FAMILY BURDEN AND HEALTH RELATED QUALITY OF LIFE OF HIV INFECTED INDIVIDUALS IN MADURAI, SOUTH INDIA

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ABSTRACT

Introduction: With the advent of Highly Active Antiretroviral Therapy (HAART) in 1996, HIV-infected patients are living longer and are concerned not only with treatment's ability to extend their life but also with the quality of the life they are able to lead, because, efficacy of treatment is strongly related to meaningful outcome i.e., better Quality of Life. Especially Health related quality of life has not been studied well. Hence, this study was necessitated with the objectives to evaluate Health Related Quality of Life (HRQoL) in HIV infected persons on ART. The secondary objectives were to assess the family burden experienced by the families of HIV infected, and measure influence of family burden on overall quality of life.

Methodology: The HIV infected individuals who were started on treatment six months prior to date of interview were considered for the study The SF36 (Short Form with 36 questions) was used to evaluate function and mental Health while Pai and Kapur's Family Burden Interview schedule was used to assess family burden. Interview schedule was pre-tested on 10 HIV infected individuals for consistency. Data analysis was performed using SPSS version 11 (SPSS inc. Chicago, IL, USA). Pearson product moment Correlation were computed to explore the relationships of SF36 with SLI, Family Burden and BMI. Further, Independent student "t" – test was performed to see the association between HRQoL and gender.

Results: Of 91 participants interviewed 51.6% were women. Median age (years) of the respondents was 33. The overall mean score for Physical health was 45.13 SD (12.40) and for Mental health 56.91 SD (15.52). Age of HIV infected persons had significant influence in scores in social functioning (p-value .015), emotional well being scores (.015), and Mental health (.010). Socio life Index was directly related to physical health, mental health, Vitality, social functioning and emotional scores on HRQoL. Physical health score was negatively affected by the Family burden score. Similarly, BMI status of the respondents correlated with Mental health, Body Pain, Vitality and Role emotional scores of HRQoL scale SF 36.

Conclusion: Socio Life Index and BMI appear to be the two important predictors of HRQoL. Therefore, special attention may be required to HIV infected persons with lower SLI and BMI. Nutritional supplements, in addition to ART drugs, may be provided to ensure some improvements in physical functioning.

Key words: People Living with HIV/AIDS, ART, Health Related Quality of Life, Family Burden

INTRODUCTION

With the advent of Highly Active Antiretroviral Therapy (HAART), in 1996 , HIV-infected patients are living longer and are concerned not only with treatment's ability to extend their life but also with the quality of the life they are able to lead, because better quality of life (QoL) is an important indicator for efficacy of treatment. Further, poor QoL is said to intervene in drug regularity and often associated with poorer treatment adherence.[1] In order to obtain full benefit of ART, near perfect and sustained adherence to treatment is critical. Unfortunately, non-adherence is common among individuals treated with HAART. Several studies have shown varying levels of adherence: Non-

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adherence to ART in adult population varied from 33% to 88%.[2] Studies report that more than 10% of patients report missing one or more medication doses on any given day, and more than 33% report missing doses in the past two to four weeks.[3] Studies also indicate that consistent non-adherence can lead to inadequate suppression of viral replication, continued destruction of CD4 cells, progressive decline in immune function and disease progression. Non-adherence is also an important reason for the emergence of viral resistance to one or more antiretroviral medications.[4,5]

One of the important predictors to sustain treatment adherence is the quality of life of persons infected with HIV. Many studies have reported that the QOL of the patients living with HIV/AIDS were significantly inferior to those of general population[6,7,8,9] particularly, women with HIV/AIDS experience considerable distress.[10] In fact, for most HIV infected individuals, HIV illness itself is a stressor and tends to cause emotional disturbances. Holmes et al report that financial worries were directly related to low adherence[11] as according to estimates HIV causes[12] Indian Rs. 3447 billion economic losses and Indian Rs. 64204 billion as productivity loss. Increased hospital admission, forced to sell their means of production to cover the high economic burden of treatment and their cost associated with HIV/AIDS. That means, not only the presence of HIV infected but also death of HIV infected could lead to family burden to the households. Combination of these factors have great impact on the well being of the patient and impair their quality of life and thereby influencing ART drug adherence itself. Hence, it is increasingly important for health research workers to better understand and improve the quality of life in this group. HRQoL assessment is relatively new index for health measurement. HRQoL takes into consideration those aspects of life that are directly affected by the health status.

Though there are different instruments made available to measure the QoL, the researchers adopted SF36 questionnaire which is used in a number of health outcome studies including HIV/AIDS. SF36 helps to measure the relative burden of the disease and differentiate health benefit produced by the treatment.

This scale has been tested on HIV patients in India and has been validated.[13] In the present study, we evaluate HRQoL in HIV individuals on ART. This study also assessed the family burden experienced by their families and socio-life index and tried to correlate with SF36 score to measure family burden on overall quality of life.

METHODOLOGY

Settings: National AIDS Control Organization (NACO) since the introduction of ART, has increased the number of centers providing free Anti Retroviral Treatment (ART) centres across india from 54 to 91 with another 9 more centers getting operational soon. At these 91 ART centers, medicines for treating 85000 patients have been made available. One of the first centers to come in South of Chennai is the ART centre located at Govt Rajaji Hospital, Madurai. Being a new centre and catering services to 6000 odd HIV infected individuals add significant to any study that address quality of life relating to HIV infected in this region.

Study Population: ART centre located in Government Rajaji Hospital, Madurai has 2352 patients on ART during the first quarter of year 2008 which include 1461 male, 725 women 2 Trans gender and 164 children. On an average, daily 10 to 15 new cases and 90 to 120 old cases attend for pre-treatment assessment and drug collection respectively. The HIV infected individuals put on treatment within six months prior to date of interview were considered for the study and those who gave consent for participation in the study were included in the sample.

Data collection tools: A structured interview schedule was used to collect information on the socio-demographic characteristics such as age, gender, education, occupation, marital status, spouse HIV status and income etc., A brief HIV questionnaire was administered on study participants and one of their family members. Anthropometry was performed to asses BMI. **SF36:** The SF36[14] (Short Form with 36 questions) is a well-documented, self-administered QoL scoring system that includes eight independent scales and two main dimensions. This tool is widely used and has been validated. Physical Function, Role-Physical, Bodily Pain and General Health are grouped as one to measure physical health. Likewise, Vitality, Social Functioning, Emotional well being and Mental Health are grouped as one to measure Mental Health. All questions are scored

on a scale from 0 to 100, with 100 representing the highest level of functioning possible. A higher scale score on SF-36 indicates better quality of life.

English version of SF36 scale was translated to Tamil and then back translated to English. Compared with the original version and modifications were made wherever necessary to ensure equivalence in meaning between the English and translated version.

Standard of Living Index (SLI): SLI is calculated based on the definitions used in the National Family Health Survey (NFHS-I). The factors considered are type of house, availability and type of toilet facility, main fuel used for cooking, source of drinking water, availability of separate room for cooking, ownership of house, ownership of land, ownership of livestock and ownership of other durable goods. Scoring system is used to classify the patients into 3 groups (scores 0-14 for a low SLI, 15-24 for a medium SLI and 25-67 for a high SLI).

Family Burden Interview Schedule (FBIS): Pai and Kapur's Family Burden Interview Schedule[15] was used to assess family burden. The FBIS assesses the burden placed on families of psychiatric patients living in the community setting. This scale measures objective and subjective aspects of burden and it contains six general categories of burden, each having two to six individual items for further investigation. Subcategories include: financial burden, effects on family routine, effects on family leisure, effects on family interaction, effects on physical health of family members and effects on mental health of other family members. Each item is rated on a three-point scale, where 0 is no burden and 2 is severe burden.

Data collection and Analysis: Interviews were conducted at the ART centre Govt Rajaji Hospital, Madurai. Participants were informed of the study objectives and procedures prior to data collection. Interviews were conducted in the presence of an attendant. Interview schedule was pre-tested on 10 HIV infected individuals for consistency.

Data were entered in Excel spread sheet followed by data cleaning and recoding. Further data analysis was performed in SPSS version 11 (SPSS inc. Chicago, IL, USA). Univariate analysis was performed to compare demographic and socio-economic characteristics of patients using χ^2 test. Mean differences were measured in Physical, Mental, Overall well being and Family burden score for HIV positive individuals with or without ART. Regression was performed to assess the factors influencing HRQoL of HIV infected individuals. Pearson product moment Correlation were computed to explore the relationships of SF36 with Family Burden and BMI. Further, Independent student "t" – test was performed to see the association between HRQoL and sex.

RESULTS

Demographic and HIV related variables: Of 91 participants interviewed 51.6% were women. Median age of the respondents was 33.Eighty five percent of them were married. Mean age at marriage was 22.75 SD (5.58) years for men and 21.90 SD (5.52) for women. More than 75 percent of respondents (82.4%) and their spouses (74.7%) were literate. Fifty three (53%) of respondents were daily wage earners. Fifty six percent of spouses were HIV positive. Twenty four out of 161 children born to the study participants were HIV positive of which 10 have already died. (Table 1)

Table 1. Socio Demographic Characteristic of the Participants

SN	Factors		Frequency	%	p-value
1	**Sex**	Male	44	48.4	0.753
		Female	47	51.6	
2	**Age in years**	Median age 33 yrs			
		More than 33 yrs	44 yrs	51.6	
		Less than 33 yrs	47 yrs	48.4	
3	**Marital Status**	Married	85	93.4	0.000
		Separated	6	6.6	
4	**Age at Marriage -** Mean age 22.75 SD 5.577				
5	**Family Size (Mean)**	adult	1.69	SD1.040	
		Children	1.81	SD.855	
6	**Education**	Illiterate	16	17.6	0.000
		Literate	75	82.4	
7	**Occupation**	Daily wage	52	57.14	0.000
		Skilled/salaried	21	23.07	
		House maker/ Unemployed	18	19.78	
Spouse					
1	**Spouse Age -** Median age 22.75 yrs				
2	**Spouse age at Marriage** - Mean age 21.90 SD 5.520yrs				
3	**S. Education**	Illiterate	23	25.3	
		Literate	68	74.7	
4	**Spouse Occupation**	Daily wage	53	58.24	
		Skilled/ salaried	11	12.09	
		House maker/ Unemployed	27	29.67	

Mean duration (in months) of illness from the date of diagnosis was 31.58 SD (20.15). Respondents sought HIV screening at different healthcare settings. For example 25.3% respondents sought HIV screening in private hospitals while 3 percent reported to private laboratory for HIV screening. After initial HIV screening respondents reported to have sought treatment at different healthy care settings at the initial stage before reaching government run free ART centers, However majority of the respondents (95.6%) sought screening at Govt settings before branching out to different settings for treatment. On 76.9% occasion, HIV result was disclosed by the Counselors. One man and 4 women did not disclose their HIV status to their spouses.

Health Related Quality of Life and Family Burden: The QoL scores obtained for the 91 participants based on the SF-36 schedule is give in Table 2. Eight dimensions of SF-36 is further summarized under two broad categories ie., Physical health, mental health and cumulative scores are given below:

The overall mean score for Physical health is 45.13 SD (12.40) and for Mental health is 56.91 SD (15.52). However, mean overall well being score was 51.43 SD (12.96). Difference in mean score between gender and, age groups was observed, however, the difference was not statistically different. Respondents with high Socio life Index (SLI) have had higher mean score ie. 55.61 than other groups. HIV infected individuals who were on ART medication had better mean score of 52.77 than those who are not. Likewise, respondents with normal BMI had better mean HRQoL score (55.07). Higher socio Life Index score had positive impact on physical health score (p Value -.001) and mental health (p value- .005) in HRQoL scores. Particularly better SLI score resulted in higher scores in vitality (p value- .005) and emotional well being (p value-.005) as a results respondents reported better social functioning (p value-0.001). (Table 2)

Table 2. HIV results and disclosure related factors

	Factors		Frequency	Percentage	p-value
1	Duration of illness(in Months)	Mean	31.58 SD 20.157		Range 2- 120 Months
2	Place of Treatment (Initial care seeking) seeking	Private	33	36.3	0.000
		Govt	87	95.6	
		Self	1	1.1%	
		Traditional healers	3	3.3	
		Others	1	1.1%	
3	Place of screening	Private Hospital	23	25.3	0.000
		VCTC/Govt	35	38.5	
		VCTC/NGO	3	3.3	
		Private lab	3	3.3	
		Research centre	27	29.7	
4	Result disclosure	Counselor	70	76.9	0.000
		Doctor	16	17.6%	
		Technician	4	4.4%	
		Not informed	1	1.1%	
5	Disclosure to spouse	No	1 (male) 1.1%	4 (female) 4.4% 1.1%	
		Yes	43	47.3%	
6	HIV status of Spouse	Positive	56	61.5	0.000
		Negative	26	28.6	
		Unknown	9	9.9	
7	HIV status of Children I child	No Child	8	8.8	
		Positive	7	7.7	
		Negative	69	75.8	
		Unknown	7	7.7	
	HIV status of Children II child	No Child	32	35.2	
		Positive	10	11.0	
		Negative	46	50.5	
		Unknown	3	3.3	
		Total	91	100.0	
	HIV status of Children III child	No Child	72	79.1	
		Positive	7	7.7	
		Negative	12	13.2	
		Total	91	100.0	

Factors influencing HRQoL infected Individuals: Logistic regression analysis was used to understand the **Factors influencing HRQoL of HIV Individuals.** Barring age other demographic variables did not show any significant Association with SF-36 demission such as Physical, Mental, Overall well being, Family burden and SLI component. Age of HIV infected had significant influence in social functioning (p-value 0.015), emotional well being (0.015) and Mental health (0.010). However, overall mental health (p-value.045) score did not influence the HRQoL score. Respondents receiving ART did not influence HRQoL but for physical health (p-value-0.060) it showed some influence but was not statistically significant. The same way duration of illness had some influence in the physical health (p-value-0.062) not statistically significant. (Table 3)

Table 3. Physical, Mental, Overall well being , Family burden and SLI component score for HIV positive Individuals

Factors	Physical Health	Mental Health	Overall	Family burden	Socio life Index
Sex					
Male	45.07	61.07	54.18	20.00	26.75
Female	45.20	52.93	48.80	17.60	21.94
Age					
Less than 33 years	45.43	55.04	50.37	22.02	18.55
More than 33 years	44.82	58.86	52.55	26.66	18.98
Occupation					
Employed	45.16	56.88	51.47	23.67	19.17
Unemployed	44.50	57.50	50.75	37.25	9.75
Economic status					
Low	51.27	56.60	54.67	20.25	
Moderate	39.95	50.51	45.84	19.16	
High	47.76	63.26	55.61	17.74	
ART					
Yes	45.60	59.16	52.77	19.98	24.77
No	44.70	54.85	50.21	17.62	23.79
BMI					
Underweight (Less than 19),	42.80	53.41	48.41	19.43	22.00
(ii) Normal (20-25)	47.56	61.44	55.07	18.44	26.76
(iii)Over weight (26 - 30)	47.67	48.67	48.00	12.67	25.67

Factors	Physical Health	Mental Health	Overall	Family burden	Socio life Index
		Female	Male		p-value
Family Burden	No burden	45	34	47	0.010
	Severe Burden	2	10	44	
BMI	Undernourished	22	25	47	0.228
	Good Health	25	19	44	

Correlation between Standard Living Index (SLI), Family Burden, BMI and HRQoL: Pearson Correlation test was performed to see the impact of SLI, Family Burden, BMI and HRQoL in table 4 and further details are presented in table 5. Socio life Index was directly related to physical health, mental health, Vitality, social functioning and role emotional scores on HRQoL scale SF 36. Physical health score was negatively affected by the Family burden score. Similarly, BMI status of the respondents correlated with Mental Health, Body Pain, Vitality and Role emotional scores of HRQoL scale SF 36. (Table 4)

Table 4. Pearson Correlation between SLI, Family Burden, BMI and HRQoL

HRQoL	SLI	Family Burden	BMI
Physical Health	0.216*	-.123	0.193
Mental Health	0.391**	-.131	0.232*
Physical Function	-.091	-.037	0.121
Role-Physical	0.115	0.042	-.042
Body Pain	0.110	0.061	0.226*
General Health	0.112	-.296**	-.002
Vitality	0.296**	-.202	0.227*
Social Functioning	0.207*	-.086	0.078
Role Emotional	0.296**	0.090	0.224*
Mental Health	0.174	-.134	0.058

*Significant at .001
** Significant at .005

Association between Sex and HRQoL, Family burden and BMI: Gender difference in various scores was observed in the data analysis. To get a clear picture, we performed independent sample "t" test the significance between the genders. There were significant difference between the genders in Mental health (P-value-.002), Role emotional (p-value-.011) and overall HRQoL score (p-value-.002).Significant difference in the experience of Family burden (p-value-.022) was observed. However, the scores of BMI and SLI did not show significant difference between the genders. (Table5, 6, and 7)

Table 5. Regression analysis on Factors influencing HRQoL infected Individuals

Dependent variable & HRQoL measures	Unstandardized Coefficients	Standardized Coefficients			
	B	Std. Error	Beta	T	p-value
Age					
Social Functioning	-.109	.044	-5.509	-2.489	.015
Role Emotional	-.109	.044	-9.787	-2.487	.015
Mental Health	-.117	.044	-4.274	-2.624	.010
Mental Health (Total)	.392	.193	12.094	2.034	.045
ART					
Physical Health	-.378	.197	-9.322	-1.913	.060
Duration of illness					
Physical Health	.364	.192	9.032	1.893	.062

Table 6. Independent student "t"–test association HRQoL Vs sex

	Overall	Sex	N	Mean	Std. Deviation	t	df	p-value
Physical Function	35.39	M	23	29.13	32.15	-1.057	41	.297
		F	20	39.25	30.32	-1.061	40.708	.295
Role-Physical	41.11	M	23	50.00	49.43	1.090	41	.282
		F	20	35.00	39.24	1.108	40.694	.274
Body Pain	50.14	M	23	53.87	23.49	1.451	42	.154
		F	21	45.19	14.77	1.480	37.460	.147
General Health	48.90	M	23	52.70	16.39	.941	41	.352
		F	20	48.10	15.48	.945	40.697	.350
Vitality	50.44	M	23	55.43	21.37	1.525	42	.135
		F	21	46.19	18.57	1.535	41.907	.132
Social Functioning	79.60	M	23	87.00	20.03	1.993	42	.053
		F	21	72.71	27.27	1.965	36.509	.057
Role Emotional	48.02	M	23	71.04	44.15	2.645	42	.011
		F	21	36.57	42.10	2.650	41.913	.011
Mental Health	57.63	M	23	66.09	15.63	3.330	42	.002
		F	21	51.24	13.78	3.349	41.955	.002
Physical Health	45.13	M	23	48.22	12.27	1.672	41	.102
		F	20	42.60	9.28	1.705	40.274	.096
Mental Health	56.91	M	23	66.43	11.90	3.845	41	.000
		F	20	50.80	14.76	3.787	36.470	.001
Total SF36	51.43	M	23	58.17	11.17	3.372	41	.002
		F	20	46.55	11.40	3.367	39.938	.002
Family Burden		M	23	.2174	.42174	2.360	42	.023
		F	21	.0000	.00000	2.472	22.000	.022
BMI		M	23	18.913	2.5230	-.252	42	.802
		F	21	19.133	3.2497	-.249	37.694	.804
SLI		M	23	27.26	11.577	1.737	42	.090
		F	21	22.05	7.755	1.768	38.667	.085

Table 7. Independent samples t test analysis comparing two groups on pre-intervention family burden

Family Burden subgroup	Sex	Mean	Std. Deviation	t	P-Value	Mean Difference
Financial	M	7.16	3.403	.478	.634	.393
	F	6.77	4.345	.482	.631	.393
Routines	M	2.98	2.226	1.451	.150	.616
	F	2.36	1.811	1.442	.153	.616
Leisure	M	1.91	2.351	1.188	.238	.526
	F	1.38	1.860	1.179	.242	.526
Interaction	M	2.93	2.472	-.287	.775	-.153
	F	3.09	2.611	-.288	.774	-.153
Physical health	M	.66	1.256	.236	.814	.063
	F	.60	1.296	.237	.813	.063
Psychological health	M	2.70	1.564	1.991	.050	.705
	F	2.00	1.794	2.000	.049	.705
Subjective	M	1.66	.526	2.207	.030	.297
	F	1.36	.735	2.230	.028	.297

DISCUSSION

This study perhaps first to document the HRQoL among HIV infected individuals in the region.. The study findings on HRQoL score are consistent with the other studies which reported lower QoL ratings on both physical functioning and psychological well-being components of SF-36 when compared to the general population.[16,17] Infact the score was low compared[18] to HRQoL among patients who underwent treatment for TB (mean score of 74).

Further, there were considerable differences in SF36 mean score between men and women.

Likewise, HIV infected individuals with higher socio-life index and on ART treatment had better mean SF36 score than others. On an average, persons on ART treatment had better mean score in physical health, mental health and overall SF36 score. This highlights the fact that ART does help in improved QoL score among HIV infected ---individuals. Similarly, persons normal BMI had better HRQoL score. However, when we looked at score of eight dimensions of SF36 scale, we found that physical function score did not improve much while social functioning had some improvements, perhaps due to reasons like opportunities for interaction with other HIV infected individuals and health care providers.

The higher discordant couple rate that is 28.6% observed among the study population poses additional emotional risk that could eventually disturb QoL. In many cases this could influence sexual life too. Further disclosure was problematised by 4 women perhaps due to fear of discrimination or anticipated strain in marital life.

Experience of family burden was found more among men, perhaps means that financial hardship caused owing to limitation in physical functioning and loss of employment as men are the main breadwinners in the Indian society. However, this experience of family burden did not influence overall health score on SF36 scale.

On the contrary, BMI level was directly related to mental health, body pain, vitality and emotional well being score on SF36.The same trend was observed in socio life index score too. SLI status of HIV infected individuals influenced, physical health, mental health, vitality, social functioning and role emotional scores of SF36.

The study also had certain limitations. First of all, the sample size was small and unequal in terms of gender and ART medications. Secondly, generalization becomes difficult, as we could contact only the patients who availed free treatment and not those were paying for treatment. Yet these findings assume significance as it throw new insight into HRQoL of patients in resource limited settings like ours where majority can't afford paid services.

CONCLUSION

This study finding clearly demonstrates that overall HRQoL measures are lower among HIV infected individuals irrespective of ART treatment status. Duration of illness and age are the two factors that had some impact on the HRQoL scores. Further, SLI and BMI appear to be the two important predictors of HRQoL. Therefore, special attention may be required to HIV infected persons come form lower SLI and BMI. Nutritional supplements, in addition to ART drugs may be provided to bring some improvements in physical functioning.

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