Gupta et al., J Community Med Health Educ 2012, 2:8
DOI: 10.4172/2161-0711.1000172

Community Medicine & Health Education

Research Article Open Access

A Study on the Self-Reported Quality of Life of HIV-Positive Slum-Dwellers in Mumbai, India

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Abstract

Background: HIV/AIDS emerged as one of the most important public health issues of the late twentieth and early twenty-first centuries and is now one of the leading causes of global morbidity and mortality. The objective of this study was to determine quality of life of people living with HIV/AIDS by using different Domain Scores.

Methods: This was a Bi-centric qualitative cross-sectional study, which was conducted in the three phases, by using standard, validated questionnaires used in WHOQOL HIV –BREF.

Findings: Correlation of mean score of overall quality of life and general health score were statistically significant for gender, occupation, per capita income, age, education, marital status, current illness, treatment, CD4 count, HIV status and duration of disease. Correlation coefficient of different domains viz. physical health, psychological health, leave of independence, social relationship, environment, personal belief and spirituality, with overall quality of life score and general health score ranged from +0.4 to +0.7.

Conclusions: Although overall quality of life was affected by different socio-demographic determinants, CD4 count, treatment, HIV status and duration of disease, it was contributed by six domain viz. Physical, Psychological, Level of independence, Social relationship, Environment and Spirituality / religion/ personal belief. So, a different approach under integrated program is required to strengthen the most affected domain in above variable to improve overall quality of life of people living with HIV/AIDS.

Keywords: HIV/AIDS; Quality of life; Domain score; Socioeconomic factors

Abbreviations: PLWHA: People Living with HIV/AIDS; WHOQOL: World Health Organization Quality of Life

Introduction

HIV/AIDS emerged as one of the most important public health issues of the late twentieth and early twenty-first centuries and is now one of the leading causes of global morbidity and mortality. The HIV/AIDS epidemic has prompted wide reaching changes in public health, clinical practice, and scientific research, and had a great impact upon societies throughout the world. The global prevalence of HIV infection (percentage of persons infected with HIV) is remaining at the same level, although the global number of persons living with HIV is increasing owing to the ongoing accumulation of new infections with longer survival times.

Worldwide, the number of people living with HIV has risen to 33.4 million [31.1-35.8 million] in 2008 from 29.0 million [26.9 million-32.4 million] in 2001 [1].

In 2007, an estimated 4.9 million [3.7 million-6.7 million] people in Asia were living with HIV, including 440,000 [210 000-1.0 million] people newly infected in the past year. Approximately 300,000 [250,000-470,000] people died from AIDS-related illnesses in 2007. In 2007 there were almost 20% more new HIV infections in East Asia than in 2001.

The overall adult HIV prevalence in South and South-East Asia (0.7%) regions is relatively much lower than that in sub-Saharan Africa (5.9%). However, due to the large population in these regions, even a low HIV prevalence means that a large number of people are infected. At the end of 2006, an estimated 4 million (taking into account India's recent estimate of 2.5 million) people were living with HIV in South-East Asia Region. Approximately, 550, 000 people died of AIDS related illnesses during 2006 [2].

Long standing HIV epidemics have resulted in large number of people living with HIV and AIDS in SEA countries who need prevention, care, support and treatment services [3].

Latest Technical Brief on HIV Sentinel Surveillance and HIV Estimation 2007 given by National Aids Control Organization, Ministry of Health And Family Welfare, and Government of India in October 2008 showed estimated adult HIV prevalence in India, in 2007, is 0.34% (0.25%-0.43%). Estimated HIV prevalence among males (0.40%) continues to be higher than among females (0.27%). Report shows that the total number of People Living with HIV/AIDS (PLWHA) in India in 2007 is estimated to be 2.31 million (1.8–2.9 million). Females constitute around 39% of the burden (0.9 million). Children below 15 years constitute 3.5% of the estimated number of PLWHA while elderly people with age greater than 49 years constitute 7.8%. Adults aged 15-49 years constitute 88.7% of the estimated number of PLWHA. This indicates that AIDS still threatens the cream of society, those in the prime of their working life While adult HIV prevalence among

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Received June 15, 2012; **Accepted** September 24, 2012; **Published** September 26, 2012

Citation: Gupta SK, Shrivastava AK, Gupta P, Sharma P, Sarawagi R (2012) A Study on the Self-Reported Quality of Life of HIV-Positive Slum-Dwellers in Mumbai, India. J Community Med Health Educ 2:172. doi:10.4172/2161-0711.1000172

the general population is 0.34%, high-risk groups, inevitably, show higher numbers. Among Injecting Drug Users (IDUs), it is as high as 8.71%, while it is 5.69% and 5.38% among Men who have Sex with Men (MSM) and Female Sex Workers (FSWs), respectively [4]. The highest numbers of PLWHA are in Andhra Pradesh and Maharashtra, with nearly half-a-million PLWHA in each.

Quality of life (QOL) is a term that is popularly used to convey an overall sense of well being and includes aspects such as happiness and satisfaction with life as a whole [5].

World Health Organization (WHO) has defined 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]. 'Quality of life' is a multi-dimensional concept whose definition and assessment remains controversial [7,8]. Consequently, various conceptual and operational definitions have been used in QOL [9,10]. Quality of life is conceptualized in terms of "an absence of pain or an ability to function in day to day life" [11].

A lot of researchers described Quality of life as a "fighting spirit" associated with longer survival time for individuals [12-14]. "Quality of life relates both to adequacy of material circumstances and to personal feelings about these circumstances". It includes "overall subjective feelings of well being that are closely related to morale, happiness and satisfaction [15].

Further as health is generally cited as one of the most important determinants of overall quality of life, it has been suggested that quality of life may be uniquely affected by specific disease process such as AIDS [16,17].

Quality of life measures are usually better than more traditional, clinical measures for evaluating the social and emotional outcomes of disease processes and treatments and giving an overall picture of how treatments for diseases are affecting the patients' ability to function in life. Many of the people living with HIV/AIDS find it challenging to attend to the daily routine tasks of living or participate in moderate to vigorous physical activities, or have sufficient energy or vitality to engage in an active social life while managing HIV/AIDS. Fatigue or low energy has been associated with both physical and psychological morbidity and poor quality of life in persons with HIV/AIDS [18,19]. In addition; fatigue and a CD4 T cell count less than 500 are associated with physical limitations and disability [20]. Among HIV-positive patients, disease progression is related to decreasing energy and increasing difficulties with daily activities and pain [21].

Unless a cure is found or life-prolonging therapy is made more widely available, the majority of people living with HIV or AIDS will continue to suffer with the disease, thus seriously impacting their quality of life. For this reason, quality of life measure is necessary that can be used not only to assess the physical and medical needs of HIV/AIDS people, but also their psychological, social, environmental and spiritual areas of life [22].

This is particularly pertinent for use with those living in developing countries where medical care is currently unavailable and social support is at minimum. From the advent of HIV/AIDS, more than two decades ago, different societies have continued to react undesirably to the people who are known or suspected to have HIV/AIDS. Such reactions fit in with Goffman's conceptualization of stigma as "an attribute that is significantly discrediting" [23].

This study was an attempt to examine the relationship between quality of life in a diverse, socio demographic group of people living with HIV/AIDS. Main aim of our study was to yield a measure of the relationship between the health care service and patients' quality of life, and also to find out patients' perception of the quality by studying effects of socio-demographic determinants, duration of disease, HIV status on different domains of life viz. physical health, psychological health, leave of independence, social relationship, environment, personal belief and spirituality. It is an attempt to highlight the key challenges faced by us in our quest to respond effectively to AIDS now and in the decades to come. Due to paucity of data in the Indian context it was decided to conduct the current study on quality of life of people living with HIV/AIDS in an urban slum area of Mumbai.

Material and Methods

The present study is a centre based study conducted in two Integrated Counselling and Testing Centre in the field practice area of medical college situated in an urban slum in Mumbai. Two centre working for people living with HIV/AIDS in the field practice area which were taken as study sites.

Research design

Bi-centric qualitative cross-sectional study

Study period

November 2007 to August 2008.

Sample Size

There were 524 people who came for follow-up counselling, but the sample size was 270. 421 were people suffering from HIV/AIDS; others were negative. HIV negative persons also attend follow up counselling because of their high risk behaviour, having symptom suggestive of HIV/AIDS and those who were in window period. Out of these, 79 were excluded because they were positive for less than 2 weeks. Two week period was taken as a cut off point for the enrolment of the study because the participants were asked question based on their last two week experiences. Out of 352 follow up PLWHA, 29 were excluded because of non communicable disease [19], chronic pain [8] and antenatal mothers [2]. Therefore, the follow up PLWHA who were eligible for the study were 323 people. Out of these PLWHA, 270 had given consent for the study which is 81% of the eligible population. PLWHA who refused to participate cited insufficient time as main reason and remaining preferred not to reveal their identity to strangers (researches) or talk about their illness.

Study was conducted in the three phase

Phase I

A predesigned, pretested questionnaire instrument was designed by using standard, validated questionnaires used in WHOQOL HIV –BREF [6].

In addition following background questions were added regarding the Baseline demographic information about individuals, PLWHA health status & feelings about their current illness, Documented CD4 count and HIV related information.

Phase II: Rapport Building

Data regarding HIV status is sensitive and people were unwilling to reveal such information. Therefore, assistance of counsellor working in that ICTC was taken to build rapport with participants.

Phase III: Interview of PLWHA: Structured interview based on data collection instrument conducted after taking consent from PLWHA. Interview took around 30 minutes to collect relevant information.

Ethics approval

Ethics approval for conducting the study was taken from the ethical committee of the institution i.e. Seth G.S. Medical College, and associate KEM Hospital Mumbai, with the assurance that confidentiality will be maintained and the information obtained for this study will not be used for any other purpose except for academic purpose.

Exclusion criteria: Follow-up Antenatal mothers, HIV negative person and PLWHA who were suffering from non communicable disease like hypertension, diabetes, asthma, any chronic condition like arthritis having chronic pain.

Calculation of Domain Scores: Computation of domain scores by following formula

Domain 1 = (Q3 + Q4 + Q14 + Q21)/4 * 4

Domain 2 = (Q6 + Q11 + Q15 + Q24 + Q31)/5 *4

Domain 3 = (Q5 + Q22 + Q23 + Q20)/4 * 4

Domain 4 = (Q27 +Q26 + Q25 + Q17)/4*4

Domain 5 = (Q12 + Q13 + Q16 + Q18 + Q19 + Q28 + Q29 + Q30)/8 *4

Domain 6 = (Q7 + Q8 + Q9 + Q10)/4 *4

Overall Quality of life = (Q1 + Q2)/2 * 4

General health score = (Overall Quality of life + perceived health status)/2

(These equations calculate the domain scores. All scores are multiplied by 4, so as to be directly comparable with scores derived from the WHOQOL).

Statistical analysis

It was done by using SPSS version 16 software, descriptive statistics for Socio-demographic factors, mean domain scores and overall Quality of life score, cross tabulation of significant findings. ANOVA with post hoc test, Kruskal Wallis test multivariate analysis were used where ever applicable.

Limitations of this study

The study was restricted to health related quality of life from patient's perspective. The other aspect of QOL and objective evaluation of it was not considered for the study. It was not feasible to conduct in a community, keeping in mind the confidentiality and anonymity of people, so it may not represent the quality of life of general PLWHA population.

There was no AIDS converted PLWHA in our study maybe because of no comprehensive care was available at ICTC centre so it was not possible to evaluate the QOL in them.

Results

In the present study, out of 270 respondent PLWHA, transgender respondent were 23%, while male and female PLWHA were 39.3% & 37.8% respectively. 73.3% of respondents were in age range of 25 year to 44 year. Among the respondents 45.9% were married, 39.3% were single and 14.10% were widowed. In present study 35.60% were illiterate. Only 11.10% had studied up to 10th standard and above. 37% of respondent which were mostly male had manual / semi skilled work as their occupation, 28.9% were without occupation or beggar. Only 28.10% respondents were housewife while 5.9% female were commercial sex worker. 42.2% of participant earned below Rs.500 where as respondents earned in the range of Rs. 500 to Rs.1499 and more than Rs.1500 per month were in equal proportion i.e. 28.9% (Table 1).

71.1% of the study group was asymptomatic. No participant was AIDS converted (Full blown AIDS). CD4 were documented for 106 PLWHA. Out of which, 15.1% were having count less than 200 µl/cu.mm. In this study, among the PLWHA who had documented CD4 count less than 200 µl/cu.mm 81.20% were asymptomatic. While out of 90 PLWHA who had count more than 200 µl/cu.mm 64.40% were symptomatic. Finding was statistically significant (X2=11.611, DF=1, P value<0.001) (Table 2).

The mean scores in the six domains of QOL was maximum for the spirituality/ religion/ personal belief followed by the, physical domain, level of independence, psychological domain, environment domain and social relationship in descending order. While the mean score of overall quality of life is 10.95 it is below average on the scale of 4 to 20 if 12 is taken as average and it was very well related to general health score which also show below average rating on the scale of 5 to 25 if 15 was taken as average (Table 3).

In the study, correlation of mean score of overall quality of life and general health score were statistically significant for gender, occupation, per capita income, age, education, marital status, current illness, treatment, CD4 count, HIV status and duration of disease (Table 4). All

Particulars		Percentage
Total no. of PLWHA interviewed [N] = 270		
Gender		
Male	n=106	39.30
Female	n=102	37.80
Transgender	n=62	23.00
Age in years		
18 -24	n=44	16.30
25-34	n=98	36.30
35-44	n=100	37
45-60	n=28	10.40
Per Capita Income per month (socio-economic status)*		
Less than 500	n=114	42.20
Rs. 500 to Rs.1499	n=78	28.90
Rs. 1500 to Rs.2999	n=78	28.90
More than Rs. 3000	n=0	0
Occupation		
No occupation / Beggar	n=78	28.90
Housewife	n=76	28.10
Manual /semiskilled Worker	n=100	37
Commercial Sex Worker	n=16	5.90
Educational status:		
Illiterate	n= 96	35.60
Primary(up to 5th)	n=86	31.90
Secondary(6th to 9th)	n=58	21.50
SSC and above(10th and above)	n=30	11.10

*shows socio-economic class according to B.G. Prasad classification modified in 2004

Table 1: Demographic and socio-economic profile of PLWHA Maharashtra, india.

HIV stus	CD4 Count	
	Less than 200 µl/cu.mm	**More than 200 µl/cu.mm**
Asymptomatic	13 (81.20)	32 (35.60)
Symptomatic	3 (18.80)	58 (64.40)
AIDS converted	0 (0.00)	0 (0.00)
Total	16 (100)	90 (100)

X2=11.611 DF=1 p<0.001

Table 2: Distribution of PLWHA according to CD4 count & HIV status. N=106).

Domain	Mean	SD	Minimum	Maximum
Physical	12.41	2.21	5	19
Psychological	10.67	2.33	6	20
Level of Independence	11.98	2.54	5	20
Social Relationships	8.87	2.65	4	17
Environment	9.10	2.40	4	20
Spirituality/Religion/ Personal Beliefs	12.96	2.94	5	20
Overall quality of life score	10.95	3.05	4	20
General health status score	13.73	3.75	5	25

Table 3: Distribution of mean and range of domain score obtained from the quality of life questionnaire (WHOQOLHIV BREF).

mean domain scores were correlated with overall quality of life score and general health score. Correlation coefficient of different domains with overall quality of life score and general health score ranges from +0.4 to +0.7 in level of independence, psychological, environment, social relationship, physical and spiritual/ personal belief/ religion in descending order (Table 5).

Discussion

Quality of life is an important concept in the field of international development, since it allows development to be analyzed on a measure broader than standard of living. Within development theory, however, there are varying ideas concerning what constitutes desirable change for a particular society, and the different ways that quality of life is defined by institutions therefore shapes how these organizations work for its improvement. Organizations such as the World Bank, for example, declare a goal of "working for a world free of poverty", with poverty defined as a lack of basic human needs, such as food, water, shelter, freedom, access to education, healthcare, or employment. In other words, poverty is defined as a low quality of life. Using this definition, the World Bank works towards improving quality of life through neoliberal means, with the stated goal of lowering poverty and helping people afford a better quality of life.

Other organizations, however, may also work towards improved global quality of life using a slightly different definition and substantially different methods. Many NGOs do not focus at all on reducing poverty on a national or international scale, but rather attempt to improve quality of life for individuals or communities. One example would be sponsorship programs that provide material aid for specific individuals. Although many organizations of this type may still talk about fighting poverty, the methods are obviously significantly different.

Our study found out that most of the people who were infected with HIV/AIDS were in productive group with increase in symptomatic patient in higher age group, and most of them belong to below poverty line in socioeconomic strata. Lower socioeconomic persons lead a lower quality of life. It was found that married people lead a good quality of life, which may be due to support from life partner. Recently positive patients require more attention and counselling because duration of disease is inversely related to quality of life in HIV/AIDS patient.

More attention is required in the areas of personal relationship, social support and sexual activity, social inclusion of each and every PLWHA irrespective of any socio-demographic profile. Quality of life was affected by not only occupation but by type of occupation, with lower score in lower dignified jobs. CD4 count is the positive predictor of physical and social relationship domain. Decrease in CD4 count will have increase chances of lower score in above domain, which in turn will lead to low overall quality of life. Overall quality of life of people infected with HIV was found to be low. It was seen that people infected with HIV virus perceived their health status to neither good nor bad with below average general health score.

Few studies for the assessment of quality of life of people living with HIV/AIDS have used the WHOQOL- HIV brief till date [24-26].

This study has been done using WHOQOL-HIV Brief. There are no previous studies on it in India. Others, which is not comparable to the present study, used different instruments (MOS, SF-36, HAT-QoL). Besides, the WHOQOL group developed the WHOQOL-100 and WHOQOL-HIV instruments.

In the present study, 23% of participants were transgender which form a significant high risk group of population and there was equal representation of male and female PLWHA as shown in table 1. No previous study was conducted on this high risk group population in India. In the cross sectional study carried out by Wig N et al. [27]. It was found that number of male were 88.1%, while rest were female. In a study done by Thomas B.E. et al. [28] 51% female constituted the study population. In present study, age of PLWHA ranged from 18 to 60 years with mean age of 32.99, finding corresponds to previous study conducted in India [27].

In this study, PLWHA of more than 18 years were included because they can give consent individually. Patients above 60 years mainly suffer from geriatric ailments so they were not included. By including 18-60 year age range we have covered almost 90-95% of PLWHA population as latest HIV sentinel surveillance and HIV estimation 2007 report document that children below 15 years constitute only 3.5% of the estimated number of PLWHA while elderly people with age greater than 49 years constitute 7.8%. Adults aged 15-49 years constitute 88.7% of the estimated number of PLWHA.

Largest group of PLWHA had manual or semiskilled work as

Socio-demographic variable	Overall quality of life score		General health score	
	F	P value	F	P value
Gender	3.09	0.002	2.45	0.001
Occupation	2.89	0.004	1.76	0.03
Per capita income	2.87	0.004	2.03	0.009
Age	3.14	0.002	4.79	0.000
Education	5.77	0.000	3.63	0.000
Marital status	2.13	0.033	3.99	0.000
Current illness	10.29	0.000	6.07	0.000
CD4 Count	3.31	0.002	2.28	0.006
Treatment	4.79	0.000	2.31	0.005
HIV status	2.21	0.027	-	-
Duration of disease	7.35	0.000	6.72	0.000

Table 4: Kruskal Wallis test between overall quality of life score & general health score to socio-demographic variables.

Domain	Overall quality of life score		Overall general health	
	Pearson Correlation Coefficient	P value	Pearson Correlation coefficient	P value
Physical	0.481	0.01	0.508	0.01
Psychological	0.685	0.01	0.698	0.01
Level of Independence	0.69	0.01	0.704	0.01
Social Relationships	0.573	0.01	0.571	0.01
Environment	0.589	0.01	0.6	0.01
Spirituality/Religion/ Personal Beliefs	0.385	0.01	0.399	0.01

Table 5: Correlation between overall quality of life score and overall general health to mean domain scores.

their main occupation which constitutes 37% of our study population. This study included the 16 commercial sex workers in this study. This occupation group gave a very good contrast to study because on one side all the commercial sex worker were female so that we can compare them with house wife. In the study conducted by Wig et al. [27] Unskilled workers constituted largest group and no high risk group was taken. In the present study most of the patient were earning below Rs.500. They were classified as very poor/ below poverty line according to B.G. Prasad classification modified in 2004. This shows the typical socio-economic status of a slum area. In the study nearly half of study population (45%) were married rest were single, divorcees or widowed. So there was nearly equal representation of married and single people. In other previous studies married population constituted 65-67% [27-29] of the study group.

The mean scores in the six domains of QOL was maximum for the spirituality/ religion/ personal belief followed by physical domain, level of independence, psychological domain, environment domain and social relationship in descending order. While the mean score of overall quality of life is 10.95 it is below average on the scale of 4 to 20 if 12 is taken as average. It was very well related to general health score which also shows below average rating on the scale of 5 to 25, if 15 is taken as average In the study conducted by Starace et al. [24] using WHOQOL-HIV, comprising 134 Italian men and women, lower scores were reported in the environment domain. Higher scores were found in the level of independence domain, followed by psychological health, beliefs of people living with HIV/AIDS (fear of disease progression, fear of being left alone as disease progresses, feeling uncomfortable in the presence of other people with HIV), physical health, social relationships and spirituality domains. In the cross sectional study carried out of by Wig N et al. [27] the mean scores in the four domains of QOL was maximum for the social domain followed by the psychological domain, physical domain and the environmental domain in descending order. A Study conducted by dos Santos EC et al. [30] on Quality of life of people living with HIV/AIDS in São Paulo, Brazil, all the domains had same score. A study conducted by Belak Kovacević S et al. [25] Showed average quality of life scale scores according to each domain. The lowest mean score was in the social relationships domain (X=13.79; SD=3.88) and the highest (X=15.07; SD=2.92) was in the level of personal independence domain. The internal consistency between the six domains of the instrument (WHOQOLHIV Bref) was found to be excellent (Chronbach's a=0.88). The inter-domain correlation was found positively significant, between all pairs of the five of six domains using two tailed test at $p<0.01$ (Pearson coefficient varied between +0.56 to +0.74 between the domain pairs), while correlation of spirituality / religion / personal belief with other domain were between +0.25 to +0.45. In a study, conducted by Sanja Belak Kova et al. [25] shows that internal consistency analysis of Croatian version of WHOQOL-HIV BREF instrument showed reasonably good reliability for domains (0.51–0.80) as shown by the Chronbach's alpha coefficients. Reliability coefficient for physical domain was 0.51, for psychological domain was 0.74, for level of independence domain was 0.75, for social relationship domain 0.80, for environment domain was 0.80 and for the spirituality domain was 0.67. In the cross sectional study carried out of by Wig N et al. [27] the internal consistency between the four domains of the instrument (WHOQOL-BREF) was found to be excellent (Chronbach's a=0.91). The inter-domain correlation was found positively significant, between all pairs of the four domains using two tailed test at $p<0.001$ (Pearson coefficient varied between +0.52 to +0.71 between the domain pairs).

In the present study mean score of overall quality of life and general health score showed statistically significant correlation with gender, occupation, per capita income, age, education, marital status, current illness, treatment, CD4 count, HIV status and duration of disease. The all domain mean scores were correlated with general health scores and overall quality of life. Pearson correlation coefficient of different domains with overall quality of life score and general health score ranges from +0.4 to +0.7 in level of independence, psychological, environment, social relationship, physical and spiritual/ personal belief/ religion in descending order.

Conclusion

Although overall quality of life was affected by different socio-demographic determinants, current illness, CD4 count, HIV status, treatment and duration of disease in our study, it was contributed by six domain viz. Physical, psychological, level of independence, Social relationship, environment and spirituality/ religion/ personal belief. So, a different approach under integrated program is required to strengthen the most affected domain in above variable to improve overall quality of life of people living with HIV/AIDS.

Physical domain of quality of life mainly expressed through pain and discomfort, symptom related to HIV, sleep & rest, energy & fatigue. It is advisable that, during counselling session this should be seriously probed and attended to, by suitable palliative measure. Special focus should be on females. It may be noted that physical domain is better predicted by current illness status, literacy and CD4 count. While explaining continuum, psychological feeling ranging from positive end to negative one, the aspect of self esteem is high lightened to a very large extent. Their sense of dignity and thereby their self acceptance is largely explained by their self worth. This knowledge needs to be taken in to consideration, that not only ART but constant boosting of their self esteem needs to be practiced in each and every counselling session. A person with positive self esteem is better suited for coping with various psychological upheavals in life. Various motivational techniques tailored for individual patient will go a long way in improving the quality of life.

Acknowledgement

The authors are indebted to all the participants and their family/relatives for their co-operation. We are also thankful to the staff of Integrated Counselling and Testing Centre.

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