Quality of Life (QOL) among People Living with HIV/AIDS (PLHA) attending Tertiary Care Hospital of Delhi, India.

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ABSTRACT

Background: As estimated by WHO, globally a total of 36.9 million [34.3 – 41.4 million] people were living with HIV in 2014. Quality of life (QOL) of HIV/AIDS patients is becoming an important element for understanding and assessing the overall health care and management in health care settings. The objective of this study was to determine the QOL of patients living with HIV/AIDS in Delhi. Systemic Random sampling method was used to identify the subjects from the antiretroviral therapy clinic (ART) situated in tertiary care hospital in Delhi. **Methods:** 200 patients were interviewed with the WHOQOL-HIV instrument. Questionnaire included items on socio-demographic data, multi-item scales and had six domains namely physical, psychological, level of independence, social relationships, environment and spirituality religion. **Results:** Study subjects were aged between 18-60 years with mean age of 34.46±8.76 years, and comprised of 41%females. 29 % of studied subjects were illiterate. More than 1/3rd of the patients (84% females) were unemployed and did not have any source of income. All QOL domains were observed to be higher for males in comparison to females. Single/widow patients had better QOL in comparison to married patients. QOL was observed to be better among those who were young, had better educational qualifications, were employed, asymptomatic, had shorter duration of treatment and those who stayed closer to the ART center. **Conclusion:** Correlation of scores of six domains with overall QOL score and among individual domains was found to be statistically significant.

Keywords: Quality of life (QOL), People living with HIV/AIDS (PLHA), Antiretroviral therapy (ART)

INTRODUCTION

Human Immunodeficiency virus (HIV) infects human T cells, causing a disease that progressively leads to a dramatic deterioration of the immune function. The Acquired Immunodeficiency Syndrome (AIDS) is the final stage of HIV infection, when the body can no longer fight with life-threatening infections. It is present when CD4+ cell count falls below 200 cells/mm3 or the patient has an opportunistic infection, such as esophageal candidiasis or Pneumocystis pneumonia.[1-4] WHO estimated an average of more than 36.9million people to be infected with HIV in 2014 with Sub-Saharan Africa being the worst affected. According to National AIDS Control Programme (NACP) III 2007-2012, the estimated number of people living with HIV/AIDS in India were 20.9 lakh in 2011, out of which, 39 % were female and 7% children(5). The HIV prevalence in India in the age group 15-49 is 0.27% at national level.[5] With early diagnosis and effective treatment, most people with HIV will not go on to develop AIDS. World Health Organization has defined Quality of Life (QOL), as "individuals' perceptions of their position in life in the context of the culture and value systems in which they live and in relation to their goals, standards, expectations and concerns".[6] For a person living with HIV, this means having to cope with a range of HIV-related symptoms for extended periods. Symptoms may be related to the infection itself, co-morbid illnesses, or iatrogenic effects from HIV-related medications.[7,8] Many of the HIV patients struggle with numerous social problems such as stigma, poverty, depression, substance abuse and cultural beliefs that can affect their QOL not only from the physical health aspect, but also from mental and social health point of view and cause numerous problems in useful activities and interests of the patients. The study of physical, psychological, social and environment factors those are likely to influence health outcomes in HIV - infected individuals can increase the understanding of this disease and allow

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designing more efficient interventions. Hence, the present study aims to investigate the QOL of PLHA receiving ART and identify the factors that affect it.

MATERIALS AND METHODS

The study was conducted in Antiretroviral therapy (ART) clinic of a tertiary care teaching hospital of Delhi from August 2015 to September 2015.Systemic random sampling method was used to identify subjects from the outpatient department of ART. 200 patients were interviewed using WHOQOL-HIV BREF questionnaire. The HIV/AIDS patients attending ART clinic who consented to be part of the study were interviewed..
The WHOQOL-HIV BREF is based on the WHOQOL-BREF, the shorter form of the WHOQOL-100. This contains a total of 31 items including five extra items specific to PLHA. There are also two items that examine general quality of life (an individual's overall perception of quality of life and overall perception of his/her health). The WHOQOL-HIV BREF produces six domain scores (physical, psychological, level of independence, social relationship, environment, spirituality – religion). Scoring for each item was done using five item Likert scale (1 to 5). Higher scores indicate better QOL, with the following exceptions: pain, negative feeling, dependence on therapies and all facts in the domain personal belief of PLHA (forgiveness, spiritual connection, personal spiritual experience, death and dying) where score direction is inverted. Facets scores were calculated using the mean of the four items. Domain scores were calculated by summing the facets scores and dividing it by number of facets in that domain. The result was then multiplied by four so that domain scores range from 4 (worst possible QOL) to 20 (best possible QOL). Data on socio-demographic information such as age, sex, marital status, literacy, income, and employment, distance of residence from ART center and duration of treatment was also collected. Average duration of interview was 40 minutes.
Data was analyzed using the statistical package for the social science (SPSS) 20 version. Descriptive statistics were calculated for demographic characteristics of study subjects. Student's `T`-test was used for comparison of quantitative variables. Inter domain correlation coefficient was calculated. Correlation coefficients were also calculated for correlation between age, sex, marital status, employment, income, duration treatment and distance of residence from ART center with QOL domain.

RESULTS

Out of the total 200 subjects, included in the study, majority were males (59%). Study subjects were

aged between 18-60 years with mean age of 34.46±8.76 years.Majority of the participants (89%) were married and living with their spouse. Only 29% of the participants were illiterate. 43% were unemployed and had no income and many of them were females (80%). Majority (63%) of the patients were in the clinical category B (CD4=200-499). The mean CD4 count in all the study subjects was 325±161cells/mm3.

Table 1: Socio- demographic characteristics of study subjects (N=180) *

Variabe	Male N (%)	Female N (%)	Total N (%)
Age (in years)			
18-30 yrs	32 (16)	44 (22)	76 (38)
31-45 yrs	70 (35)	34 (17)	104 (52)
46-60 yrs	16 (8)	4 (2)	20 (10)
Marital status			
Unmarried/Single	14(7)	0	14(7)
Married	104(52)	74(37)	178(89)
Widow/Widower	0	8(4)	8(4)
Educational level			
Illiterate	28(14)	30(15)	58(29)
Primary school	24(12)	22(11)	46(23)
High school	46(23)	22(11)	68(34)
Sen .Sec.sch	8(4)	2(1)	10(5)
Graduate and above	12()6	6(3)	18(9)
Occupation			
Unemployed	14(7)	72(36)	86(43)
Self employed	6(3)	0	6(3)
Private sector	92(46)	8(4)	100(50)
Govt sector	6(3)	2(1)	8(4)
Income			
0	14(7)	70(35)	84(42)
1-5000	39(19.5)	10(5)	49(24.5)
5001-8000	42(21)	2(1)	44(22)
8001-10000	9(4.5)	0	9(4.5)
Above 10000	14(7)	0	14(7)

Table 2: Mean Scores (± SD) of WHOQOL-HIV Domains

Domains	Male (N=118) Mean± S.D	Female (N=82) Mean± S.D	Total(N=200) Mean± S.D	P value
Physical	15.95±3.78	15.59±3.38	15.80±3.61	.485
Psychological	13.15±2.91	12.94±2.92	13.06±2.90	.607
Level of independence	10.86±3.08	10.12±2.92	10.56±3.02	.088
Social relations	11.73±3.68	10.10±3.23	11.06±3.58	.001
Environment	13.62±2.78	12.51±2.92	13.17±2.88	.007
Spiritual	13.37±3.51	12.80±2.61	13.14±3.17	.215

[Table 2] shows mean score and standard deviation of subjects on different domains and facets of WHO QOL-HIV. Overall QOL was higher for males in comparison to females in all six domains. Mean scores in the six domains of QOL were maximum for physical domain (mean=15.80+3.61) and minimum for Level of independence (10.56±3.02). Analysis based on education level showed statistical

significant difference in physical, level of independence and environmental domain, higher the education higher the QOL.

Age correlates with level of independence, physical and environment domain. Unmarried participants and widows had better psychological and spiritual QOL in comparison to married participants. Unemployed and zero income participants were associated with lower QOL in all the domains.

Longer duration of ART treatment (>8 years) were associated with lower QOL in comparison to shorter duration of treatment (<3 year). 95% of the participants were satisfied with the services (information, counseling and treatment) provided in the ART clinic. Asymptomatic subjects had higher QOL than symptomatic and AIDS converted subjects. People who were staying within 10km had better QOL than people who were staying far.

Table 3. Correlation between Domains of WHOQOL-HIV

Domains	Physical	Psychological	Level of independence	Social relations	Environment	Spiritual
Physical	1					
Psychological	.725**	1				
Level of independence	.666**	.772**	1			
Social relationship	.537**	.627**	.593**	1		
Environment	.605**	.764**	.792**	.724**	1	
Spiritual	.487**	.526**	.476**	.466**	.462**	1
Overall QOL SCORE	.000	.000	.000	.000	.000	.000

Correlation index of WHOQOL-HIV domains with overall QOL and among individual domains, calculated by Pearson's statistics, are shown in [Table 3]. Each domain was significantly related with overall QOL using two-tailed `t` test (p<0.001). Moreover, each domain was significantly related with others (p<0.001).

Age, education, employment, income and CD4 count had positive correlation with QOL, whereas distance of residence from the ART center and duration of treatment had negative correlation with QOL domains.

DISCUSSION

With advance research and treatment options to slow disease progression, patients are living longer after diagnosis and initial treatment. Hence, interest has been increasingly focused on the quality of life of patients. The present study specifically evaluates QOL among HIV/AIDS patients. Globally several instruments have been specifically developed to assess the QOL of people living with HIV/AIDS (PLHA) like Medical Outcome Study (MOS-QOL),[9] AIDS Health Assessment Questionnaire AIDS-HAQ) etc.,[10] but among many QOL instruments used globally, WHOQOL-HIV has been used widely.

Our study showed a statistically significant difference with age in Level of Independence, social relationship and environmental QOL domain. Marceline F et al,[11] also showed similar results in his study. Most of the subjects were young and the disease was leading to morbidity, unemployment and ultimately no income, similar finding were observed by Yadav et al,[12] and Giri S et al,[13] which ultimately contributes to less productive population in the society. Our Study showed that QOL was lower among females in comparison to males in all the QOL domains.

Lowest score was found with social relationship domain among females, which signifies that female experiences low family support, personnel relationship, poor sexual activity, and low social acceptability in comparison to males. In contrast Zinkernagel C et al,[14] reported better QOL scores for female in his study. Psychological and spiritual QOL was higher for unmarried and widow /widower participants in comparison to married participants. It can be attributed to the fact that the married people have to take care of the family along with the morbidities, liabilities and future concerns for them and their family. Higher education showed a statistical significant difference with physical, level of Independence and environmental domain. Likewise, Hay R D et al,[15] reported a linear relationship between education and QOL. Employment and income status had positive association with QOL and similar finding were reported by Hays RD et al,[15] and Swindles S et al.[16] Our study showed the scores in all the 6 domains were lower for those who were on treatment for more than 8 years in comparison to who were on treatment for less than 3 years, Rajeev K et al,[17] Munene E et al,[18] Beck EJ et al,[19] also showed that longer the patients were on treatment, lesser they adhere to the treatment as the medicine shows improvement in health condition or they get fed up by the long regime and compromise their QOL in future. There was a statistical significant difference found between CD4 count and Physical QOL. Sudhir G et al,[20] and Call S et al,[21] also found that higher the CD4 count, higher is the QOL. Asymptomatic subjects had better QOL score in comparison to those who were symptomatic or AIDS converted. Hays R D et al also reported poorest health with AIDS patients. Each domain was significantly related with each other's (p<0.001) and with overall QOL using two tailed t test (p<.001). Similar findings were

reported by Marashi T et al,[22] and Gupta S K et al,[23] in their studies. Age, education, employment, income and CD4 count had positive correlation with QOL, whereas distance from the ART center and duration of treatment had negative correlation with QOL. Gupta SK, et al,[23] also showed correlation of mean score of overall quality of life score were statistically significant for gender, occupation, income, age, education, marital status, current illness, treatment, CD4 count, HIV status and duration of disease.

CONCLUSION

To conclude it was observed that a significant relationship of quality of life with age, sex, education, employment, income and CD4 count exists. PLHA with better education, employment and income had better quality of life. Level of Independence domain had the minimum mean domain score and physical domain had the maximum mean domain score and we found significant correlations between scores of six domains with overall QOL. Age, education, employment, income and CD4 count had positive correlation with QOL, whereas distance from the ART center and duration of treatment had negative correlation with QOL.

Recommendations
- Planning for PLHA should focus on broad range of services including primary medical care, social support, education and employment opportunities with help of Government schemes and involving NGOs.
- More information, education, and communication campaigns should be provided in general public to eliminate or reduce stigma to the barest minimum.
- Policies should be made and rules should be enforced to protect the rights of PLHA in the work place as well as prevent any form of discrimination against them in the society.
- All staff and health professional in ART centers should be regularly sensitization about the condition of PLHA, so that at any time of the treatment they should maintain the focus, affection and empathy towards these patients.
- Sometime hospital-based care is not feasible or the patient is enable to come due to his personnel reasons, home or community-based care is one appropriate option for better care and compliance.

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