

## **Quality of life of the people living with HIV/AIDS registered in designated anti retro viral treatment centres in Assam (North East, India)**

**DHRUBA JYOTI BORAH<sup>\*1</sup>, RATAN KUMAR KOTOKEY<sup>2</sup>, PRANJYOTI KALITA<sup>3</sup> AND DIMPLE BARUAH<sup>4</sup>**

<sup>1&3</sup>Ph.D. Scholar, <sup>2</sup>Retd. Professor and <sup>4</sup>Resident Medical Officer

<sup>1&3</sup>Srimanta Sankaradeva University of Health Sciences, Guwahati (Assam) India

<sup>2</sup>Assam Medical College and Hospital, Dibrugarh (Assam) India

<sup>4</sup>The Assam Valley School, Balipara, Tezpur (Assam) India

### **ABSTRACT**

**Background:** HIV/AIDS has become endemic disease in the world since its first detection in 1981. Globally 36.7 million people are estimated to be living with HIV/AIDS with occurrence of new infection of 2.1 million in 2015. In India, first case was detected among FSW in Chennai in 1986 and since then HIV/AIDS has emerged as the most dreaded killer disease till advent of Anti Retro Viral drugs. The quality of life of people was extremely low as HIV/AIDS was a virtual death sentence. The ART drugs gave PLWHAs longevity, productivity and quality of life.

**Objective:** To assess the Quality of Life of the people living with HIV/AIDS who are newly initiated on ART Drugs.

**Methodology:** The study is an observational longitudinal study conducted in three ART Centres in Medical Colleges of Assam in Dibrugarh, Guwahati and Silchar. WHO QOL BREF questionnaire and structured interview schedule were put to the respondents. Laboratory investigations were done. Ethical clearance was obtained from concerned authorities. Study tools were used at enrollment of the subjects and then every six monthly for 18 months. Data were analyzed by using bivariate, multivariate analysis, ANOVA, Chi square, Correlation, Multiple logistic regression.

**Results:** There were total 450 (58.8 %-Men, 41.1%-women) respondents. 69% live in rural areas and 31% in urban areas. Majority were housewife (31.5 %). Risk factors for HIV transmission are through heterosexual route (91.8%), MSM-3.1%, blood transfusion-3.1%, IDU-0.6%, and unsafe injection 0.9%. The domains, Physical, Psychological, Social and Environment are found to be inter related and have a positive correlation. The QOL of the PLWHA was significantly improved after being enrollment on ART drugs.

**Key Words :** FSW, PLWHA, WHO, IDU, MSM, QOL

### **INTRODUCTION**

HIV/AIDS have become an endemic disease in the world since its first detection in 1981 in Los Angeles among homosexuals in USA. Globally 36.7 million people are estimated to be living

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with HIV/AIDS with occurrence of new infection of 2.1 million in 2015.<sup>1</sup> The most worst affected region is being Sub Saharan Africa and South East Asian Region. In India, the first case was detected in a Female Sex Worker in Chennai in 1986 and since then HIV/AIDS has emerged as one of the most dreaded killer disease till the advent of the Anti Retro Viral drugs. The quality of life of the people was extremely low as HIV/AIDS was a virtual death sentence during this period. New ARV drugs were evolved and there was pill burden as one client had to take 32 tablets in a day which compelled many HIV clients to stop the drugs and they developed many opportunistic infections and many of them died. Anti Retro Viral (ART) Drugs was started on 01 Apr 2004 by Government of India free of cost to all the People Living with HIV/AIDS (PLWHA). The ART drugs gave the PLHAs longevity and productive life and gave them a quality of life. In 1992, Government of India had set up National AIDS Control Organization (NACO), State AIDS Cell in 25 states and in 7 UTs with an objective to slow down the spread of HIV infections so as to reduce morbidity, mortality and impact of AIDS in the country.<sup>2</sup> It was the NACP-I phase of NACO. (1992-1999). In 1999, NACP-II came in to effect with the goal of reducing of HIV through prevention, care and surveillance services. Prevention activities were targeted on both high and low risk populations. Low cost care was emphasized. PPTCT services and PEP drugs was enrolled. Annual sentinel surveillance was started. In NACP-III (2007-2012), the goal was to halt and reverse the epidemic in India. In NACP-IV (2012-2017), the goals and objective were to reduce new infections by 50% (2007 Baseline of NACP III) and Comprehensive care, support and treatment to all PLWASs. At present 2.1 million people are estimated to be HIV positive in India.<sup>3</sup> It is observed that with proper and continuum care, the quality of life of PLWHAs has been increased. This will enable the health professionals to assess changes in quality of life over the course of care. This study aims to assess the quality of life of PLHAs registered for HIV care in ARTCs in Assam Medical College, Dibrugarh and Gauhati Medical College, Guwahati in Assam in North East India.

The World Health Organization (WHO) defines health as “A state of complete physical, mental and social well being and not merely an absence of a disease. It indicates that the measurement of health and the effects of health care must include not only the changes in the severity and frequency of diseases but also an estimation of well being. This can be measured by assessing the improvement in the quality of life related to health care<sup>4</sup>.

Quality of life (QoL) is an 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.<sup>5</sup> The QoL consists of both objective and subjective dimensions that may change over time in response to experience and events in life.<sup>6</sup> The social stigma attached with HIV/AIDS has a reflection on the QoL. Many a times, the individual has to face discrimination in the society. The person has to work under very stressful situation with low self esteem and morale. The working environment compels the person to change or to leave the job in many instances. Assessing the impact on the QoL in HIV/AIDS clients, it is very important to estimate the burden of the disease.<sup>7</sup> Health is considered as one of the determinants of QoL and HIV/AIDS distinctively affects on QoL.<sup>8,9</sup> The assessment of QoL provides a thorough evaluation of the individual's well- being that includes assessment of their personal adjustment, community assimilation and role functioning.<sup>10</sup> The impact on QoL of PLWHAs was significantly observed following use of Highly Active Anti Retro Viral Treatment (HAART)<sup>11-15</sup> and the mortality rate decreased.<sup>16-19</sup> The desire for care, support and treatment significantly influenced the keeners of the PLWHAs to disclose information about HIV positive status.<sup>13</sup> The social support and psychological factors have a definite influence on health outcomes of PLWHAs.<sup>20</sup>

The WHO QoL instrument provides new insights into the nature of disease by assessing how disease impairs the subjective well-being of a person. WHO QoL BREF is a sound, cross culturally valid assessment tool of QoL as reflected by its four domains (Physical, Psychological, Social, Environmental) and 26 items.<sup>21-22</sup> In some resource poor developing countries, treatment aimed at improving QoL through palliation which is cost effective and very useful.<sup>23</sup> The WHO QoL BREF will enable the health professionals to assess changes in QoL over the course of the treatment. In one study it was concluded that Health Related Quality of Life (HRQoL) was improved with ART, including those with immune compromised status in South Africa.<sup>24</sup> Peter et al demonstrated that the Psychosocial challenges including anxiety, depression, and social support have a huge impact upon all domains of health related Quality of Life of PLWHAs.<sup>25</sup> UNAIDS (Gap Report) 2014 mentioned about stigma, discrimination and other human right violations against PLWHAs limit the access of HIV related services. On average one in eight PLWHAs being denied HIV related service and one in nine is denied employment because of HIV positive status. Fear of stigma and discrimination results in health seeking for HIV testing and follow up treatment which results in poorer health output<sup>26</sup>. In a hospital based retrospective cross-sectional study it was found that ART adherence is one of the major challenges in HIV treatment. Good adherence to ART is essentially important for the success of therapy for on ART patients as it prevents viral replication, slows down disease progression, delaying mortality, improving immunity and QoL. In this study the ART drug adherence rate was 50% to 70% which has major contribution to self reported adherence cases<sup>27</sup>. Battegay *et al.* revealed that Psychological and social factors have a deep impact on the treatment of HIV-infection, from the preparedness counseling to start ART and further follow up and ARV drug adherence. Anxiety affect PLWHAs in all stages of disease, from the disclosure of HIV diagnosis to the decision to start treatment and further follow up visits. This is a lifelong challenge. Psychiatric co morbidities (depression, addiction) enhance negative psychological effects of HIV. Stigma and discrimination occur in families and at work place leads to a loss of social support resulting in isolation and poverty which prevent PLWHAs from seeking health care. These aspects are predominantly common in high risk group people such as injecting drug users, MSM, FSW, migrants<sup>28</sup>. A study by Hassan et al in May, 2015 concluded that a third of the persons enrolled on ART were either reported dead or LRU during two years of care, with more than a half of these occurring within six months of treatment initiation. Practical and sustainable biomedical interventions and psychosocial support systems are warranted to improve ART retention in this setting. At ART initiation, men were older and reported with more advanced stages of HIV/AIDS and thereby had higher rates of attrition, especially within the first year of treatment. Younger participants had higher rates of attrition compared to the older participants. Whilst ART scale up and treatment coverage has been impressive overall, high attrition remains a major challenge for the success of ART program. Poor pre-ART lab monitoring systems, late ART initiation, advanced HIV disease at time of ART initiation and weak support systems after treatment initiation contributed to the high attrition rates<sup>29</sup>. In a study conducted by Liping M *et al.* in 2015 found that 97.5% clients contracted HIV infection through sexual route and 29% of them were attributed to MSM. They found significant difference in QoL in Environmental domain. In this study they did not find significant difference in Physiological, Psychological and Social domain that might be attributed to free ART treatment, CD4 count >200<sup>30</sup>. In one study in Nigeria on QoL, researchers found that the lowest mean QoL scores were in Environmental and Social domains. Study subjects of age more than 40 years had better QoL in Environment domain and those with relationships had a better QoL. Participants with AIDS had a low QoL. Marital relationship, absence of tuberculosis, CD4 count >350

cells/cu mm and use of ART had a positive impact in QoL<sup>31</sup>. In a study in Northern Florida on health related QoL among PLHIVs by Nicole I Cesnales et al, they found that PLHIVs with symptoms and functional impairment attributed to poorer QoL<sup>32</sup>. In a study on QoL in Ghana they found the overall median percentage score of QoL was 71.29. HIV/AIDS negatively affected the quality of life of 11.39% clients with the most affected domain being the spiritual/religious/personal belief domains. The least affected domain was the environmental domain<sup>33</sup>. Fidèle Bakiono et al in their study found the QoL global score of  $82.4 \pm 10.8$ . The lowest scores was found in the environmental domain, with better scores associated with QoL with good family cohesion, medical care. These findings highlighted the importance of the socio-psychological support. They suggested the HIV services providers to focus on a better accessibility to social and health care, on the promotion of income-generating activities, especially for women and youth living with HIV<sup>34</sup>. In a study among PLHIVs in Nigeria, the researchers found the lowest mean QoL scores in the environment and social domains. Participants more than 40 years older had better QoL in the environment and spirituality domains and those in relationships had better QoL in the social relationship domain. Respondents with no or primary education had good QoL in all domains. Participants with AIDS had significant lower QoL. Clients with CD4 count = 350 cells /mm<sup>3</sup> had better QoL scores in the physical, psychological and level of independence domains. Subjects without tuberculosis co-infection and those on ART reported significantly better QoL in the physical, psychological, level of independence and spirituality domains<sup>35</sup>. Oguntibeju O in his study at Bellville in South Africa found that the invent of ARV drugs has significantly changed the perception of HIV/AIDS from a very fatal to a chronic manageable disease, and availability of ART has significantly reduced mortality and morbidity. There is a relationship between ART and QoL. The QoL and different domains improved with ART initiation with a good adherence<sup>36</sup>. Aswin Kumar et al in their study in India found that QoL was rated as poor by 26% of study subjects and 27% were dissatisfied with overall health status. QoL score was highest in environmental domain ( $11.61 \pm 1.83$ ) and lowest in Social relationships domain ( $8.97 \pm 3.36$ ). Age lesser than or equal to 30 years had better QoL in environmental and social domain. Subjects from urban area had better QoL in physical, psychological and environmental domain. Education associated with social and environment domain. Higher CD4 count is associated with better mean in physical domain<sup>37</sup>. In a study in Brazil, they found that there was a predominance of male gender, lower educational level. The Level of Independence and Environment domains had very poor scores in QoL. Paid occupation, the income per capita, religion, a longer time since diagnosis and adherence to treatment were positively associated with QoL. Stigmatized or suffered prejudice, presence of psychosocial symptoms, and having opportunistic infections were predictors associated with a poorer QoL.<sup>38</sup> In a study in Southern India, Emanuel Peter et al found a significant difference in mean QoL score with respect to level of anxiety in physical, psychological, level of independence, social relationships, environment and spirituality domain. Significant difference in mean QoL score was also observed with depression in these domains. Friend and family support and ART was positively associated with HRQoL in all the domains. A significant difference was observed with respect to affiliation to social organization in social relationships domain.<sup>39</sup> In a study in Zimbabwe, N. Mafirakureva et al found high HRQoL. Income, education and employment were positively and significantly associated.<sup>40</sup> In a study in Ethiopia, the researchers found higher level of depressive-symptoms that was most strongly associated with a lower HRQoL. Also, a higher level of HIV-stigma was associated with a lower HRQoL except for the physical domain.<sup>41</sup> They found mean score of WHO QoL-HIV-BREF was 14.1 (SD = 2.9). Lower education level and believing to be ill were associated with poor QoL in the

psychological and Environment domains. Time since diagnosis (within the past five years,  $p=0.029$ ) was found to be associated with poor QoL in the social relationships domain and believing to be ill was associated with all domains<sup>42</sup>. Karl Peltzer et al in their study in South Africa found low degree of overall QoL with a mean score of 13.4. Spirituality, environment, psychological health, and level of independence were found to be the predictors for overall QoL. Higher CD4 cell count and fewer/no HIV symptoms were identified as predictors for overall QoL. Among socio-economic variables, nutritious food and a higher educational level were identified as predictors.<sup>43</sup>

## METHODOLOGY

### Study type :

The study is an Observational longitudinal study.

### Study setting :

The study was conducted in the three major ART Centres in Assam. These are Assam Medical College, Dibrugarh; Gauhati Medical College, Guwahati and Silchar Medical College, Silchar in Assam.

### Study period :

The study was started from February 2014. A pilot survey was conducted by the principal investigator in the proposed study area in the month of June 2013 and valuable information was collected in January 2014. Then the study was designed as Observational longitudinal study. A pre structured interview schedule was developed and it was translated into local regional Assamese language. It was again back translated by another person. The WHO QOL BREF questionnaire (a standard tool of WHO to measure QOL) was used for all the respondents. The study was carried out till February 2018.

### Ethical clearance:

The proposals with required documents were submitted to the Institutional Ethics Committee (IEC) and the IEC approved the study after thoroughly verifying the study protocol and the documents. The permission was also obtained from the Director of Medical Education, Assam and from the North East Regional Office of National AIDS Control Organization, India.

### Sample selection procedures :

The three major ART Centres were selected in Assam as they cater for the maximum number of PLHIVs registered in HIV care in Assam and also their strategic location and easy accessibility enabled the PLHIVs to avail the services in both the Brahmaputra and Barak valley in Assam. Although the prevalence of HIV in Assam is low but it is highly vulnerable as all the borders of Assam is surrounded by the high prevalent states Nagaland and Mizoram. At present Mizoram is the highest prevalent state with an adult HIV prevalence of 1.15 in India. The newly ART initiated PLWHA were enrolled in the study. The clients were selected randomly.

### Sample size :

On the basis of NACO estimation (NACO estimate 2015), total number of PLHAs in Assam is 12804. The new adult infections (15 years+) in Assam are 18.8% and need for ARV Drugs is

16.24%. Considering to get a Confidence Interval (CI) of 95% within plus or minus of 4% of the sample, all the newly initiated PLWHAs on ART Drugs is found to be 326. For design effect it is multiplied by two and the final sample size is found to be 652.

#### **Data collection techniques and tools**

The data were collected in the three ART Centres in Assam by using WHO QOL BREF questionnaire and structured interview schedule.

The data was collected using pre-tested structured interview schedule. The language of the interview was Assamese, the local language and also in English who did not understand Assamese. The principal investigator is a public health specialist and a MBBS doctor and familiar with the geographic location and climatic condition of the study area carried out the interviews of the respondents and filled up the schedule. Also two co investigators were engaged in ART Centres in Assam Medical College and Silchar Medical College. The respondents were the patients themselves.

#### **Data analysis :**

Data collected were entered in Epidata version 3.1 on daily basis by the principal investigator. After completion of data entry, the data were exported to SPSS version 21.0 and then Univariate, bivariate and multivariate analyses were done. The various methods used for this were Independent samples T test, One way ANOVA, Cross tabulation, Chi square test. The 'p' value of = 0.05 was considered for statistical significance. Pearson's correlation technique was used to assess the relationship between HRQoL and socio-demographic and clinical characteristics. Finally multiple logistic regression was used to determine factors associated with HRQOL.

#### **Significance of the study:**

This study enables to assess changes in QOL over the course of HIV care in the ART Centres. It will also yield the difference in QoL of PLWHAs who are newly initiated on ART in comparison to those who were already on ART Drugs. It will prove useful in health policy research and will make upon important aspect of the routine auditing of health and social services which will enable the policy makers to implement health policy implication in relation to QOL.

#### **Scope of the study:**

The present study covers the areas of Assam which consists of various ethnic groups and diverse cultures. It is very important to know the QOL and perception of PLWHAs in these different societies with different ethos and principles with limited resources.

#### **Limitation of the study:**

The study and research is limited to Assam. It may not be generalized for the whole country of India.

#### **Inclusion criteria :**

- a. The clients who were registered in the designated ART Centres and newly initiated on ART Drugs were enrolled in the study.
- b. Each newly initiated case was counted as one case even if within the same household.

#### **Exclusion criteria :**

Children less than 15 years, mentally ill and terminally ill patients were excluded from the study. Those patients who were not available during the study period were excluded from the study.

## RESULTS AND DISCUSSION

### Characteristics of the study population:

<b>Table 1: Sex</b>		
Sex	Number	Percentage
Male	265	58.8
Female	185	41.1

Out of 450 participants in the study, 58.8 % were men and 41.1 % were women.

<b>Table 2 : Age in year</b>		
Age in years	Number	Percentage
15-30	166	37.3
31-45	220	49.2
46-60	64	14.2
60 above	0	0

Majority of the study population (49.2 %), were aged between 31 to 45 years, 37.3% were in between 15 to 30 years, 14.2 % were in between 46 to 60 years and there was no respondent above 60 years.

<b>Table 3 : Marital status</b>		
Marital status	Number	Percentage
Married	341	75.8
Single	72	15.9
Widow/Separated/Divorce	37	8.2

Among 450 respondents, majority of them, 75.8 % (n=341) were married, 15.9% were single and 8.2 % were Widow/Separated/Divorcee.

<b>Table 4 : Income</b>		
Income	Number	Percentage
1000-5000	198	44
5001-10000	104	23.1
10001-15000	96	21.3
>15001	52	11.5

The average monthly household income was Rs.1000.00 to Rs.5000.00 for 44% respondents, Rs.5001.00-10000.00 for 23.1 %, Rs.10001.00-15000.00 for 21.3 % and above Rs.15001.00 for 11.5 % respondents.

**Table 5 : Residential status**

Residential status	Number	Percentage
Urban	139	31
Rural	311	69

In the residential status, majority of the respondents (69 %) live in rural area and 31% live in urban area.

**Table 6 : Literacy status**

Literacy status	Number	Percentage
Literate	323	71.8
Illiterate	127	28.2

Among the respondents, 71.8 % were literate and 28.2 % were illiterate.

In occupation, majority respondents were housewife *i.e.* 31.5 %, secondly 19.3.6 % were having Petty business/ large business/Small shop/ self employed and thirdly 18.6 % were engaged in different government and Non Govt. sector. Risk factors for HIV transmission are through heterosexual route (91.8 %) higher than other routes *i.e.* MSM 3.1%, blood transfusion 3.1 %, IDU 0.6 %, Probable unsafe injection 0.9%.

**Table 7 : Laboratory parameters**

Parameters	At Baseline	6 Months	12 Months	18 Months	p-value
Hb.%					
>12 (Normal)	178 (39.5%)	213 (47.3%)	261(58%)	280 (62.3%)	0.000*
<12	272 (60.44%)	237(52.66%)	189 (42%)	170(37.7 %)	
TLC					
<4000	12 (2.9%)	8 (1.7%)	9 (2 %)	10 (2.1%)	0.457
>11000	14 (3.1%)	8 (3.6% )	11 (2.8%)	4 (0.9%)	
Normal(4000-11000)	424 (94.3%)	424 (94.3%)	428 (95.2%)	436 (97 %)	
Blood Urea					
<15	35 (7.5 %)	22 (4.9%)	9 (1.9 %)	6 (0.9%)	0.000*
>50	15 (3.5%)	14 (3.1%)	9 (2.1 %)	8 (1.9%)	
Normal (15.1-49.9)	400 (89%)	414 (92 %)	432 (96 %)	436 (96.9%)	
S. Creatinine					
<0.5	3 (0.7%)	5(1.1%)	3 (0.4%)	8 (1.7%)	0.869
>1.2	69 (15.3%)	64 (14.2%)	65 (14.6%)	46 (10.3%)	
Normal (.6-1.1)	378 (84%)	381(84.7%)	382 (85%)	396 (88 %)	
S. Bilirubin					
<1.9( Normal)	427 (94.8%)	434 (96.3%)	442 (98.2%)	442 (98.3%)	0.130
>1.10	23 (5.2%)	16 (3.7%)	8 (1.8%)	1 (.1%)	
SGOT					
< 10	9 (1.7% )	11 (2.8% )	8 (1.7% )	(0.5% )	0.249
>40	171 (38.2%)	178 (39.7%)	151 (33.5%)	135 (30.1%)	
Normal(11-39)	270 (60.1%)	261 (58.1%)	291 (64.6 %)	314 (69.8 %)	
SGPT					
<7	0	0	0	0	0.479
>56	109 (24.3%)	119 (26.4%)	138 (30.6%)	125 (27.7%)	
Normal(8-55)	341 (75.7%)	331 (73.5%)	312 (69.3%)	325 (72.2%)	
Alk. PO4					
<40	7 (1.5%)	20 (4.4%)	4 (0.8%)	11 (2.48%)	0.144
>140	52 (11.5%)	45 (10.0%)	28 (6.2%)	25 (5.5%)	
Normal(41-139)	385 (85.5%)	385 (86.2%)	408 (90.6%)	414 (92.0%)	
S. Amylase					
<40	1 (0.5%)	2 (0.9%)	0 (0.0%)	0 (0.0%)	0.351
>140	1 (0.5%)	1 (0.5%)	4 (1.9%)	2 (0.9%)	
Normal(41-139)	448 (99.1%)	447 (98.6%)	445 (98.1%)	448 (99.1%)	

Contd.. Table 7



Table 7 contd...

S. Cholesterol	<200 Normal	428 (95.1%)	428 (95.1%)	430 (95.5%)	435 (96.6%)	0.854
	>200	22 (4.8%)	22 (4.8%)	20 (4.4%)	15 (3.3%)	
Triglycerides	<150 Normal	374 (83.2%)	380 (84.4%)	386 (85.7%)	385 (85.5%)	0.819
	>150	76 (16.8%)	70 (15.5%)	64 (14.2%)	65 (14.4%)	
S. HDL	<100 Normal	402 (89.3%)	402 (89.3%)	404 (89.7%)	397 (88.2%)	0.972
	>100	48 (10.6%)	48 (10.8%)	46 (10.2%)	53 (11.7%)	
S. LDL	<100 Normal	431 (95.7%)	435 (96.6%)	431 (95.7%)	434 (96.4%)	0.950
	>100	19 (4.2%)	15 (3.3%)	19 (4.2%)	16 (3.5%)	
VDRL	Reactive	1 (0.5%)	0	0	0	0.393
	Non reactive	449 (99.5%)	450 (100%)	450 (100%)	450 (100%)	
HBsAg	Positive	0	0	0	0	----
	Negative	450 (100%)	450 (100%)	450 (100%)	450 (100%)	
Anti-HCV	Positive	1 (0.5%)	1 (0.5%)	1 (0.5%)	1 (0.5%)	1.00
	Negative	449 (99.5%)	449 (99.5%)	449 (99.5%)	449 (99.5%)	
CD4	100 to 300	310 (68.8%)	186 (41.3%)	143 (31.7%)	94 (20.8%)	0.000*
	301 to 600	128 (28.4%)	214 (47.5%)	260 (57.7%)	272 (60.4%)	
	601 to 900	11 (2.4%)	48 (10.6%)	35 (7.7%)	76 (16.8%)	
	901 above	1 (0.2%)	2 (0.4%)	12 (2.6%)	8 (1.7%)	

\*Significant at 0.01 level

The highly significant values were found in Hb % where among the 450 respondents, normal range at base line is 38.3% and after 6 months is 46.7% and 56.8% after 12 months and 61.5% after 18 months. Highly significant values were found in Blood Urea also. The normal range at base line was 87.9% and it was found to be 92.5% after 6 months and 96.2% and 97.7% after 12 months and 18 months respectively. The CD4 count was found to be highly significant in this study. Majority of the clients (68.8%) had CD4 count in the range of 100 to 300 at the base line. The CD4 count gradually increased over time after enrollment on ART in the follow up period. 57.7 % clients had CD4 count in the range of 301 to 600 at the end of 12 months and 60.4% in the same range at the end of 18 months on ART.

### Frequency responses (%) for the items of the WHOQOL-BREF:

Table 8 : General QOL					
Scale Points / Domains	Responses				
	Very poor	Poor	Neither poor nor good	Good	Very good
General QOL	8.4	22.0	46.3	22.9	0.5

In General QOL domain, majority among the respondents (46.3%) responded as Neither poor nor good.

Table 9 : General Health					
Scale Points / Domains	Responses				
	Very dissatisfied	Dissatisfied	Neither satisfied nor dissatisfied	Satisfied	Very satisfied
General Health	8.9	32.7	43.9	14.5	0

General Health condition: 43.9% responded as “Neither satisfied nor dissatisfied”, 14.5% responded as “Satisfied” and 32.7% were dissatisfied.

<b>Table 10 : Physical Health</b>					
Scale Points / Domains	Responses				
Physical health	An extreme amount	Very much	A moderate amount	A little	Not at all
Physical pain	2.8	13.6	36.4	41.6	5.6
Medical treatment	1.4	8.9	21.5	61.7	6.5
Energy	8.9	30.8	37.4	21.0	1.9
Mobility	3.3	6.4	59.3	20.6	0.5
Sleep	4.7	20.1	34.1	40.2	0.9
Ability to perform daily activities	6.1	25.7	41.6	25.7	0.9
Capacity to work	6.5	30.8	29.0	32.2	1.4

Physical pain prevented 41.6% clients from what they wished to do. 61.7% needed any medical treatment to function in daily life a little. Majority of respondents (37.4%) had enough energy for everyday life is a moderate amount. Highest 40.2% clients were little satisfied with sleep. 41.6% respondents were little satisfied with their abilities to perform daily living activities. Highest 32.2% clients were found to be little satisfied with their capacity for work.

<b>Table 11 : Psychological</b>					
Scale Points / Domains	Responses				
Psychological	An extreme amount	Very much	A moderate	A little	Not at all
Enjoyment in life	18.2	33.6	39.3	8.4	0.5
Positive feelings of life to be meaningful	6.1	26.6	36.0	29.0	2.3
Concentration	7.0	34.1	41.6	17.3	0.0
Bodily appearance	1.9	27.1	39.7	28.5	2.8
Satisfaction	3.3	33.6	36.9	25.2	0.9
Negative feelings	0.9	29.0	39.3	28.0	2.8

Majority of the respondents (39.3%) enjoyed their lives to a moderate amount. Majority 36.0% a moderate amount positive feelings of life to be meaningful. Highest 41.6% clients were able to concentrate moderately. Majority 39.7% (a moderate amount) were able to accept their bodily appearance. Majority 36.9% (a moderate amount) were satisfied with their capacity for work. Negative feelings was experienced by 39.3% respondents to a moderate amount.

<b>Table 12 : Social relationship</b>					
Scale Points / Domains	Responses				
Social relationship	Very dissatisfied	Dissatisfied	Neither satisfied nor dissatisfied	Satisfied	Very satisfied
Personal relationship	9.3	13.6	40.2	35.5	1.4
Sexual life	8.9	36.0	32.7	22.0	0.5
Support from the friends	2.3	13.6	39.7	41.1	3.3

Among the respondents, highest 40.2% were neither satisfied nor dissatisfied with their personal relationships. Highest 36% respondents were dissatisfied with their sex lives. Majority of the respondents (41.1%) were satisfied with support from the friends.

Table 13 : Environment					
Scale Points / Domains	Responses				
Environment	Not at all	A little	A moderate amount	Very much	Extremely
Safety	7.5	22.0	45.8	24.8	0.0
Physical environment	5.1	13.6	57.0	23.8	0.5
Financial	13.1	25.2	42.5	18.7	0.5
Information	2.8	15.9	50.0	31.3	0.0
Leisure activities	0.5	15.4	60.7	22.9	0.5
Home environment	0.5	6.5	53.7	38.8	0.5
Access to health services	0.9	5.6	35.0	57.9	0.5
Transportation	3.7	33.2	37.4	23.4	2.3

Highest 45.8% respondents felt safety in a moderate amount in their daily life. 57.0 % (A moderate amount) felt healthy of his/her physical environment. Majority ( 42.5%) respondents had enough money to meet their needs. Fifty percent of the respondents got available information which they actually needed. 60.7% of the respondents felt moderate amount of opportunity for leisure activities. Among the respondents, highest 35.0% responded a moderate amount of satisfaction with access to health services. 37.4% respondents were neither satisfied nor dissatisfied with the transportation system.

Table 14 : Transformed of the different Domains					
Scale Points (Transformed) of the different Domains					
Domains	Number	Minimum	Maximum	Mean	S.D.
Physical Health	450	21.43	89.29	52.32	11.21
Psychological	450	12.50	79.17	45.68	12.90
Social Relationship	450	0.00	100.00	50.39	17.26
Environment	450	9.38	75.00	51.42	10.88

Under Physical Health domain among 450 respondents, QOL mean score was found to be 52.32 with SD 11.21 and minimum value of 21.43 and maximum value 89.29. Under Psychological Health domains, the mean score was 45.68 with SD 12.90, where minimum value is 12.50 and maximum value is 79.17. Social relationships domain showed the score of mean 50.68 among this study participants. In Environmental Domain mean score was 51.42 with SD 10.88.

Table 15 : Paired Differences for the four domains of WHOQOL-BREF						
Pair	Paired Differences					p-value
	Mean	Std. Deviation	Std. Error Mean	95% Confidence Interval of the Difference		
				Lower	Upper	
Domain1 – Domain 2	6.64219	9.41495	0.64359	5.37356	7.91082	0.000*
Domain1 – Domain 3	1.93035	17.31292	1.18349	-0.40249	4.26320	0.104
Domain1 – Domain 4	0.90329	10.25335	0.70090	-0.47831	2.28489	0.199
Domain 2 - Domain3	-4.71184	17.49305	1.19580	-7.06896	-2.35472	0.000*
Domain 2 - Domain 4	-5.73890	9.96463	0.68117	-7.08160	-4.39621	0.000*
Domain3 - Domain 4	-1.02706	17.47522	1.19458	-3.38178	1.32765	0.391

\*significant at 0.01 level

For the four domains, paired differences were done and it is found to be highly significant in between D1 and D2; D2 and D3 and D2 and D4.

Comparison of the WHOQOL-BREF mean scores in four domains according to sex, age, educational status, marital status, income level, duration on ART and residence:

The mean scores in this four domains were found to be significant in Literacy Status where in Physical Health domains literate rate  $52.77 \pm 11.18$  and Illiterate rate  $45.92 \pm 9.89$ , Psychological literate rate  $46.17 \pm 12.84$  and Illiterate rate  $38.69 \pm 12.17$ . Beside of this in Marital Status significant found Social Relationship *i.e.* Married  $52.10 \pm 15.80$  Single/Divorced  $45.45 \pm 20.27$ . Again we significant value found in under Environment of Income Level where 1000 to 5000 Mean  $\pm$  SD  $49.00 \pm 9.67$ , 5001-10000 Mean  $\pm$  SD  $51.62 \pm 8.99$ , 10001-15000 Mean  $\pm$  SD  $53.50 \pm 13.81$  and  $>15001$  Mean  $\pm$  SD  $55.23 \pm 12.48$ .

### Discussion:

Out of 450 participants in the study, 58.8 % were men and 41.1 % were women. In other studies women constituted 53%, 58% respectively.<sup>27</sup>

Majority of the study population (49.2 %), were aged between 31 to 45 years, 37.3% were in between 15 to 30 years, 14.2 % were in between 46 to 60 years and there was no respondent above 60 years.

Among 450 respondents, majority of them, 75.8 % (n=341) were married, 15.9% were single and 8.2 % were Widow/Separated/Divorcee. Other studies also found that majority (60%) were married<sup>4</sup> and 25% single.

In the residential status, majority of the respondents (69 %) live in rural area and 31% live in urban area.

Among the respondents, 71.8 % were literate and 28.2 % were illiterate. In a study Illiterate was found to be 33.9%.<sup>29</sup>

Majority of the respondents were housewife *i.e.* 31.5 % and unemployed as found in other studies as well<sup>12,24</sup>, secondly 19.3.6 % were having Petty business/ large business/Small shop/ self employed and thirdly 18.6 % were engaged in different government and Non Govt. sector. Risk factors for HIV transmission are through heterosexual route (91.8 %) higher than other routes *i.e.* MSM 3.1%, blood transfusion 3.1 %, IDU 0.6 %, Probable unsafe injection 0.9%. In other studies also heterosexual route (97.5%) was the major route of transmission.<sup>30,34</sup>

The highly significant values were found in Hb % where among the 450 respondents, normal range at base line is 38.3% and after 6 months is 46.7% and 56.8% after 12 months and 61.5% after 18 months. Highly significant values were found in Blood Urea also. The normal range at base line was 87.9% and it was found to be 92.5% after 6 months and 96.2% and 97.7% after 12 months and 18 months respectively. The CD4 count was found to be highly significant in this study. Majority of the clients (68.8%) had CD4 count in the range of 100 to 300 at the base line which is also evident in some other studies.<sup>14,18,24,27,29</sup> The CD4 count gradually increased over time after enrollment on ART in the follow up period. This was found in other studies as well.<sup>15,18,24,37</sup> The overall QoL improved after initiation on ART over the period of time which was also found in other studies.<sup>11,12,17,19,23,24,30,33,34,35,36</sup> 57.7 % clients had CD4 count in the range of 301 to 600 at the end of 12 months and 60.4% in the same range at the end of 18 months on ART. In a study it was found that the PLWHAs who had been on ART for more than 18 months had higher mean scores in all the domains with the exception of social domain.<sup>35</sup>

In General QOL domain, majority among the respondents (46.3%) responded as Neither poor

nor good which was also evident in some other studies.<sup>10,37</sup>

General Health condition: 43.9% responded as “Neither satisfied nor dissatisfied”, 14.5% responded as “Satisfied” and 32.7% were dissatisfied.

Physical pain prevented 41.6% clients from what they wished to do. In some other studies, Physical pain prevailed among 57%, 27.3% clients that restricted their wishes to do their work.<sup>12,24,33</sup> 61.7% needed any medical treatment to function in daily life a little. Majority of respondents (37.4%) had enough energy for everyday life is a moderate amount. Highest 40.2% clients were little satisfied with sleep. 41.6% respondents were little satisfied with their abilities to perform daily living activities. Highest 32.2% clients were found to be little satisfied with their capacity for work.

Majority of the respondents (39.3%) enjoyed their lives to a moderate amount. Majority 36.0%, a moderate amount had positive feelings towards life to be meaningful. Highest 41.6% clients were able to concentrate moderately. Majority 39.7% (a moderate amount) were able to accept their bodily appearance. Majority 36.9% (a moderate amount) were satisfied with their capacity for work. Negative feelings was experienced by 39.3% respondents to a moderate amount. It was found among 12.4 % PLWHAs in a study<sup>24</sup> and 11.39% in another study<sup>33</sup>.

Among the respondents, highest 40.2% were neither satisfied nor dissatisfied with their personal relationships. Highest 36% respondents were dissatisfied with their sex lives which was also evident in one study.<sup>10</sup> Majority of the respondents (41.1%) were satisfied with support from the friends. Highest 45.8% respondents felt safety in a moderate amount in their daily life. 57.0 % (A moderate amount) felt healthy of his/her physical environment. Majority (42.5%) respondents had enough money to meet their needs and they experienced a better QoL which was found in other studies also.<sup>24</sup> Fifty percent of the respondents got available information which they actually needed. 60.7% of the respondents felt moderate amount of opportunity for leisure activities. Among the respondents, highest 35.0% responded a moderate amount of satisfaction with access to health services. 37.4% respondents were neither satisfied nor dissatisfied with the transportation system.

Under Physical Health domain among 450 respondents, QOL mean score was found to be 52.32 with SD 11.21. Under Psychological Health domains, the mean score was 45.68 with SD 12.90. Social relationships domain showed the score of mean 50.68 among this study participants. In Environmental Domain mean score was 51.42 with SD 10.88. In a study in southern India, the environment domain got the maximum mean score and the social relationship got the lowest mean score.<sup>37</sup> In another study, the Physical, Psychological and Environmental Domain mean scores were found to be similar and significant.<sup>6,25,30,37</sup> In a study they found similar score in physical and Environmental Domain.<sup>7</sup> In a study in Nigeria, they found lowest mean score in Environment and Psychological domain.<sup>31</sup> In a study the lowest mean score was found in psychological domain and highest was evident in Social relationship domain.<sup>33,35</sup> Environment domain had the least score in a study<sup>34,35</sup> and other three domain scores were similar in another study.<sup>34</sup> A south Indian study concluded the Environment domain to have the highest score and the Psychological domain to have the least score.<sup>37</sup>

For the four domains, paired differences were done and it is found to be highly significant in between D1 and D2; D2 and D3 and D2 and D4.

The mean scores in Physical and psychological domains were found to be significant. The mean score of Physical health domain,  $52.77 \pm 11.18$  with Literacy Status is found to be significant ( $p < .027$ ) which was also evident in other studies.<sup>30,34</sup> But it was found in a study that subjects with no formal and primary education reported better QOL in all domains.<sup>35</sup> And also it is significant ( $P < .036$ ) in Psychological domain with Literacy Status with a mean score of  $46.17 \pm 12.84$  where

in Physical Health domains, the Illiteracy mean score is  $45.92 \pm 9.89$ . The Psychological domain mean score is  $46.17 \pm 12.84$  and Illiterate rate is  $38.69 \pm 12.17$ . Significant value was observed ( $P < .014$ ) between Marital Status and Social Relationship i.e. Married  $52.10 \pm 15.80$  Single/Divorced  $45.45 \pm 20.27$  which was evident in other studies as well.<sup>31,34,35</sup> But in one study significant value was observed in all domains with marital status.<sup>30,31</sup> Again significant value was found in Environment domain under Income Level where Mean  $\pm$  SD was  $49.00 \pm 9.67$  for INR 1000 to 5000,  $51.62 \pm 8.99$  for INR 5001-10000,  $53.50 \pm 13.81$  for INR 10001-15000 and  $55.23 \pm 12.48$  for INR  $>15001$ . Income was also significant in another study.<sup>33</sup>

### **Conclusion :**

In conclusion, our study revealed the present Quality of Life domain of PLWHA. Social determinants influence the QoL of PLWHAs. All the four domains; Physical, Psychological, Social and Environment are found to be closely inter related and have a positive correlation and a significant paired difference. Risk factors for HIV transmission is through heterosexual route (91.1%). Laboratory parameters are found to be improved during course of ART than at the initiation of ART.

All the four Quality of Life domains have significantly been improved. Factors such as being initiated on ART drugs and continuing for a longer duration, literacy, high level of CD4 count and good ART adherence have positive effects on QOL of PLWHA. WHO QOL-BREF mean scores have been found to be significant between Physical health domain and Literacy status, between Psychological domain and Literacy status, between Social Relationship and Marital status, between Environmental domain and Income and Residence. Higher QOL will enable the PLWHAs to cope with illness. Healthcare providers along with the policy makers need to plan and implement a robust programs to routinely assess the HRQoL in a systematic way to facilitate a holistic management of HIV.

### **Conflicts of interest:**

We the authors declare that there is no conflicts of interest involved in this study.

### **Authors'contributions:**

The first author cum principal investigator contributed to the conception of the study. All the authors coordinated with the ART centres for data collection. The first author analyzed data and drafted the manuscript. All authors discussed the results, read and approved the final manuscript.

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