL compared asymptomatic HIV positives. [24]

reported an inverse relationship between stage of disease and quality of life. [30] study showed a poor Psychological QoL scores for symptomatic and AIDS patients.

62(39.5%) of study subjects with ART treatment less than 3 years and 60(46.9%) with more than or equal to 3 years had poor overall quality of life but not significant (OR=1.35, CI=0.82-2.23). [38] in their study in French people reported that difficulties as a result of adverse HIV treatment reactions lower QoL. [14] study done in Canada reported that ART has the potential to confer significant benefits by controlling HIV disease and extending life, while posing unpleasant side effects that erode QoL.

Those with CD_4 count ≤200cells/µL, 15(71.4%) and those above 200cells/µL, 107(40.5%), had significantly poorer overall quality of life (X^2 = 7.59, df= 1, **P= 0.006***).Those with a CD_4 count of 200 or below had 3.67 times higher risk of poor quality of life(OR=3.67, CI=1.38 - 9.76). This is like other reports. A study by [21] and a study done in Bangladesh by [20] found that those with CD_4 counts <200/µL had significantly lower quality of life. Study done in Estonia by [19] reported a good QoL score for those whose CD_4 count ≥300/ µL. Study done at Varanasi [23] and China [32] showed that those who had higher CD_4 count had good QoL score. 10(62.5%) of those with opportunistic infections and 112(41.6%) without infections had a poor overall quality of life but not significant. Those with opportunistic infections have poor overall quality of life but not found to be statistically significantly different (OR= 2.34, CI= 0.75-7.47). A study done in Estonia by [19] and [20] in Bangladesh reported a poor QoL score for subjects with opportunistic infections.

Association of QoL with Various Factors – Multivariate Analysis

The variables which were significantly associated with poor overall QoL on univariate

analysis were considered for binary logistic regression. The adjusted odds ratio and 95% CI are given in Table 13.

Table 13. Adjusted Odds Ratio and 95% CI of Factors affecting Poor Overall QoL

Factors		Adjusted odds	95% CI	P-value
Occupation	Unemployed vs	2.14	1.19-3.87	**0.011***
	Employed			
Living arrangement	Single/separated/divorced vs	2.36	1.39-4	**0.002***
	Married living together			
CD4 count	≤200	5.06	1.84-13.86	**0.002***
	>200			

10.9% of variation in the overall QoL of this study is explained by the above logistic model ($R^2 = 0.109$). The overall accuracy of this model to predict QoL is 63.5%. The sensitivity is 51.6% and specificity is 72.4%. Increased risk of poor quality of life was seen in the unemployed (2.14 times), single/separated/divorced (2.36 times) and those who have a CD4 count 200 cells/mm³ or below (5.06 times). A multivariate analysis of factors including occupation, living arrangement and CD$_4$ status affecting overall QoL by Kristi ruutel etal[19] reported that unemployment was significantly associated with poor QoL (AOR=2.27, CI=1.18-4.38).

Multiple Linear Regression of Factors Influencing QoL Domains of PLHA

Multiple linear regression was done and the variables which were significantly associated with the various domains of QoL are given in Table below.

Table 14. Factors Influencing QoL Domains 1 and 2

Factors		Domain 1		Domain 2	
		Adj. R^2=0.14		Adj. R^2=0.17	
		B value	P	B value	P
Occupation	Unemployed	-	**-**	0.24	**0.016***
	Employed				
Socio-economic status	Kuppuswamy 3 to 29 score	-	**-**	-0.15	**0.04***
Living arrangement	Married living together	- 0.16	**0.039***	-	**-**
	Others				
HIV in family (Infection in children)	Absent	-0.59	**<0.001***	-0.47	**<0.01***
	Present				
Social support	Absent	0.37	**<0.001***	0.45	**<0.01***
	Present				
Duration of ART	Increasing duration	-0.01	**0.021***	-	**-**
Opportunistic infections	Absent	-	-	-0.32	**0.02***
	Present				

In the current study Physical domain of QoL was significantly higher among those who were married and living together, whose children were not HIV infected, those who were availing peer group support, those who were in the early periods of ART and those who were not suffering from opportunistic infection. Similar results were obtained in a study done by Imam et al in Bangladesh who reported that Physical QoL was better for those who were employed, those who had social support, those in the early stages of infection and those who were not suffering from opportunistic infection [20]. Puducherry study reports that those who were

availing peer group support and taking ART had significantly improved physical quality of life [16]. Preau et al study in French people reported improved Physical QoL among those who were married living together and whose children were not HIV infected [38]. Study done in Iran by Marzieh et al reported better Physical QoL for those married living together [39]. In the current study psychological domain of QoL was significantly higher among those who were employed, those who had high socio-economic status, those whose children were not HIV infected, those who were availing peer group support and those who were not suffering from opportunistic infection. Similar results were obtained in a study done by Imam et al in Bangladesh [20] who reported that Psychological QoL was better for those who were employed, those who were availing peer group support and those who were not suffering from opportunistic infection. Puducherry study [16], New Delhi [1] and study done in Belgium by [25] reports that those who got higher income and those who were availing peer group support had better Psychological QoL.

Table 15. Factors Influencing QoL Domains 3 and 4

Factors		Domain 3		Domain 4	
		Adj. R^2=0.12		Adj. R^2=0.21	
		B value	P	B value	P
HIV in family (Infection in children)	Absent	-0.33	**0.007***	-0.27	**0.02***
	Present				
Social support	Absent	0.37	**<0.01***	0.56	**<0.01***
	Present				
Opportunistic infections	Absent	-0.29	**0.03***	-0.26	**0.05***
	Present				

In the current study Level of independence and social relationship domains of QoL were significantly higher among those whose children were not HIV infected, those who were availing peer group support and those who were not suffering from opportunistic infection. Similar results were obtained in a study done by Imam et al in Bangladesh who reported that Level of independence and social relationship domains of QoL were significantly higher among those who were availing peer group support and those who were not suffering from opportunistic infection [20]. Puducherry study reports that those who had social support had better Level of independence and social relationship domains of QoL [16].

Table 16. Factors Influencing QoL Domains 5 and 6

Factors		Domain 5		Domain 6	
		Adj. R^2=0.23		Adj. R^2=0.35	
		B value	P	B value	P
Occupation	Unemployed			0.38	**0.001***
	Employed				
Family income	0 to 20,000 INR			4.7	**0.006***
Socio-economic status	Kuppuswamy 3 to 29 score			-0.06	**0.007***
Living arrangement	Married & living together			-0.24	**0.004***
	Others				

HIV in family (Infection in children)	Absent	-0.70	**<0.01***	-0.37	**0.007***
	Present				
Social support	Absent	0.51	**<0.01***	0.83	**<0.01***
	Present				
Opportunistic infections	Absent	-0.29	**0.028***	-0.42	**0.007***
	Present				

In the current study Environment domain of QoL was significantly higher among those whose children were not HIV infected, those who were availing peer group support and those who were not suffering from opportunistic infection. Similar results were obtained in a study done by [24] in Bangladesh who reported that Environment domain of QoL was significantly higher among those who were availing peer group support and those who were not suffering from opportunistic infection. Puducherry study [16] reports that those who had social support had better Environment domain of QoL.

In the current study Spirituality/Religion and Personal beliefs domain of QoL was significantly higher among those who were employed, those who had good family income, those who had high socio-economic status, those who were married and living together, those whose children were not HIV infected, those who were availing peer group support and those who were not suffering from opportunistic infection.

Similar results were obtained in a study done by Imam et al in Bangladesh who reported that Spirituality/Religion and Personal beliefs domain of QoL was significantly higher among those who were employed and those who were availing peer group support [20].

Conclusion

The current study shows a good overall quality of life. The study shows a better score for physical domain, psychological domain, independence domain, social relationship domain, Environment domain but a lower score for spirituality/ religion/ personal belief domain. Social support given to PLHA was found to be an independent determinant which significantly improves Overall QoL and all its domains. Absence of HIV infection among children significantly improves all domains of QoL. Absence of opportunistic infection significantly improves all domains except Physical domain which shows improvement but not significant. All factors that improve Overall QoL were found to be improving all six domains of QoL.

Limitations

1. People living with HIV and AIDS and taking antiretroviral treatment from the private sector could not be included in the study due to feasibility issues.
2. Reporting bias may be there in relation to sexual practices and substance use.

Declaration

Conflict of Interest

Author declares that there is no conflict of interest.

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