

PEOPLE LIVING WITH HIV/AIDS UNDER ART IN KASKI DISTRICT IN NEPAL: QUALITY OF LIFE AND RELATED FACTORS

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ABSTRACT:

Background: Assessing quality of life is an important aspect of clinical practice. HIV not only affects the physical well-being of an individual but also the overall Quality of life (QoL). The assessment of QoL is more important to understanding how the people's lives are affected by it. The purpose of this study was to determine the association of the HIV/AIDS on the quality of life of the infected individuals in Kaski district of Nepal.

Methods: A cross-sectional study was done among 268 individuals attending antiretroviral therapy in ART center in Western regional hospital. Quality of life was evaluated with the help of World Health Organization Quality of life questionnaire (WHO QOL- HIV-BREF). SPSS version 22 was used for the data analysis.

Results: People Living with HIV/AIDS in Nepal (PLWHA) were having the poor quality of life in psychological domain of QOL. Marital status (p -value 0.007), being employed (p -value 0.002), taking self-care (p -value <0.001), and CD4 count (p -value 0.040) were the predictors for having the good QOL in PLWHA.

Conclusion: Old age, being unemployed, and low CD4 count were associated with the low QOL. Lowest score in the psychological domain suggested the need of the psychological interventions in order to decrease the discrimination and to improve attitude in PLWHA.

Keywords: Quality of life, HIV/AIDS, People Living with HIV/AIDS, Nepal

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INTRODUCTION

The first case of human immunodeficiency virus/acquired immunodeficiency syndrome (HIV/AIDS) was reported in USA 1981. The global pandemic of human immunodeficiency virus/acquired immunodeficiency syndrome (HIV/AIDS) has crippled the lives of many and caused millions of death. At present there are 37 million people living with HIV/AIDS with 2 million people newly infected taking lives of 1.5 million of people worldwide [1]. It is now regarded as the chronic illness; and there is still no definite treatment for it. It has been now a serious public health problem and a main concern for all the health providers in the

world [2]. In the low income countries like Nepal the first case was reported in 1988; and until now it is estimated that 39,249 people are living with HIV/AIDS [3].

QoL is the term which is now used to define the overall well-being, degree of satisfaction or dissatisfaction felt by the people with various aspects of life [4]. It is a complex perception of condition in life in the context of the cultural and system in which they live in relation to their goals, expectations, standards and concerns. It is a broad concept, defining in a complex way by the person's physical, psychological state as well as their personal belief with social and environmental relationships [5]. It can also be described according to the researcher's point of view, to prove their objectives in their research topics.

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Since the introduction of the antiretroviral therapy, the main goal in the management of HIV/AIDS has been increasing the quantity and quality of the life (QoL). As survival periods from the time of an infection has been increasing among those people living with HIV/AIDS (PLWHA); with the death rate and new infections going down, it shows that world is going towards achieving the millennium development goal 6 [1]. Although there has been an increase in the quantity of life, there is a concern for all the providers for their quality of life that has been extended. There has been a change in the traditional health indicators as well as in the modern medicine. Mortality and morbidity were the indicators to measure the impact of disease and outcome of an intervention for the traditional health indicators; but in modern medicine they are only concern with the eradication of the disease. In the recent years all the health care providers are concerned in the measurement of QoL to assess the burden of diseases [6]. However no studies have been done among PLWHA in Nepal to assess their quality of life. It thus follows that studies are needed. The main purpose of the study was to assess the QoL among PLWHA under antiretroviral therapy and their related factors in Kaski district in Nepal. The conceptual framework that guided the research was from the different literatures reviews. Numerous studies have shown socio-demographic factors [7], CD4 count [8], social support [9], self-care [10], self-esteem, employment [11] and duration of ART [12] have a significant association with Quality of life among these patients, but no evidence to support this in PLWHA in Nepal. For this reason, a study was done so that all the health personnel, physicians, nurses, counselors, who are directly or indirectly working for the PLWHA will be thinking quality is important than quantity; and this give importance in factors which were related to improve their QoL.

MATERIALS AND METHODS

Participants

The research was conducted in the Infectious Department of Western Regional Hospital, which is the second largest care service provider for the PLWHA in Nepal. This cross sectional survey was conducted in May 2016. There were 810 participants receiving the treatment from this care center. Individuals who were diagnosed with HIV/AIDS, with age group of 18 years to 60 years seeking ART services for the clinical care or for the follow up, Nepalese citizens, and all the stages on ART therapy

were included in this study. Those who were not willing to give the consent, individuals who have been diagnosed with the mental disorders were excluded in the study.

Sample size calculation

The sample was determined by using ANOVA sample size calculation. Clients on ART were identified via the ART and pre-ART registers maintained at the center. A random sampling technique was employed to select 268 prospective research participants to know their quality of life and the factors related to it.

Ethical consideration

This study was ethically approved (Reg.no. 2128 on 9th June 2016) by the ethical board of Nepal Health Research Council (NHRC), Nepal.

Data analysis

Data regarding demographic, self-care, with their current CD4 count was gathered using the structured questionnaire. QoL was measured with the World Health Organization Quality of life questionnaire (WHO QOL-BREF) instrument [13]. The WHOQOL-HIV BREF is derived from the WHOQOL-100, which contains five more extra specific items; and in total it has 31 items. WHO QOL-BREF has been well validated for measuring quality of life in people living with AIDS across different countries; it has been used for the similar study.

Since this study was first to be done in Nepal to access the Quality of life among PLWHA using WHO QOL HIV BREEF, English version was translated to Nepali language with the help of the bilingual physicians and other research expertise. The translated Nepali questionnaire was reviewed by the monolingual Nepalese. Back translation to English was again done by other bilingual physicians and public health expertise. The similarity and the comfort of the questionnaire was analyzed by the statistician and senior health personal and professors from Community medicine as well as with those who had been working in the HIV/AIDS field. Any error in the translation had to go through the entire process again until maximum similarity was obtained. The final version of the questionnaire was then pretested in 30 individuals LWHA. The pretested PLWHA were excluded from the final data analysis. For descriptive statistics, frequencies, percentage, mean and standard deviation were calculated. T-test and one way ANOVA were used to examine the associations

Table 1 Socio-demographic characteristics of the PLWHA

Characteristics	Participants (n=268)	%
Gender		
Male	139	51.9
Female	129	48.1
Age (years)		
20-24	9	3.4
25-29	50	18.7
30-39	129	48.1
40-49	55	20.5
50-60	25	9.3
Mean (SD) = 36 (8.01)		
Marital status		
Single	77	28.7
Married	156	58.2
Divorced	15	5.6
Widowed	20	7.5
Education		
Not at all	62	23.1
Primary	110	41.0
Secondary	83	31.0
Tertiary	13	4.9
Employment		
Employed	100	37.3
Unemployed	168	62.7
Current CD4 count		
<299	52	19.4
≥300	216	80.6

between population characteristics and quality of life. Age group was grouped as 20-24, 24-29, 30-39, 40-49 and 50-60 years old. Independent variables including population characteristics were put into categorical data; and dependent variable was continuous data. One way ANOVA is used to examine the associations between each variable with each subscale of QOL. The information which was given by the patients were sorted, coded and was entered in a data sheet created in SPSS (Statistical Package for Social Sciences) version 16. Double data entry system was rechecked in the values of the variables during the data analysis. Socio-demographic factors (age, sex, marital status, education), social and family support were presented by frequency, percentage, mean, and standard deviation. The statistical significance was kept as $p < 0.05$.

RESULTS

Table 1 shows the general characteristics of two hundred and sixty eight patients living with HIV/AIDS in infectious department in Western regional hospital. From the two hundred and sixty-eight patients, it appeared that almost half (51.9%)

of them were males. The maximum and minimum age were 21 and 60 years respectively with the average age of 36 years old (SD=8.01). In this research more population of age group was 30-39 consisting of 48.1%. For the marital status of the patients, more than half 58.2% of the populations were married; and more than two third 28.7% were single and living with their family; divorced participants were 5.6% with widowed participants of 7.5%. Less than half of the patients received primary level education with almost one fourth 23.1% of the population not receiving any education at all. From the study, none of participants received the university degree. For the employment, 62.7% of the patients were currently unemployed with just 37.3% of them being employed. 78.4% participants have been visiting the hospital for the ART care for more than 24 months and receiving first line or second line of treatment; whereas less than three quarter of the participants were on the first line of treatment visiting the ART care center for less than 24 months. The maximum and minimum level of the CD4 count were 150 and 872 mm^3 respectively with 80% of the participants having their CD4 count more than 300 mm^3 as shown in the Table 1.

Table 2 Quality of life

Characteristics of quality of life	Participants (n=268)	%
Poor	26	9.7
Neither poor nor good	203	75.8
Good	39	14.5

According to WHO, there are six different domains which sum up to form the quality of life as a whole. Different questions were asked in order to examine physical, psychological, level of independence, social relationship, environment, spirituality/religion leading to a quality of life. All the participants completed the entire WHO QOL HIV BREF questionnaires. Table 2 highlights about the distribution of the quality of life of all the participants who participated in the research. From the table, it indicates that more than two third 75.8% of the participants reported to be living in neither poor nor good quality of life, nor nearly 10% of PLWHA still are having the poor quality of life. Out of all less than one fifth of the participants were having good quality of life.

From the t-test (p -value 0.41), there was no association between the gender and the quality of life among people living with HIV/AIDS under ART. There were 51.9% of males in this study, while comparing the quality of life among these two groups 66.7% and 33.3% of males and females respectively were having the good quality of life. There was no significant difference in males and females who were living in neither good nor poor quality of life (Table 3). There were high number of the males; 61.5% of them were living in poor quality of life; whereas just 38.5% of the females were having the poor quality of life.

From the study, there was no association between the ages of the patients with the quality of life of people living with HIV/AIDS under ART. One way ANOVA was used to analyze the result with p -value 0.215. Looking at the quality of life, there were no participants who were having very poor quality of life as well as having very good quality of life. If compared in the different age group for the good quality of life, just 2.6% of the participants aged group 20-24 were having the good quality of life; with 30-39 age group 51.3% were living in the good quality of life. For poor quality of life, participants in age group 30-39 were having poor QOL; and there were no participants in age group 50-60 with poor QoL. There were 9.4% of the participants age group 50-60 having neither poor nor good quality of life, with 18.2% of age group 25-30

having the same result (Table 3). Likewise for the association between marital status and quality of life, one way ANOVA was used. The result showed there was an association between the marital status and the QoL in PLWHA (p -value 0.007). 19.2% of the participants who were divorced were having the poor quality of life. More than one fourth of the participant who were single were living in neither good nor poor quality of life. Likewise if looked only in the neither poor nor good quality of life, more than half of the participants were living in the neutral QOL. From the literature review it was found that people who were married would have good quality of life more than the people who were single or divorced. In this study there were more than four fifth of the participants who were married were having the good quality of life; with 28.7% of the participants who were single were living in good quality of life (Table 3). From the result it can be conclude that marital status has a positive relationship with the quality of life. A relationship was between employment and quality of life among people living with HIV/AIDS. To support this, t-test analysis was used with p -value 0.009. From the data analysis, it showed that people who were employment were having the better quality of life than those who were unemployed. 73% of participants who were unemployed were having the poor quality of life. More than half of the participants who were employed were having the good quality of life. More than one third of the participants 37% were having neither good nor poor quality of life; and 65.6% of the participants who were unemployed were living with neutral quality of life Table 3. All the participants who were in this study, there was no relationship between the education and QoL among people living in HIV/AIDS p -value 0.096. If looking at scores in the good quality of life, almost half of the participants who had achieved the secondary education were having the good QoL. With 20.5% of those who did not receive any education responded of having good quality of life. Almost 40% of the participants who had no education background responded in having the poor quality of life with more than one quarter of them having poor quality of life. From this result, it can be interpreted

Table 3 Association of socio-demographic characteristic of PLWHA and QoL

Characteristics	Quality of life			t-value or f-value	p-value
	Poor N (%)	Neither poor nor good N (%)	Good N (%)		
Gender					
Male	16(61.5%)	97 (47.8%)	26(66.7%)	9.472	*0.41
Female	10(38.5%)	106 (52.2%)	13(33.3%)		
Age (years)					
20-24	1 (3.8%)	7 (3.4%)	1(2.6%)	1.460	**0.215
25-29	6 (23.1%)	37 (18.2%)	7(17.8%)		
30-39	12(46.2%)	97 (47.8%)	20(51.3%)		
40-49	7(26.9%)	43 (21.2%)	5(12.8%)		
50-60	0 (0)	19 (9.4%)	6(15.4%)		
Marital status					
Never Married	9 (34.9%)	58(28.6%)	10(25.6%)	4.154	**0.007
Married	11(42.3%)	117(57.6%)	28(71.8%)		
Divorced	5(19.2%)	10(4.9%)	0(0)		
Widowed	1(3.8%)	18(8.9)	1(2.6%)		
Education					
None	10(38.5%)	44(21.7%)	8(20.5%)	2.13	**0.096
Primary	6(23.1%)	92(45.3%)	12(30.8%)		
Secondary	7(26.9%)	58(28.6%)	18(46.2%)		
Tertiary	3(11.5%)	9(4.9%)	1(2.6%)		
Employment					
Employed	7 (26.9%)	71(35.0%)	22(56.4%)	2.640	*0.002
Unemployed	19(73.1%)	132(65.6%)	17(43.6%)		
CD4 count					
0-299	11(42.3%)	34(16.7%)	7(17.9%)	2.064	*0.040
≥ 300	15(57.7%)	169(83.3%)	32(82.1%)		

*p-value from t-test analysis

** p-value from one way ANOVA analysis (95% C.I)

that greater education had an association of improved quality of life (Table 3). CD4 count was kept as the cutoff point of 300 mm³ as in ART care center in Kaski district in Nepal. Those who had the CD4 count less than 300 were likely to have opportunistic infections and other health related symptoms, for instance, loose motions, and fever. Moreover, there was the high prevalence of tuberculosis infections; so special care were given to them. There was an association between the CD4 count and the quality of life among the people living with HIV/AIDS under ART in Kaski district in Nepal t-test (*p*-value 0.040). More than 50% of the participants with more than 300 mm³ CD4 count were having the poor quality of life. For living in neither good nor poor quality of life, more than three quarter of the participants 83.3% of them who had CD4 count; more than 300 mm³ responded, with less than one fifth of the participants responding of having neutral QoL. Likewise in the good quality of life 82.1% and 17.9% of the participants with CD4

count more than 300 mm³ and less than 300 mm³ responded of having the good quality of life. From the result as shown in the Table 3, there were more significant number of the people living with HIV/AIDS who had CD4 count; more than 300 mm³ were living in neither good nor bad and good quality of life.

DISCUSSION

Marital status plays a role in improving the quality of life. In this study, those participants, who were divorced, were living in the poor quality of life. There was a significant difference in the quality of life among the single and divorced as well as in between married and divorced (Table 3). It can be concluded that single and divorced people who are infected with HIV/AIDS had to do all their works by themselves; and they are more likely to be depressed than those who are married. Moreover, in a low income country like Nepal, there are still discrimination and stigma towards the HIV/AIDS,

more common in those people who were single or widowed. Similar on the other studies done among HIV infected participants, they all highlighted that marital status had a significant association with their QoL. [14-16] Individuals with better education were living in the good quality of life. There was an association between the education with the physical, level of independence, social relationship, environmental and spiritual religion and personal belief domain of QoL. Education helps the individual to know about the risk factors and some knowledge about their disease state. Educated people are more likely to be employed; as a result, they are dependent upon themselves. They try to make themselves fit by doing regularly exercise, as well as by taking proper balanced diet. They have less chance of practicing the risky health seeking behaviors. They know about the disease better; this leads to the better coping attitude. They are also likely to interact with people in the society which it will help them to cope with the stigma. With the better education, it improves the people's standard of living. Other studies done to assess the quality of life also showed that there was a positive relationship between these two variables. They all highlighted that education had the positive impact in the quality of life and increased education; also there is a decrease in stigma and discrimination. As a result, there is the increase in access to the health care facilities ultimately improving the quality of life [17-19]. Employed participants were living in the better quality of life than the unemployed participants. It may be due to individuals who were employed had the better financial support with, which they can get the proper balance diet as well as get the proper health facilities. Moreover, they don't want to be unemployed; so they try to make themselves fit for the work by doing regular exercise and proper diet. Not only they get the social support from the environment they work, but also employed people may act as the role model among the PLWHA. As a result they have a better self-esteem. Employment have a positive relationship with the better quality of life [11]. Those participants who were having CD4 count more than 300 mm³ had the better quality of life. Those participants who were having CD4 count less than 300mm³ were living in the poor quality of life. The reason could be because they have the low viral load in their body as a result of which the chance of getting the opportunistic infection is decreased; and increase

in CD4 count mean living in a near normal life people; as a result, their immune power is increased ultimately decreasing in getting infected by common disease problems. These findings were similar to the study in Uganda and other studies which showed that there is an association in the CD4 count more than 300 mm³ and the mental health and ultimately to the better quality of life [12, 20, 21].

CONCLUSION

This study provides the understanding that ART improves the quantity of life; but their quality remains the main concern since it didn't show any improvement. Since HIV/AIDS is a chronic disease, attention needs to be paid to the various factors by the health personel and other professionals who are linked to provide care to PLWHA. From the study, it was concluded that WHO-HIV BREF tool is reliable, valid and suitable to measure the quality of life among PLWHA in Nepal. Low level of education, unemployment, marital status, patient visiting hospitals only when symptoms arises or patient having low level of CD4 count were associated with the low level of quality of life. This is consistent with the findings from the literature; and it has a vital role in treating the PLWHA to develop their way of living.

RECOMMENDATION

Findings suggest that marital status, employment, and CD4 count will help to improve their quality of life. Less score in the psychological domain of the health and the social relationship domain of quality of life means that additional laws and resources are required to tackle stigma and discrimination. There should be not only policy for the free of medication, but also there should be a nutritional program. There should be a decrease in treatment gap by implementing the universal coverage of ART to improve the quality of life as well as to decrease the transmission of the virus to the uninfected partners.

LIMITATIONS

From this study, only adult patients with HIV/AIDS were subjects of this study. Thus, the results cannot be applied to other populations of HIV/AIDS patient's less than 18 years from Kaski district population with HIV/AIDS taken under ART. It can be that similar research at the other center could come up with different results.

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