Original Article

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Health related quality of life among people receiving highly active antiretroviral therapy at Bharatpur Hospital, Chitwan, Nepal.

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Abstract:

Background: Health-related quality of life (HRQoL) is one of the most important outcome measures among HIV-infected patients receiving highly active antiretroviral therapy (HAART). Likewise, improved quality of life (QoL) is one prominent goal of patient treatment. This study was conducted to investigate the QoL of people living with HIV/AIDS (PLWHA) receiving HAART at the antiretroviral therapy (ART) center of the Bharatpur Hospital in Chitwan, Nepal.

Methods: This was a cross-sectional study conducted among 271 PLWHA receiving HAART at the ART center of Bharatpur Hospital in the Chitwan district in April, 2016. Participants were recruited purposely and interviewed with a structured questionnaire. Quality of life was assessed using the World Health Organization Quality of Life HIV- BREF (WHOQOL-HIV-BREF) standard tool. Data was entered to Epi-Info version 3.5.3 and analyzed using SPSS version 21 for windows. A bivariate analysis was fitted to identify factors associated with QoL.

Result: A total of 271 participants, with a mean age of 36.86 (SD = 9.62), were included in the study. This study found that the majority of participants had moderate general QoL, except for the spiritual domain, which contains information about personal beliefs, forgiveness and blame, and concerns about future, death, and dying. Younger patients, religious minorities, literate patients, unmarried patients, those on ART for more than three years, and those who adhered to ART were associated with good general QoL across all domains.

Conclusion: The participants' self-reported HRQoL was generally satisfactory except for Spiritual-domains. Since HIV is a chronic illness, the spiritual need of patients requires attention, including religious coping or support to find a sense of meaning/support in life, to cope with issues of guilt and shame, and to deal with the grief and bereavement associated with the disease.

Keywords: *HIV/AIDS; Quality of Life; Nepal.*

1. Introduction

The implementation of highly active antiretroviral therapy (HAART) has caused a marked decline in HIV/AIDS-related morbidity and mortality.[1] HIV infection is considered a chronic disease.

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Measuring health-related quality of life (HRQoL) is increasingly considered a relevant assessment of the follow-up judgment criterion of PLWHA, particularly the effectiveness of therapeutic strategies.[2] HRQoL is a multidimensional concept that includes independence, physical health, spiritual health, social health, psychological health, and environmental health.[3] Unfortunately, there is still relatively little empirical research in understanding the health-related quality of life in PLHIV in developing countries like Nepal. To overcome this gap, this study was conducted to assess the health-related quality of life among people living with HIV/AIDS receiving antiretroviral therapy clinics in the Chitwan district of Nepal.

2. Methods

The health facility based cross-sectional study was conducted among HIV patients, who initiated HAART at the ART clinic center of Bharatpur Hospital, Chitwan from April 1-28, 2016. Patients were eligible for the present study if they were on HAART at least for 6 months, aged 18 years or older, and if they gave their informed consent to participate in the study. More than 700 patients (including pediatric and adult) were receiving ART from this center at the time. Out of these, a total of 271 adult patients who fulfilled the inclusion criteria and agreed to participate were included in the study. The sample size was calculated using the single population proportion formula. Considering a z value of 1.96 for 95% confidence interval, 20 % prevalence of ART and 5% of margin of error, the initial sample size was 246. The initial sample was adjusted using a non-response rate of 10%, giving the final sample size of 271. In this study, the principal investigators and trained nurses used a predesigned, semi-structured interview schedule consisting of background characteristics and disease-related variables. The WHOQOL-HIV BREF was used to assess the QoL of PLWHA receiving ART[1].The tool consisted of 31 items, of which 29 items were used to measure individual QoL across six domains, and two items were used to measure patients' perception of their general QoL and health status. The six domains are physical health, psychological health, level of independence, social relationships, environmental health, and spirituality, religion, personal beliefs (SRPB). Each item is rated on a five-point Likert scale where 1 indicates low, negative perception and 5 indicates high, positive perception. However, the score for pain and discomfort, dependence of medication, fear of death and dying, and negative feelings and other negatively phrased items were reversed using the formula 6-X.

Two trained data collectors (nurses) interviewed the study participants and reviewed patient charts and medical records for the respective information after all data collection tools were pre-tested. Data about HRQoL was collected using a standard questionnaire mentioned above (PROQOL-HIV). Patient self-reports, and- utilizing medication(s) as a proxy indicator for chronic non-communicable disease diagnosis, were used to identify the presence of non-communicable diseases (NCDs). Since the study was conducted in a clinic setting, individual factors like CD4+ cell counts, comorbidities, self-reported symptoms, and immunological state were considered.

Descriptive statistics for patient characteristics were calculated. Demographic data was reported as frequencies and percentage, or mean (SD) values. Participant characteristics and HRQoL outcomes were tabulated and stratified. Independent sample t tests and one-way analysis of variance (ANOVA) tests were applied to determine the differences in HRQoL (EQ-5D index score and EQ-VAS score) caused by patient characteristics.

The study was approved by the Chitwan Medical Institutional Review committee (CMC-IRC), with reference number CMC-IRC /072/073-107, Chaitra 04, 2072 (17 March, 2016) and written informed consent was taken from each study participant after a clear orientation of the study objective.

3. Results

Sociodemographic and clinical characteristics of PLWHA in Nepal

Of the total 271 participants, more than half the participants were male (59.0%). They were mostly (40.6%) between 30-40 years of age, were

predominantly married (92.3%), and most of them (69.4%) were Hindu. Almost all of the participants (99.1) were literate. Ethnicity/caste data were self-reported and categorized into six major groups based on the caste coding by government of Nepal and STEPS Survey Nepal's 2013 categorisation[4]. In the final analysis, we merged disadvantaged and relatively advantaged janajati together, as the number of individuals for these categories was too low. Most of the participants (40.2%) belonged to disadvantaged and relatively advantaged *janajatis*. **(Table 1)** Furthermore, a majority (91.1%) of the participants' duration of HIV diagnosis was more than one year. A majority (87.5%) of the patients were on regular ART. Almost all participants (98.5%) started ART on the basis of CD4 count. Baseline average CD4 count of participants before therapy was 230.38±100.32. Many of the participants (65.1%) started ART immediately after diagnosis. The top 3 common opportunistic infections reported among the participants were tuberculosis, herpes simplex virus (HSV) and skin infection. **(Table 2)**

Unadjusted Analyses

We examined the association between the mean scores of HRQoL and socio-demographic and disease related variables using the student's t-test and one-way ANOVA. The resulting mean HRQoL scores according to demographic and disease related characteristics was analyzed. **(Table 4,5)** The analysis revealed that the perception of overall health was higher in religious minority groups, participants with an age of less than 20 years, and patients who were on ART for more than three years. Subjects who belong to disadvantaged and advantageous *janajatis,* with a current CD4 count greater than 500 cell/mm3 had a significantly greater mean score of HRQoL in the spiritual domain. The mean scores of HRQoL in the environmental domain were significantly higher for males and those receiving ART for more than three years. Participants within the age group of 30-39 years, female participants, and religious minorities had a significantly higher mean score in the social domain. In the level of independence domain, participants under 20 years of age, female, religious minorities, and patients receiving ART for more than three years had higher mean score. Participants with an age of less than 20 years, male participants, religious minorities, literate participants, unmarried participants, patients receiving ART for more than three years, and participants demonstrating strong adherence to ART gave significantly higher ratings for the psychosocial domain. In the physical domain, participants within the age group of 30-39 years, unmarried participants, literate participants, and religious minorities, those on ART for more than three years had significantly higher mean scores.

Table 1. Sociodemographic characteristics of study participants.

Socio-demographic Characteristics	Frequency	Percentage
Age (in year)		
< 20	4	1.5
20 – 29	63	23.2
30 – 39	110	40.6
40 – 49	62	22.9
50 – 59	22	8.1
60+	10	3.7
Mean± SD 36.86± 9.627		

Sex		
Male	160	59.0
Female	111	41.0
Marital Status		
Married	250	92.3
Unmarried	21	7.7
Religion		
Hindu	188	69.4
Buddhist	63	23.2
Christian	19	7.0
Islam	1	0.4
Ethnicity		
Dalit	98	36.2
Disadvantaged and relatively advantaged *Janajaties*	109	40.2
Disadvantaged non-Dalit terai caste	6	2.2
Religious minorities	9	3.3
Upper caste group	49	18.1
Educational Status		
Literate	269	99.3
Illiterate	2	0.7

Table 2. Clinical characteristics of the study participants.

Characteristics	Frequency	Percentage
Duration of HIV/AIDS Infection		
Less than one year	24	8.9
More than one year	247	91.1
Duration of taking antiretroviral therapy		
Up to three years	152	56.1
More than three years	119	43.9

Immediately start ART after diagnosis		
Yes	178	65.7
No	93	34.3
Baseline CD4 count		
CD4 count ≤500/mm3 at Start	271	100
Before therapy (Mean±SD) 230.38±100.32		
Start ART on the basis of CD4 count		
Yes	267	98.5
No	4	1.5
Regular intake of drugs		
Yes	237	87.5
No	34	12.5
Non-compliance to the drug in the last 30 days (n=34)		
<3 Times (>95% adherence)	24	8.9
≥3 Times (80-95% adherence)	10	3.6
Reason for not taking drugs regularly (n=34)		
Busy at work	12	4.4
To hide the HIV Status among peers	2	0.7
Forgetfulness	10	3.7
Away from the home	10	3.7
Types of OI (n=152)*		
Diarrhea	17	6.3
Skin infection	38	14.0
Candidiasis	7	2.6
Tuberculosis	44	16.2
Pneumonia	14	5.2
Abscess	16	5.9
Oral infection	10	3.7
Herpes simplex virus	35	12.9

The Mean scores of HRQoL in different domains

The mean score of HRQoL was the highest for the environmental health domain (13.80), followed by the social relationship domain (12.47), the psychological health domain (12.19), the physical health domain (12.03), the level of independence domain (11.14) and the spiritual health domain (5.19) . **(Table 3)**

Table 3. the mean scores of domains of HRQoL and overall perception of HRQoL

Domains	**Mean (±SD)**
Physical health	12.03 (3.63)
Psychological health	12.19 (3.11)
Level of independence	11.14 (3.06)
Social relationship	12.47(2.14)
Environment health	13.80(1.92)
Spirituality health	5.91(0.73)
Overall perception of HRQoL	14.92 (2.60)

Table 4. Domain wise scores of the patients based on background characteristics

Variable		Physical health	Psychological health	Level of independence	Social relation	Environmental health	Spirituality	Overall QoL
Age (in years)								
	< 20	14.25	14.60	12.50	12.00	12.87	6.00	16.00
	20 – 29	13.34	13.06	12.11	12.46	14.20	5.90	15.46
	30 – 39	12.84	12.72	11.68	13.00	14.25	5.81	15.54
	40 – 49	10.53	11.32	10.37	12.14	13.19	5.93	14.32
	50 – 59	8.45	9.81	8.04	11.09	12.61	6.15	12.54
	60+	10.90	10.40	10.30	12.00	13.15	6.40	12.54
	<0.001	<0.001	<0.001	0.003	0.001	0.117	<0.001	0.001

Sex	Male	11.66	12.28	11.10	12.35	13.81	5.99	14.93
	Female	12.54	12.06	11.21	12.63	13.79	5.80	14.91
p-value		0.001	0.001	0.001	0.003	0.000	0.117	0.954
Ethnicity	Dalit	10.56	11.25	10.08	12.05	13.40	5.86	14.32
	Disadvantaged and relatively advantaged janajaties	13.18	12.97	12.20	12.62	13.98	6.05	15.04
	Disadvantaged non-Dalit terai cast	11.50	12.00	10.16	11.33	13.16	5.66	14.66
	Religious minorities	13.66	13.15	12.55	13.55	14.94	5.77	16.44
	Upper caste group	12.14	12.16	10.79	12.91	14.09	5.75	15.63
p value	0.000	0.002	0.000	0.032	0.037	0.093	0.016	0.016
Educational attainment	Literate	12.07	12.22	11.17	12.49	13.83	5.91	14.95
	Illiterate	5.50	7.60	7.00	10.00	10.25	6.50	12.00
p-value		0.011	0.036	0.054	0.102	0.102	0.262	0.111
Marital status	Married	11.79	12.02	11.00	12.51	13.81	5.90	14.85
	Unmarried	14.76	14.13	12.85	11.95	13.66	6.09	15.80
p value		0.000	0.003	0.008	0.248	0.730	0.249	0.108

Table 5. Domain-wise scores of the patients based on their disease-related characteristics.

Variable		Physical health	Psychological health	Level of independence	Social relation	Environmental health	Spirituality	overall QoL
Status of CD4 count	<500	11.89	12.05	11.22	12.49	13.95	5.84	15.11
	≥ 500	12.30	11.22	10.97	12.42	13.49	6.07	14.54
p value		0.370	0.610	0.52	0.789	0.064	0.015	0.093
Duration of ART	Up to 3 years	12.71	12.81	11.82	12.54	14.17	5.85	15.25
	More than 3 years	11.14	11.4	10.28	12.37	13.34	5.99	14.52
p value		0.001	0.001	0.001	0.523	0.001	0.140	0.022
Adherence to antiretroviral therapy	Yes	12.10	12.33	11.23	12.43	13.86	5.91	14.97
	No	11.44	11.20	10.52	12.79	13.38	5.89	14.64
p value		0.317	0.047	0.209	0.498	0.170	0.866	0.500
Side effect present	Yes	11.96	12.30	11.37	12.32	13.76	5.93	15.12
	No	12.15	11.94	10.63	12.80	13.90	5.88	14.48
p value		0.695	0.381	0.069	0.087	0.558	0.641	0.060
Opportunistic infection after therapy	Yes	11.56	11.55	10.12	13.04	13.76	6.04	14.32
	No	12.07	12.25	11.25	12.41	13.81	5.90	14.99
p value		0.501	0.281	0.07	0.160	0.901	0.380	0.221

4. Discussion

The aim of this study was to evaluate the HRQoL through WHOQOL-HIV BREF scale, and to examine the association of socio-demographic and disease-related factors with general and domain-specific QoL among HIV-positive patients receiving HAART at the ART clinic Center of Bharatpur hospital Chitwan, Nepal. This study, among 271 PLHIV, suggests that the majority of participants had moderate general QoL. Among the study participants, the best QoL was observed in the dimensions related to the patient's environment, and the worst QoL was observed in the spirituality. This suggests that the participants had relatively better physical safety and security, quality of health services, and adequate access to them. Spiritual domains were, however, badly affected, indicating poor self-esteem and the necessary spiritual needs of participants, as well as their concerns and fears for stigma. Overall, QoL scores found in the present study were lower than findings from other studies conducted in Nigeria[5], Thailand,[6] India[7] and Ethiopia.[8] All the domains of QoL showed similar mean scores in studies conducted in Nepal; the only exception being the

spiritual domain.[9] The reason for this may be the different experimental designs used, differences in the socio-demographic characteristics of patients, or the presence of comorbidities. In our study, younger participants, religious minorities, literate participants, unmarried participants, those on ART for more than three years, and those who adhered to ART were associated with good general QoL across most domains.

A significant association was observed between education and QoL in our study. Literate participants with higher education were more likely to have good general QoL as well as better QoL scores in the physical, environment, and independence domains as compared to illiterate participants. Previous studies showed that people with higher education (e.g. those who received higher degrees) were more likely to have a good general QoL, as well as better QoL scores across all domains.[10,11] Education potentially provides opportunities for employment and social support, and thus can contribute to perceptions of good QoL. Likewise, people living with HIV who received ART were more likely to have good general QoL, as well as better physical and social QoL as compared to those not utilizing ART, which is well documented in low-income countries and in line with studies conducted in Georgia,[11] and China.[12] The beneficial effects of ART on QoL is likely a result of the decreased intensity of the clinical symptoms of the disease.

Comparisons between the genders were considered. In this study, females had significantly lower scores than males in the psychological domains of HRQoL, which is consistent with studies conducted in Vietnam[13] and Italy.[14] Furthermore, an inverse relationship was found between age and QoL; the mean QoL score was found to be decrease with increasing age. This could be related to the part of the physiological process. Older people are expected to have worse QoL due to factors related to aging (physical conditions, cognitive impairment, disability, and fears about the future). There was an association between having a CD4 count greater than 500 and high QoL in the domain of spirituality. There is no description of this association in the literature.

To the best of our knowledge, this is one of the few facility-based studies conducted to assess the HRQoL among PLWHA and the impact of ART. The findings of this study should be interpreted with consideration of the following limitations. The study is a single facility, and is not representative of the whole country. The design was a cross-sectional study, which has its own disadvantages.

5. Conclusions

The level of HRQoL observed in this study was generally moderate with a lower score of QoL observed in the spirituality domain. Younger participants, religious minorities, literate participants, unmarried participants, those on ART for more than three years and those who adhered to ART were associated with good general QoL across most domains. Efforts to further improve quality of life PLWHA should be strengthened and future research should be done with longitudinal and qualitative designs to ascertain the findings.

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