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RESEARCH ARTICLE

FACTORS AFFECTING QUALITY OF LIFE OF PEOPLE LIVING WITH HIV/AIDS ATTENDING A COMMUNITY CARE CENTRE IN CHENNAI, INDIA

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ABSTRACT:

Introduction : Health is defined by WHO as "complete physical, mental and social well-being". Though the physical well-being is improved with antiretroviral therapy, it does not guarantee mental and social well-being. Hence we wanted to assess the Quality of Life (QOL) and to identify the factors that influences QOL in People Living with HIV/AIDS (PLHA).**Materials and methods :**A cross sectional study of 141 adult PLHA attending the out patient department of a community care center in Chennai during the period from 1st January to 31st August 2011 were included in the study.QOL was evaluated using WHOQOL-HIV BREF questionnaire. Analysis: Mean Scores of QOL was calculated using SPSS syntax file developed by WHO, Geneva.The One way Analysis of Variance (ANOVA) was performed to find out significant difference between the socio-demographic variables and clinical categories on QOL domains.**Results:** In study population 76 (53.9%) were males, 59 (41.8 %) were females and 6 (4.3 %) transgender. The overall QOL mean score on a scale of 0-20 was found to be 13.1. The mean scores of six domains of QOL in descending order were Spirituality/Religion/Personal beliefs (SRPB) (14.5); level of independence (LOI) (14.3); physical (13.3); environmental (12.5); psychological (12.3) and social relationships domain (11.7): (p-value=0.000). QOL in physical domain was high among transgenders (17.3) when compared with males (12.7), and females (13.7): (p=0.019). Social relationships domain scores between those who were single (11.5), married (12.8), and separated/widowed/divorced (10.9):(p=0.000). Significantly better QOL scores in the LOI domain (15.2) (p=0.000) with respect to the CD4 count category.**Conclusions :** In our study, QOL was associated with gender, marital status, and CD4 counts of the patients .

Keywords : WHOQOL- HIV, TRANSGENDER, CD4 COUNT, BREF QUESTIONNAIRE

INTRODUCTION

The World Health Organization statistics reports that the number of people living with HIV/AIDS(PLHA) at the end of 2012 was 35.3 million (32.2- 38.8 million) [1]. As per the 2009 estimates released by the Ministry of Health & Family Welfare and National AIDS Control Organisation (NACO), HIV prevalence in India is approximately 0.31%. The total number of PLHA in India is estimated at 2.4 million (1.9 million – 3.0 million) in 2009 [2] . The prevalence of HIV infection in Tamilnadu is 0.33% in 2009. The estimated number of PLHA in Tamilnadu is 1, 54, 742 in 2009 [3] .Implementation of free ART (Antiretroviral Therapy) programme began in India during April 2004. By the end of April 2005, the government reported that 7333 people were receiving free antiretroviral therapy through the public sector [3] . The number of people receiving ART in India as of 2009 is 3,20,074 [4] . The National AIDS Control Organisation (NACO) has also started providing second-line ART (SLA) since January 2008 in India [5]

Even though there is no cure for HIV infected individuals, with the provision of ART, life of PLHA is prolonged. It was estimated that the median remaining lifetime of a newly diagnosed 25 year old HIV infected individual is 39 years [6] . Health is defined by WHO as "complete physical, mental and social well-being". Though the physical well-being is improved with antiretroviral therapy, it does not guarantee mental and social well-being [7] . Hence just measuring morbidity and mortality will not give the holistic picture on well-being of PLHA. A more comprehensive measure taking into account the physical, mental and social well-being is needed. This measure should incorporate the person's values, expectations, and perception.

A well studied indicator for this will be the measure of Quality of Life (QOL).Hence we wanted to measure the quality of life of PLHA using the WHOQOL-HIV BREF questionnaire. A similar

pilot study was done by the same principal investigator with a sample size of 30 and was published in International Journal of Medical and Applied Sciences. As that study sample size was only 30 , we undertook this separate study to get more sample size and this study was done for longer duration of 7 months when compared with the previous study which was done only for a month period. More over not much studies were published regarding the QOL of PLHA living in and around Chennai with large sample size.

METHODOLOGY:

Study design: Cross sectional study**.** It was a one time interview of 141 PLHA. **Duration of data collection:** 1st January 2011 to 31st August 2011. **Setting:** Outpatient department of a community care centre in Chennai. **Sample Size:** Based on the data collected from the community care centre(CCC) the number of PLHA attending the CCC in a month including both the new and old case was approximately 30 and also depending upon the feasibility and the number of PLHA available , a sample size of around 120 to 140 was decided. All patients attending the community care center from 1st Jan 2011 to 31s August 2011, who gave consent were included in the study. Convenient sampling was used.

Instruments used for the study: There are two version of WHOQOL-HIV specific questionnaire available, namely WHOQOL- HIV BREF [8] and WHOQOL-120 HIV [9] .In our study we used the WHOQOL-HIV BREF questionnaire. The WHOQOL-HIV BREF questionnaire contains six domains namely physical, psychological, level of independence, social relationship, environment and spirituality / religiousness/personal belief domain. Under each domain there are four to eight facets. WHOQOL-HIV BREF has 24 'general facets' and 5 'HIV specific facets'. Each facet has four questions in the long version (WHOQOL-120 HIV) and has one question in the short version (WHOQOL-HIV BREF). In addition to these, there are two general questions which assess a person's perceived general health and satisfaction with life. Each question grades QOL on a 5 point Likert scale [10] . HIV specific WHOQOL has excellent internal consistency with an alpha coefficient of 0.98 [11]. WHOQOL- HIV BREF was translated to Tamil version .

Method of Interview: The principal investigator visited the CCC on all days except on sundays and briefed the participants about the study and informed writtern consent was obtained from the participants. The principal investigator briefed the study subjects about the study and obtained an written consent for participating in the study. All those subjects who gave consent , who were adults ,who were not very sick and who were aware about HIV status were included in the study. They were assured that they can utilize the services provided by CCC irrespective of their participation in the study.

In the study the questionnaire was interviewer-administered . Initially rapport building questions were asked followed by WHOQOL-HIV questionnaire. Socio demographic details were also collected. Ethical approval for the study was obtained from the Institutional Ethics Committee of Sree Balaji Medical College and Hospital, Chromepet, Chennai. Permission for conducting the study was also obtained from the Managing director of the CCC. **Data Analysis**: WHO SPSS Syntax file developed by WHOQOL-HIV Group, Department of Mental Health and Substance Dependence, Geneva was used to calculate the domain scores of QOL. When the WHO SPSS Syntax file is run it automatically recodes the scores of the negatively phrased questions into

their appropriate scores and then it will automatically generate the individual domain scores . The SPSS (Statistical Package for the Social Sciences) version 15 were used for subsequent analysis of the data collected. Then the mean scores of the QOL for individual domains and the overall mean scores for all the domains were calculated using SPSS version 15. Subjects were grouped based on their socio demographic profile, CD4 counts, clinical categories and other parameters collected. The mean QOL scores of individual domains and the overall domains scores were analysed against the various groups . 'One way ANOVA' were used to compare the mean scores across groups greater than 2 and student t test for 2 groups.

RESULTS: In our study nearly 76 (53.9%) were males, 59(41.8%) were females and 6 (4.3%) were

TABLE 1 BASELINE CHARACTERISTICS N= 141		
Place of Residence	**N**	**%**
Urban	80	56.7
Rural	61	43.3
Marrital Status		
Married	56	40
Single	20	14
Widowed	43	30
Separated	21	15
Divorced	1	0.7
Educational Status		
None	33	23.4
Primary	24	17
Middle School	37	26.2
Secondary	28	19.9
Higher Secondary	12	8.5
Tertiary (Graduate & Post graduate)	7	5
Type of Family		
Nuclear	67	47.5
Joint	45	31.9
Individuals (Not living as family)	24	17
Others (Individuals from different family join together and living as a family)	5	3.5
Occupational Status		
Skilled	5	3.5
Semiskilled	43	30.5
Unskilled	67	47.5
Unemployed	26	18.4

transgenders. The mean age of the study population was 39 years. Other baseline characteristics are given in table 1 and in table 2.

TABLE 2 BASELINE CHARACTERISTICS N= 141		
WHO Clinical staging	**N**	**%**
Stage 1	102	72.3
Stage 2	8	5.7
Stage 3	26	18.4
Stage 4	5	3.5
CD4 Counts (cells/cu mm)		
< 200	22	15.6
200 to 500	67	47.5
>500	52	36.9
HIV Status		
Asymptomatic	23	16.3
Symptomatic	11	7.8
AIDS Converted	107	75.9
ART Treatment Categories		
Yes	107	75.9
No	34	24.1
Type of ART		
First line ART	92	65.2
Second line ART	15	10.6

TABLE 3- MEAN SCORES OF 6 DOMAINS OF QOL

Domains	**Mean scores**	**Median scores**	**Range**	**p value**
Physical	13.3 (4.0)	13.0	4 to 20	0.000*
Psychological	12.3 (3.2)	12.0	5.6 to 19.2	
Level of Independence	14.3 (2.7)	15.0	7 to 20	
Social Relationships	11.7 (2.6)	12.0	5 to 18	
Environmental	12.5 (2.1)	12.5	7 to 19.5	
SRPB	14.5 (3.1)	15.0	6 to 20	
Over all	13.1 (2.9)			

Values given within brackets are standard deviation (SD) *significant at p value < 0.05

TABLE 4- COMPARISON OF MEAN SCORES OF QOL WITH GENDER

Domains	Males n = 76	Females n = 59	Transgenders n = 6	p value
Overall	13.0 (2.1)	13.1 (2.1)	14.7 (0.6)	0.152
Physical	12.7 (3.6)	13.7 (4.4)	17.3 (4.0)	0.019*
Psychological	12.3 (3.2)	12.1 (3.1)	15.0 (3.1)	0.108
Level of Independence	13.6 (2.7)	14.9 (2.5)	16.5 (1.2)	0.004*
Social Relationships	11.9 (2.7)	11.7 (2.6)	10 .0 (2.6)	0.239
Environmental	12.6 (2.3)	12.3 (2.0)	13.8 (1.6)	0.270
SRPB	14.9 (2.9)	13.9 (3.4)	16.0 (1.6)	0.126

Values given within brackets are (SD) *significant at p value < 0.05

TABLE 5- COMPARISON OF MEAN SCORES OF QOL AND MARITAL STATUS

Domains	Unmarried n = 20	Married n = 56	Others Group n = 65	p value
Overall	13.9 (1.8)	13.4 (2.3)	12.6 (1.9)	0.027*
Physical	14.7 (3.4)	13.4 (4.1)	12.8 (4.0)	0.201
Psychological	13.4 (3.3)	12.6 (3.4)	11.8 (2.9)	0.101
Level of Independence	15.3 (2.8)	14.0 (2.8)	14.3 (2.5)	0.174
Social Relationships	11.5 (2.1)	12.8 (2.7)	10.9 (2.4)	0.000*
Environmental	13.1 (2.2)	12.8 (2.3)	12.1(1.9)	0.109
SRPB	15.3 (2.3)	14.9 (3.0)	14.0 (3.4)	0.152

Values given within brackets are (SD). *significant at p value < 0.05

TABLE 6- COMPARISON OF MEAN SCORES OF QOL AND CD4 COUNT

Domains	CD4 Count < 200 cells/µl n = 22	CD4 Count 200 to 500 cells/µl n = 67	CD4 Count > 500 cells/µl n = 52	p value
Overall	12.4 (2.3)	13.2 (1.9)	13.3 (2.1)	0.222
Physical	12.5 (4.4)	13.0 (3.7)	14.0 (4.1)	0.264
Psychological	11.7 (3.1)	12.5 (3.2)	12.4 (3.2)	0.571
Level of Independence	12.1 (2.3)	14.3 (2.5)	15.2 (2.6)	0.000*
Social Relationships	11.4 (2.7)	12.1 (2.7)	11.4 (2.6)	0.303
Environmental	12.4 (2.5)	12.8 (2.0)	12.3 (2.1)	0.334
SRPB	14.4 (3.7)	14.6 (3.0)	14.5 (3.1)	0.951

Values given within brackets are (SD). *significant at p value < 0.05

DISCUSSION:

Mean QOL Scores of 6 domains: In our study the table- 3 shows the various QOL domain scores. Our study showed the over all mean QOL scores of 6 domains on a scale of 0- 20 was 13.1. A pilot study done by Ganesh et al[12] in Chennai in similar settings also showed similar over all mean scores of 13.2 .Our study showed the worst affected domain was social relationships domain and highest score for SRPB domain. In our study the social relationships domain had an average score of 11.7 which was the least score. A study done by Anand. D et al [13] showed similar findings with high QOL score in SRPB domain and low score in social relationship domain. Even in the study conducted by Nirmal B et al in Chennai[14] also showed that the social relationships domain were the least . This may be because of the fact that PLHA face social isolation, stigma and discrimination[15]. In contrary the another study done in puducherry by Mahalakshmy T at al[16] showed that SRPB domain scores were most affected. So this shows that QOL has wide variations even within South India.

The mean score in the SRPB domain was 14.5. The SRPB domain score was the highest. Even in study done in Ethiopia[17] showed similar findings. SRPB domain contains facet like, concern for future, fear of death and dying etc. In the Pre ART era there were uncertainty about survival and future faced by the PLHA. But after the introduction of first-line ART in 2004 and second-line ART in 2008 those uncertainties have gone.

QOL in relation to Gender : Our analysis showed (Table – 4) that the gender had significant impact on physical and level of independence domain. The physical domain was highest in the transgenders when compared with the males and females. However the result are to be interpreted with reservations because of the small sample of transgenders (n= 6). The physical domain was high in females when compared with the males. The preliminary study for the validation of WHOQOL-HIV found that women scored less across all domains [11]. On the contrary in the field study of WHOQOL HIV questionnaire it was found that men scored less in the 'energy and fatigue' and 'sleep and rest' facets. The study done in Chennai found that the physical domain scores were similar between genders. It also found that men reported a poor QOL in the psychological domain and women in the sociological domain[18]. Hughes J et al in the study in Africa, found no significant difference in the QOL scores between genders[19]**.** Most studies have found that women have a lower QOL than men[20, 21].

QOL in relation to Marital Status (Table 5) : Loss of spouse has an impact on the QOL especially in the cultural setting of India. Loss of spouse may lead to loss of both social and economic support leading to poor QOL. This was reflected in our study. In the analysis we included the separated, widowed and divorced in one group and compared with the married and unmarried. The overall QOL was low in the group of separated, widowed and divorced when compared with the married and unmarried group.

The social relationships domain were significantly low in the group of separated, widowed and divorced when compared with the married and unmarried.

The study done by Nojomi M et al[22] showed the QOL was low in separated individuals when compared with those who were married and single. The social relationships domain consists of social support, and sexual activities, So naturally this domain was affected in our study in the

group which consists of separated individual's from spouse, widowed and divorced. Of the 43 PLHA who had lost their spouse, 29 (67.4%) were females. Owing to the strong family system in India, those who have lost their spouse may be supported by other relatives. But that does not mean the person's all social needs can be satisfied.In contrary two studies found no relation between QOL and marital status[23, 24] . Campsmith ML et al found single person have poor QOL when compared to those with partners[25].

QOL in relation to CD4 Counts (Table 6) : The level of independence domain was high in PLHA with CD4 count > 500 cells/µl. Even the study done in Chennai[13] showed that PLHA with higher CD4 counts had higher overall QOL. When the CD4 Count is very low the PLHA are more prone for various opportunistic infections. On the other hand when the CD4 count increases the chance of the PLHA getting AIDS related illness is not possible. So as the count increases there is improvement in clinical staging and hence improvement in QOL also.

LIMITATIONS : The study results should be interpreted with certain reservations because of absence of multivariate analysis.

CONCLUSIONS :

The study has identified both modifiable/non-modifiable factors which affected the QOL of PLHA. The certain modifiable factors were the marital status, and CD4 count. The CD4 count was identified as an important factor, which is modifiable to an extent with the use of antiretroviral therapy leading to an improvement in their CD4 counts, subsequently leading to improvement in QOL. The non-modifiable factor identified were gender. Interventions focusing the modifiable factors will improve the QOL of PLHA and help them lead a normal life.

RECOMMENDATIONS

It is recommended that the health care personnel should assess the QOL of PLHA using WHOQOL-HIV questionnaire. The worst affected domain can be identified and appropriate interventions can be planned accordingly. Health education and proper counselling of the PLHA about CD4 Counts can motivate the PLHA to get initiated on ART when they become eligible for it. Antiretroviral therapy was found to improve the person's QOL by improving his / her symptoms and stage of the disease. Hence ART should be made accessible to all eligible PLHA . The pre ART patients should be followed up carefully and initiated on ART immediately when they become eligible for ART.

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