Assessment of the Quality of Life of Art Defaulters among People Living with Human Immunodeficiency Virus (PLHIV) Visiting Selected Art Centers

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Abstract: *HIV cannot be cured but it can reduce the viral load by taking a drug called antiretroviral therapy for lifelong. Adherence to ART will expand the life of people. The main objective of this study is to assess the factors affecting quality of life of people living with HIV/AID among ART defaulters. A descriptive study of 50 subjects and a purposive sampling technique was used to select the sample. All HIV positive adults above 18 years' old who fulfilled the criteria were included in the study after the informed consent. An individual rated defaulter by an expert after 3 consecutive months of missed ART were included in the study. WHO_QOL_BERF_HIV tools were administered to the patients for 15-20 minutes. The overall total quality of life ART defaulters was moderately good. The overall quality of life of CD4 count is highly significant with CD4 >200, mean and standard deviation (n=19) (3.5±1.0) as compared to CD4 ≤200 (n=18) with mean and standard deviation (2.3±1.1) with t value (3.3) and pvalue (0.001). The quality of life of general health perception is moderately significant with the CD4 count >200 (n=19) mean and standard deviation (3.2±0.8) with t value (1.8) and p value (0.07) as compared to CD4 count ≤200 (n=18) mean and standard deviation (2.5±1.4). Out of 50 subjects, the quality of life of physical domain is highly significant with the CD4 count >200 (n=19) with mean and standard deviation (13±2.6) with t value (2.6) and p value (0.012).*

Keywords: HIV, antiretroviral therapy, quality of life, ART defaulters, CD4 count

1. Introduction

Infection with the Human Immuno Deficiency Virus (HIV) frequently results in progressive, chronic disease known as Acquired Immuno Deficiency Syndrome (AIDS). HIV belongs to a unique class of viruses, the retrovirus. The retrovirus is unusual because, unlike any other knownliving matter; they carry RNA rather than DNA and require an enzyme, reverse transcriptase, to transcribe RNA into double-stranded DNA.[1] HIV is a virus that attacks the cells in the body to fight infection, HIV viruses are of two types, that is, HIV 1 which is the most common and HIV 2 which is uncommon and less infectious, HIV 1 worldwide is 95% and 55% HIV 2 is estimated.[2] HIV can cause AIDS, and AIDS is the late stage of HIV infection that occurs when the body's immune system is damaged by the HIV, the viral load can be reduced by taking a drug called Antiretroviral therapy lifelong . Adherence to ART will prolong the life of people. It prevents the transmission of HIV from infected human to sexual partners.[3]

ART and quality of life for HIV patients have a strong positive relationship and several studies have reported that for people who are on ART with good adherence, the quality of life is improved with different domains. The quality of life of an HIV infected individual may get influenced by stigma, depression, poverty, violence and other cultural belief, all these may affect the willingness of an individual to seek medical intervention or therapy and lead to a poor qualityof life.[6] Assessing the quality of life of an HIV infected person is essential for documentation regarding the effect of treatment, burden of the diseases and tracking of health changes of an individual.

Quality of life is not only from physical aspect but also from social and mental health point of view.[7]

Global HIV statistics state that 38.0 million [31.6 million - 44.5 million] people globally were living with HIV in 2019, 36.2 million [30.2 million-42.5 million] adults, 1.8 million [1.3million-2.2 million] children (0-14 years), 81% [68-95%] of all people living with HIV knewtheir HIV status. About 7.1 million people did not know that they were living with HIV; 1.7 million [1.2 million-2.2 million] people became newly infected with HIV in 2019. 690,000 [500,000-970,000] people died from AIDS- related illnesses in 2019, Since the beginning of the epidemic, 75.7 million [55.9 million-100 million] people have become infected with HIV, 32.7 million [24.8 million-42.2 million]died from AIDS since the start of epidemic (2019).[20], 2.1 million people live with HIV in India and it's the third largest HIV epidemic in the World, As ofthe tip of June 2020, 26 million [25.1 million-26.2 million] people were accessing antiretroviral therapy.[29] During Covid-19 pandemic up to 7,000 of HIV positive individuals in Maharashtra have been missed for detection and also the newly diagnosed of HIV in Maharashtra within the year 2019-2020 were about 17,674 and within the year 2020-21 January almost 4,669 people [30]

Objectives
- To assess the factors affecting quality of life of ART defaulters among people living with Human Immune deficiency Virus (PLHIV).
- To associate the quality of life of ART defaulters among people living with Human Immune deficiency Virus

(PLHIV) with selected demographic, clinical and physiologicalvariables.

2. Materials and Methods

Research Design

Sample Setting
The present study was conducted at a selected ART center. Availability of permission from higher authority to conduct the research and familiarity of the environment were also considered while selecting the study setting.

Sampling Technique
Non- probability purposive sampling was adopted for the present study. Non-probabilitysampling was done in which samples were selected by non-random methods. This was selected based on the purpose of the study, which assessed the quality of life of peopleliving with HIV who are ART defaulters.

Sample Size
The sample comprised of 50 subjects who were ART defaulters in a selected ART center.

Criteria For Sampling:

Inclusion
- PLHIV who were diagnosed as defaulters by the expert provider
- ART defaulters who were in the age group from 18-75 years old.
- Both male and female who were ART defaulters.
- PLHIV who have a history of missed dose of ART of 3 consecutive months.
- ART defaulters who can read/ write Hindi or Marathi or English.

Exclusion
- ART defaulters with severe symptoms of HIV such as central Nervous system toxoplasmosis, HIV encephalopathy, extra pulmonary tuberculosis.
- ART defaulters who were having sensory and communication impairment.
- ART defaulters who were not willing to participate in the study.

Tool Preparation
WHO-HIV-BREF questionnaire is a standardized tool from World Health Organization (WHO) which includes 31 items covering 6 domains: the overall quality of life, general health perception, physical, psychological, spiritual, environmental dimensions and level of Independence. The tool has been used indifferent countries and found having good psychometric properties and also found evidence of its validity.[73]

The demographic tool of this study was prepared by the investigator and validated by different experts. The tool consists of:
Section 1: To find out the demographic variables of the subject.
Section 2: Information related to diseases and treatment.

Section 3: WHO-QOL-HIV-BREF instrument to assess the quality of ART defaulters amongPLHIV.

Data Collection
A formal written permission was obtained from the Principal of the college to conduct the study. Through the Principal, permission was obtained from the Management and the Administrator of the selected hospital to conduct the main study. The subjects who had come to the ART center, after verifying the records from the ART book, subjects who fulfilled the inclusion criteria were selected as sample. The purposes of the study, time, duration, confidentiality, method of data collection were explained to the subjects. The subjects were selected using the purposive sampling method. Informed consent was obtained from the subjects indicating their willingness to participate in the study before the collection of data. Assurance was given to the subjects regarding the confidentiality of the information. Demographic variable was identified using semi-structured interview and WHO-QOL-BREF instruments 5.0 generic core questionnaire was administered to the subjects

3. Results

- In the present study assessment of the overall quality of life of ART defaulters showed that the overall QOL mean score of people living with HIV was 2.94 with standard deviation of 1.300.
- The Overall total quality of life of defaulters had a moderately good quality of life (52%) which is the highest.
- Majority of ART defaulters were male (66.00%). Out of 50 subjects 19(38%) were in the age group of 36-45 years.
- The study finding revealed that most of the subjects belong to the education level of secondary and above 39 (78%) whereas illiterate and primary are 6 (12%) and 5(10%).
- The study showed that most (27) of the subjects are married (54%). Most (48) belonged to Hindu religion (96%). The study revealed that most (26) of the subjects were self- employed (52%), (14) were employed (28%) and (10) were un-employed (20%).
- The finding revealed that 18 (36%) of the subject were physiologically feeling very bad, 18 (36%) of the subject have low CD4 count <200.
- Most of the subjects (21) were diagnosed in between 2007-2013 (42%).
- Majority of the subjects (37) had to travel for 1-hour distance (74%) to the ART center, (46) (92%) of the subjects travelled by public transport to the ART centers. 92% of the subject's transport was available every day.
- The finding revealed that 30(60%) subjects were defaulters from ART in between 1-5 years.
- Majority of the subjects (32) showed no side-effect to the ART medication (64%) and 16 (32%) of the subjects reported only one side effect and 2(4%) reported more than one side effects. 80
- Majority of the subjects (27) did not have any Opportunistic Infection (54%), whereas 16(38%) were affected by 1 Opportunistic Infection and 7 (14%) affected with > 1 which is the lowest.
- The Gender-wise total quality of life of ART defaulters was similar compare males (n=33) (98.3±22.8) to females (n=17) (96.5±13.7) showed no significant.
- The total quality of life in age group of ≤45 and >45 was

significantly high in age of >45 (n=21) (102.4±21.8) as compared to age ≤45 with mean and standard deviation of (n=29) (94.3±18.3).

- The marital status total quality of life of ART defaulters was similar in single (n=10) (94.2±22.4), married (n=27) (98.4±23.0) and widows (n=13) with mean and standard deviation (98.9±10.2) showed no significant.
- According to education-wise total quality of life of ART defaulters was moderately high in illiterate + primary (n=11) (106.8±17.4) as compared to Secondary and above (n=39) (95.1±20).
- The total quality of life in economic status of ART defaulters was similar in comparing to employed (n=9) (99.3±16.5), self-employed (n=31) (98.1±22.5) and unemployed (n=10) (95.1±15.8) showed no significant.
- The total quality of life in physiological feeling showed high significance in moderately physiological feeling (n=20) (104.75±15.9), as comparing to bad physiological feeling (n=12) (104.2±18.6) and very bad physiological feeling (n=18) (85.6±20.3)
- According to CD4 count wise total quality of life of ART defaulters showed significantly high score of quality of life in CD4 >200 (n=19) (104.7±10.9) as compared to CD4 count ≤200 (n=18) (91.5±22.5).

Table 1: Shows the description of subjects with regard to demographic information in terms of frequency and percentage.

Demographic Variables	Frequency (f)	Percentage (%)
GENDER		
i. MALE	33	66.00%
ii. FEMALE	17	34%
AGE		
i. 15-25	6	12%
ii. 26-35	4	8%
iii. 36-45	19	38%
iv. 46-55	16	32%
v. 56-65	3	6%
vi. 66-75	2	4%
EDUCATION		
i. ILLITERATE	6	12%
ii. PRIMARY	5	10%
iii. SECONDARY AND ABOVE	39	78%
MARITAL STATUS		
i. SINGLE	10	20%
ii. MARRIED	27	54%
iii. WIDOW	13	26%
RELIGION		
i. BUDDHIST	1	2%
ii. CHRISTIAN	1	2%
iii. HINDUS	48	96%
OCCUPATION		
i. EMPLOYED	14	28%
ii. SELF EMPLOYED	26	52%
iii. UNEMPLOYED	10	20%

Table 2: WHO_QOL_HIV_BREF Overall QOL and domain mean and standard deviation of ART defaulters.

Domains	Quality of Life	
	Mean	Standard Deviation
Overall quality of life	2.94	1.300
Physical Domain	11.9	3.290
Psychological Domain	15.680	4.048
Level of Independence	13.08	3.568
Social Domain	11.94	4.012
Environmental Domain	27.84	5.698
Spiritual Domain	11.46	3.715

Table 2: Overall quality of life score of ART defaulters.

Parameter	No. of Participant	Percentage
Poor	4	8%
Average	16	32%
Moderately Good	26	52%
Good	4	8%

Table 3: Analysis of data to find out the factors affecting quality of life of ART defaulters with respect to demographic variables

Qol Domains	Overall Qol	General health perception	Physical	Psychological	Social	Environmental	Spiritual	Level of independence	Total quality of life
Gender									
Male	29±1.3	2.78±1.3	11.6±3.5	16.1±4.3	12.0±4.2	27.5±6.4	12±4.01	13.0±3.6	98.3±22.8
Female	3±1.3	2.7±1.0	12.2±2.6	14.7±3.2	11.6±3.5	28.3	10.8	13.1±3.4	96.5±13.7
p. value	0.81	0.82	0.54	0.22	0.71	0.65	0.29	0.8	0.7
Age									
≤45	3±1.2	2.7±1.1	11.6±3.1	15.0±3.8	10.8±3.8	26.6±5.5	11.9±3.15	12.5±3.52	94.3±18.3
>45	2.8±1.3	2.7±1.4	12.2±3.4	16.5±4.1	13.3±3.9	29.4±5.6	11.0±4.4	13.8±3.5	102.4±21.8
p. value	0.7	0.99	0.48	0.18	0.02	0.09	0.42	0.22	0.16
Marital status									
Single	3.2±1.5	2.8±1.3	11.8±4.4	15±4.3	10.5±4.4	27.1±6.4	11.5±3.5	12.3±4.9	94.2±22.4
Married	2.8±1.3	2.6±1.2	11.7±3.2	16±4.2	12.7±4.0	27.6±6.6	11.7±4.1	13.0±3.4	98.4±23.0
Widow	3±1.0	3±1.1	12.2	15.3	11.3±3.4	28.8±2.0	11.4±3.0	13.7±2.5	98.9±10.2
p. value	0.72	0.68	0.91	0.71	0.25	0.74	0.97	0.62	0.82
Education									
Illiterate+Primary	2.8±1.4	2.7±1.2	13.2±3.7	16.4±3.3	15.2±3.2	30.6±5.3	11.3±3.82	14.2±3.0	106.8±17.4
Secondary and above	2.9±1.2	2.7±1.2	11.5±3.0	15.4±4.2	11±3.7	27.0±5.5	11.6±3.7	12.7±3.6	95.1±20
p. value	0.72	0.92	0.11	0.47	0.001	0.06	0.81	0.21	0.08
Economic status									
Employed	2.8±1.2	3.2±1.3	12.4±3.0	16±3.3	9.6±3.5	28.1±6.17	12.2±3.23	14.7±3.0	99.3±16.5
Self-employed	2.8±1.3	2.6±1.2	11.6±3.6	15.6±4.4	12.2±4.21	28.2±6.1	11.5±4.2	12.7±3.59	98.1±22.5

Not-employed	3.3±1.2	2.7±1.1	12.2±2.5	15.4±3.6	11.4±3.0	26.4±3.9	11.2±2.7	12.5±3.7	95.1±15.8
p. value	0.62	0.002	0.77	0.95	0.1	0.67	0.83	0.28	0.89

4. Discussion

The discussion of the present study is organized under the following sections:
- Baseline variables of ART defaulters.
- Association of quality of life with selected baseline variables.

Baseline variables of ART defaulters
In the present study, majority of ART defaulters were male **(66.00%)**. Out of the **50** subjects **19(38%)** were in the age group of **36-45** years. The study finding revealed that most of the subjects belong to the education level of secondary and above **39 (78%)** whereas Illiterate and primary were **6 (12%)** and **5(10%)**. The study showed that most of the subjects are married **27(54%).** Most **48 (96%)** belonged to the Hindu religion. The study revealed that the numbers of the subjects who were self- employed was **26(52%),** employed **14 (28%)** and un-employed **10 (20%).** The finding revealed that **18 (36%)** of the subjects were physiologically feeling very bad, **18 (36%)** of the subjects have low CD4 count <**200**. Most of the subjects **21** were diagnosed in between **2007-2013 (42%)**, a majority of the subjects have to travel for 1-hour distance **37 (74%)** to the ART center, **46 (92%)** of the subjects travelled by public transport to the ART centers. **92%** of the subject's transport was available every day. The finding revealed that **30(60%)** subjects were defaulters from ART in for **1-5** years. A majority of the subjects **32** showed no side effect to the ART medication **(64%)** and **16 (32%)** of the subject reported only one side effect and **2(4%)** reported more than one side effects. Majority of the subjects did not have any Opportunistic Infection i.e. **27 (54%),** whereas **16(38%)** were affected with 1 Opportunistic Infection and **7 (14%)** were affected with **> 1** which is the lowest.

This study, supported by another study among people living with HIV/AIDS showed that those who are on ART with good CD4 count, higher education and young adult have higher Quality of life. Physiological (14.9), psychological (14.25), social relation (13.22) and environment (13.33) with pValue<0.05. [62]

Factors affecting quality of life among ART defaulters
It was found that the quality of life of social domain of age **>45 (n=21)** is significantly high with mean and standard deviation **(13.3±3.9)** comparing to age **≤45 (n=29)** **(10.8±3.8)** with t-value **(2.24)** and p- value **(0.02).** There is moderately significant in the quality of life of the environmental dimension of age **>45 (n=21)** with mean and standard and deviation **(29.4±5.6)** comparing to age **≤45 (n=29)** **(26.6±5.5)** with t-value **(1.71)** and p value **(0.09).** The finding revealed that quality of life of social domain of education is highly significant in Illiterate + primary **(n=11)** with mean and standard deviation **(15.2±3.2)** with t-value **(3.44)** and p value **(0.001).** The environmental dimension quality of life of education is moderately significant in Illiterate + primary **(n=11)** with mean and standard deviation **(306±5.3)** with t value **1.89** and p value **0.06.** The total quality of life of education is moderately significant **(n=11)** with mean and standard deviation **(106.8±17.4)** with t value **1.73** and p value

0.08. The overall quality of life of physiological feeling about health status of the subjects is highly significant in moderately **(n=20)** with mean and standard deviation of **(3.6±1.0)** with F value **(5.23)** and p value **(0.008).** There is a highly significance in the general health perception of quality of life of physiological feeling about health status of subjects with mean and standard deviation were **(n=20)** moderately **(3.4±1.0)** with F value **(6.88)** and p value **(0.002).** The quality of life of physiological feeling in physical domains is moderately significant with mean and standard deviation **(n=20)** **(12.8±3.1)** with F value **(2.99)** and p **(0.05).** There is a high significance in the quality of life in psychological domains of feeling about health status of subjects with mean and standard deviation **(17.1±3.0)** with F value **(5.641)** and p value **(0.006).** The quality of life in spiritual domain of the physiological feeling about the health status of the subjects is significantly bad **(n=12)** with mean and standard deviation **(13.1±3.6)** with t value **(5.95)** and p value **(0.05).** There is moderately significantly difference in the quality of life of level of independence of physiologicalfeeling about the health status (n=20) with mean and standards deviation **(14.3±3.1)** with F value **(4.15)** and p value **(0.02).** The physiological feeling about the health status of the total quality of life is moderately significant **(n=20)** with mean and standard deviation (**104.75±15.9**) with F value **6.21** and p value **(0.004).** The overall quality of life of CD4 count is highly significant with **CD4 >200**, mean and standard deviation **(n=19)** **(3.5±1.0)** as compared to CD4 **≤200 (n=18)** with mean and standard deviation(**2.3±1.1**) with t value **(3.3)** and p value **(0.001).** The quality of life of general health perception is moderately significant with the CD4 count **>200 (n=19)** mean and standard deviation **(3.2±0.8)** with t value **(1.8)** and p value **(0.07)** as compared to CD4 count **≤200 (n=18)** mean and standard deviation **(2.5±1.4).** Out of 50 subjects, the quality of life of physical domain is highly significant with the CD4 count **>200 (n=19)** with mean and standard deviation **(13±2.6)** with t value **(2.6)** and p value **(0.012).**

These findings were supported by another study. A similar study conducted among people who live withHIV reveals that there is a negative co relation between the CD4 count and the Quality of life. The studyconcluded that there is a significant relationship with a higher QOL and CD4 count <**200**. [61]

Another author conducted a study on QOL with people living with HIV The result showed that the mean and standard deviation of overall domains and facets of WHO-QOL-BREF were **(48.9±14.8)** social relationship, **(56.2±9.8)** physical health, **(63.1±8.7)** psychological health and **(51.3±13.7)** environmental health, and out of 220 PLHA rated their QOL as neither good nor bad **(55.5%),** dissatisfied **(38.6%),** good **(28.2%)** and **(41.4%)** neither satisfied nor dissatisfied with their health. This study concluded that emotional and social support must implement to improve QOL (quality of life). [55]

5. Conclusion

This study's results explain that overall total quality of life of ART defaulters is moderately good. There are numerous

factors potentially associated with quality of life of ART defaulters. Age >45, education i.e. illiterate +primary, and CD4 count >200 are highly significant with the quality of life. Research finding helps the nurses in various ways such as reason of discontinuing of medication and what the barriers are those make the health care provider unable to trace the patients. Hence, promotion of health education and Counselling on ART medication should be our priority.

6. Recommendations

- The study can be conducted with a large sample size group.
- A qualitative study can be conducted on assessing the causes of defaulting of ART.
- More studies can be conducted on quality of life of long term survivors with ART adherence.

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