Health Related Quality of Life among People Living with HIV /AIDS in Pakistan

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Abstract

Objective
To assess quality of life in HIV /AIDS patients on Anti-retroviral therapy using WHO QOL- BREF instrument.

Study design
Cross sectional study.

Place and duration of study
The study was conducted in outpatient department of The Indus Hospital, Karachi from January to July 2016.

Methodology
Quality of life (QOL) was evaluated using the WHO QOL BREF instrument (translated Urdu version) using 31 items grouped under 6 domains: namely physical, psychological, level of dependence, social relations, environment and spirituality.

The demographics along with CD_4 counts, stage of disease and viral loads and duration of Anti-retroviral therapy were recorded. It was a cross sectional study and sample size was 109 patients. Data was entered and analyzed using SPSS version 21.0. The equation suggested by WHO was applied to overall estimation of each domain with scores ranging from 4 to 20.

Results
A total of 109 participants completed the questionnaire out of which 76 (69.7%) were males, 28 (25.7%) were females and 3 (1.8%) were transgender. Mean (SD) age of patients was 39.2 (10.9) years. Regarding marital status 77(70.6%) were married, 20(18.3%) were single, 4(3.7%) were divorced and 7(6.4%) were widowed. Majority 94 (86.2%) had revealed their sero-status to their relatives and 8 (7.3%) did not reveal their illness99 (90.8%) were in stage 1 of AIDS, 5 (4.6%) were in stage 2, 1 (0.9%) were in stage 3 and 4respectively. Majority of patients were illiterate comprising 36 (33%), 21(19.3%) had primary/middle education, 18(16.5%) had degree graduation and above. Regarding marital status 77(70.6%) were married, 20(18.3%) were single, 4(3.7%) were divorced and 7 (6.4%) were widowed. Highest scores were noted in domains of physical health, spiritual, and religious beliefs. (Median scores 15 in both). Psychological domain scored average, social relations and environment were the two domains in which low scores were noted as compared to other domains. Overall the quality of life of the patients was found to be fair to average. (Mean score: 13.7).

Conclusion
Our study WHO-QOL BREF instrument Urdu version showed that QOL scores were high in physical health, spirituality/ religious domains, fair scores were obtained in psychological domains whereas social relations, and environmental aspects scored less.

Key words
WHO QOL BREF, HIV, and AIDS.

Introduction
HIV/AIDS pandemic has affected different aspects of a society involving individuals, families, sectors and institutions. It has distorted and ruined the social framework of many communities and countries, especially the heavily infected ones.[1]

The estimated global number of people living with HIV (PLHIV) including adults and children at the end of 2009 was 33.3 million. The majority is in Sub –Saharan Africa which is estimated at 22.5 million, but there is a rising trend in the epidemic in Asia and Eastern Europe. New HIV infection worldwide is estimated to be 2.6 million and the number of death due to AIDS defining illness was 1.8 million in the year 2009.[1]

Although initially Pakistan was depicted as a country free of HIV, first case was reported in1986 and since then the number of HIV patients is rising gradually but steadily.

As per Asian Pacific Model Asian countries with rampant HIV spread, Pakistan ranks fourth, others are Indonesia,Malaysia and Philippines.[11] In these countries the HIV epidemic is spreading with high new cases being reported each year as compared to the previous year, in 2014 roughly 15606 cases were reported as new cases.[11]

According to the statistical analysis of Asian Epidemic Modelling (AEM), conducted in 2015, use of contaminated injections among people who inject drugs (PWID) remains the main mode of HIV transmission in the Pakistan. Due to advances in Anti-retroviral therapy (ARV) there has occurred marked improvement

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in life expectancy and quality of life in patients with HIV infection.

ARV was introduced in Pakistan in 2006 through National AIDS Control Program. The Indus Hospital is one of the sub recipients of ARV, and has been providing consultation, counseling, lab tests and ARV completely free of charge. Patients are referred to the AIDS clinic through physicians, self-referral or through friends or family members. The initial phase of denial, anger, anxiety, guilt and depression are gradually replaced with acceptance. As patients' clinical symptoms improve on ARV, and follow up at the clinics, it is expected that they will return to their normal lives. However quality of life remains a paramount issue.

WHO has defined QOL as the individual's perception of their position in life in the context of culture and value system in which they live, and in relation to their goals, expectations, standards and concerns.[2] QOL is a newly developed, multidimensional, generic cross cultural instrument developed for use across patients groups in various countries.[9] It applies to many chronic diseases such as tuberculosis, diabetes, heart disease, etc. It is now a cost effective and essential tool for analysis of HIV disease as well.[3] HRQOL gives an insight on the quality of health care system.[3]

In an era of advanced Anti Retro Virals (ARV) the life expectancy of HIV /AIDS patient has increased, highlighting the importance psychosocial aspect in quality of life in such patients.[12]

Other than the disease process, such patients suffer a decline in quality of life due to multiple factors like addictions, poverty, social stigma, depression and violence, which adversely affects the disease process and causes poor out comes.[12]

The WHOQOL-BREF was developed as a cross cultural instrument whose contents are easily applicable to different cultures worldwide.[12]

This is a multi-faceted generic profile which includes 31 items covering six main domains including physical, psychological, level of independence, social relationships, environment and spirituality. The physical health domain consisted of seven items, including impact of disease on daily activities, medicinal dependence, fatigue, presence of pain discomfort restricted mobility, sleep and rest, lack of energy and initiative and working ability.

The psychological well-being domain included eight items assessing patient's thoughts about body image, appearance, positive and negative feelings, self-esteem and personal beliefs, higher cognitive functions, anxiety, suicide, depression.

Third domain was social relationships consisting of three items that assesses personal relationships, social support and sexuality.

Environmental domain has eight facets like home environment,

financial resources, physical safety security, health social care transport, physical environment, opportunity for leisure activities, acquiring new information and skills. Spiritual, personal and religious belief domain has four aspects like forgiveness, blame, personal belief, death /dying and concern about the future.

Methodology

It was a cross sectional survey of patients living with HIV/AIDS visiting the Infectious Diseases outpatient department of The Indus Hospital Karachi. The duration of study was six months from January till June 2016.

The participants were explained the purpose of the study and potential benefits, confidentiality was ensured, written consent was taken and the patients were given the questionnaire. The World Health Organization Quality of life HIV BREF Instrument (WHO QOL-HIV BREF Urdu questionnaire Urdu version) was used. It was reviewed by expert members of Institutional Review Board, and Ethical approval was obtained.

For analysis the following factors were evaluated as independent variables like age, gender, marital status (married, single, widowed and divorced), level of education (illiterate, elementary, diploma and university degree), income along with work status, CD_4 counts, stage of disease and viral loads and duration of Anti-retroviral therapy.

The questionnaire consisted of six domaincomprising31 questions; it was designed to assess quality of life of participant in terms of individual's perception of their life in context of physical health, level of dependence, spiritual, social, financial and psychological aspect. Participants answered each question using a 5 item Likert scale where 1 shows low and negative perceptions and 5 indicates high and positive perceptions. Facet scores were calculated as means of their items scores and range between 1 and 5. Patients who were educated filled the questionnaire themselves and those who were uneducated or too ill to fill the form were be helped by us.

Inclusion criteria were HIV/AIDS positive registered patients at the Indus Hospital, those on ARV for at least six months, age above 18 years and willing participants.

The patients who were excluded from study were terminally ill or newly diagnosed patients, and unwilling participants.

Data was entered and analyzed using SPSS version 21.0. The equation suggested by WHO was applied to overall estimation of each domain with scores ranging from 4 to 20. Independent sample T-test/ Mann-Whitney U test was applied to assess significant difference in overall scores and scores of each domain between both the genders. ANOVA/Kruskill Wallis test was applied to assess significant differences in scores among marital status, education level and age groups. For easy and better interpretation of results, scores were categorized as low

level (between 4 and 10), intermediate scores (between 10 and 14.9) and high scores (between 15 and 20). Chi-square/Fisher-exact/Likelihood ratio chi-square test were applied as appropriate to find association of gender, education level, marital status and age groups with score categories of different domains. *P*-value <0.05 were considered significant.

Results

A total of 109 participants completed the questionnaire out of which 76 (69.7%) were males, 28 (25.7%) were females and 3 (1.8%) were transgender. Mean (SD) age of patients was 39.2 (10.9) years. Regarding marital status 77(70.6%) were married, 20(18.3%) were single, 4(3.7%) were divorced and 7(6.4%) were widowed. Majority 94 (86.2%) had revealed their serostatus to their relatives and 8 (7.3%) did not reveal their illness Table (1).

99 (90.8%) were in stage 1 of AIDS, 5 (4.6%) were in stage 2, 1 (0.9%) were in stage 3 and 4 respectively.

Highest scores were noted in domains of physical health, spiritual, and religious beliefs. (Median scores 15 in both). Psychological domain scored average, social relations and environment were the two domains in which low scores were noted as compared to other domains. Overall the quality of life of the patients was found to be fair to average. (Mean score: 13.7) Table (2).

Table 2: Mean scores for quality of life in six domains of WHO QOL (N=109)

WHO QOL Domain		Mean SD Median IQR	Min-Max
Physical Health[a]	109	14.8(3.1) 15 (13-7)	6-20
Psychological	109	14.1(2.9) 4.4 (12-16)	6.4-20
Level of Independence[a]	109	13.9(3.1) 14 (1216) 12.9(3.9) 13 (10-16)	5-20
Social Relations[a]	109	12.7(3) 12.5 (11-14.5)	5-20
Environment	109	14.8(3.2) 15 (12-17)	5-20
Spiritual / Religion / Personal Beliefs[a]	109	13.7(2.8) 14 (11.6-15.6)	7-20
Overall	109		7.3-20

Table 1: Sociodemographic characteristics of the participants.

Variables		Frequency (%)
Gender	Male	76(69.7)
	Female	28 (25.7)
	Transgender	2 (1.8)
Mean age in years ± SD		39.2 years
Marital status	Married	77 (70.6)
	Single	20 (18.3)
	Widow	7(6.4)
	Divorced	4(3.7)
Education	Illiterate	21(19.3)
	Primary/middle	20(18.3)
	College and above	18(16.5)
Friends knowing serostatus of patient	Yes	94(86.2)
	No	8(7.3)
Stage of HIV infection	Stage 1	99(90.8)
	Stage 2	5(4.6)
	Stage 3	1(0.9)

Majority of patients were illiterate comprising 36 (33 %), 21(19.3%) had primary/middle education, 18(16.5%) had degree graduation and above. Regarding marital status 77(70.6%) were married, 20(18.3%) were single, 4(3.7%) were divorced and 7 (6.4%) were widowed.

Statistically significant difference was observed in physical health and social relations scores between both the genders (*P*-value: 0.041 and 0.049 respectively). Males were found to have higher scores in these two domains as compared to females (Median scores: 16 vs 14; 13 vs 12; respectively). However, in the remaining domains both males and females had approximately similar scores. Overall, males were found to have better health than females, but result was not statistically significant (Mean overall scores: 14.4 vs. 12.9, *P*-value: 0.127) Table (3).

No statistically significant difference was observed in scores of any WHO QoL domain among marital status.

Discussion

In our study highest QOL scores were obtained in domains of physical health and religious beliefs. It showed that majority of patients compliant on anti-retroviral therapy enjoyed a satisfactory physical health, they had minimal medicinal dependence for body aches and pain, enjoyed good sleep and had a positive outlook towards life. Spirituality and social

Table 3: Showing gender based WHO QOL domain scores.

WHO QoL domains' score	Gender				P-value
	Male		Female		
	n	Mean (SD) Median (IQR)	n	Mean (SD) Median (IQR)	
Physical health	76	15.1 (3.4) 16 (13-18)	28	14.2 (2.5) 14 (12-16)	0.041*†
Psychological	76	14.3 (3) 14.4 (12-16.6)	28	13.8 (2.8) 14 (11.4-15.2)	0.479‡
Level of Independence	76	14.1 (3.1) 14.5 (13-16)	28	13.6 (2.9) 14 (11-16)	0.523‡
Social Relations	73	13.5 (3.9) 13 (10.5-16)	28	11.7 (3.7) 12 (8.2-13.8)	0.049*†
Environment	75	12.8 (3.1) 12.5 (11-14.5)	27	12.4 (3.1) 12.5 (11-13.5)	0.477‡
Spiritual / Religion / Personal Beliefs	76	15.1 (3.2) 16 (12.25-18)	26	14.3 (3.1) 14.5 (11-17)	0.218†
Overall scores	76	14 (2.9) 14.4 (11.8-15.8)	28	13.1 (2.6) 12.9 (10.9-14.9)	0.127‡

*P-value<0.05, **p-value<0.0001, ‡Independent sample T-test; † Mann-Whitney U test

support system may influence survival in patients with chronic, life threatening illnesses.[10] Spirituality and religion is a significant yet an overtly neglected facet of quality of life in patients with chronic, debilitating and stigmatizing diseases like HIV /AIDS.[12]

A high scoring QOL was related with drug adherence along with strong spiritual/religious beliefs leading to optimistic approach for future and positive self-perception. It is also believed that addressing spiritual needs of a patient may serve to decrease depressive symptoms.[7,12]

Psychologically our patients scored well, majority of the patients had an optimistic approach towards life, had intact cognitive functions which helped them to cope up with the challenges of daily life. They had minimal to nonexistent suicidal tendencies and had an energetic and hopeful approach towards future.

Social relations and environmental domains were the two domains scoring less, the reasons being multi factorial such as illiteracy, poverty, scarcity of robust health care system, lack of leisure activities, limited resources for acquiring new information and an unsatisfactory transport system as many patients were coming from far flung areas of Pakistan. High degree of stigmatization hindered opportunities for better job prospects.

Social relations domain also scored low. Majority of patients had poor interpersonal and sexual relations and especially the female patients who got infected from husbands often had resentment, guilt and negative emotions. Males comparatively had better scores in physical health and social relations as compared to females.

Overall males enjoyed a better health as compared to females but it was not statistically significant. Surprisingly, marital status, CD_4 count, income did not have a statistically significant impact on over all QOL. Majority of patients were virally suppressed and immunologically stable.

Study limitations
The present study had some limitations like small sample size (109) and especially less number of female patients. Most importantly the participants were selected on hospital based

consultations therefore due to convenient sampling method the instrument could not be used in community level causing a bias in results. As such the result of study is not a depiction of all HIV/AIDS patients in Pakistan.

Conclusion

In brief our study WHO-QOL BREF instrument Urdu version proved to be a useful convenient and cost effective method for assessing quality of life in HIV / AIDS patients.

It further showed that QOL scores were high in physical health, spirituality/religious domains, fair scores were obtained in psychological domains whereas social relations, and environmental aspects scored less. The Indus Hospital Karachi has an integrated and programmatic approach towards patient management involving qualified clinicians, well trained counselors, paramedical staff, rehabilitation centers and uninterrupted medicinal supply by (Sindh Aids Control Programme). This collaborated approach thus has significant impact on QOL of our patients.

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