

Caregiving burden and depression among caregivers of people living with HIV/AIDS attending anti-retroviral therapy unit of Kaski

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ABSTRACT

Introduction: A descriptive cross-sectional study was conducted among caregivers of people living with HIV/AIDS (PLHIV/AIDS) attending anti-retroviral therapy (ART) unit of Kaski. The study aimed to assess the caregiving burden and depression and their relationship among caregivers of PLHIV/AIDS. **Methods:** Purposive sampling technique was adopted and total 238 caregivers were interviewed. Standard tool Zarit Burden Inventory and Beck Depression Inventory was used to assess burden and depression among caregivers of HIV/AIDS. For data analysis, data were entered in EPI 3.1 version and then exported to SPSS version 16.0. Descriptive statistics frequency, percentage, mean and standard deviation were calculated and for inferential analysis, Man-Whitney U test and Kruskal Wallis H test was used. **Results:** The study revealed about one third of the caregivers experienced caregiving burden and few have depression. There is statistically significant difference in burden of caregivers with regard to gender, occupation, family income, relation with patient and HIV status. Similarly, caregiver burden was found to be high if the PLHIV/AIDS was male and age ≤ 38 years old. The study showed significant difference in caregiver's depression with caregiver's burden and moderate positive correlation between caregiver's burden and depression. **Conclusions:** The study concluded burden and depression among caregivers of PLHIV/AIDS is alarming. Burden was found to be high in caregivers who are female, unemployed, having sufficient family income, family members and those who have HIV positive status. Regular Screening program among caregivers for depression should be conducted in anti-retroviral therapy unit on periodic time interval.

Keywords: Burden, caregivers, depression, PLHIV/AIDS.

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INTRODUCTION

Globally, 39.9 million people were living with HIV by the end of 2023, 65% of whom are in the WHO African region. In 2023, 630,000 people died from HIV-related causes and 1.3 million people acquired HIV.¹ UNAIDS reports that in Asia and the Pacific region, 6.7 million people were living with HIV with 300,000 newly infections and 150,000 AIDS related deaths. Sixty seven percent people living with HIV are on anti-retroviral therapy (ART) leading to 51% decrease in AIDS related deaths since 2010.² With consistent HIV prevalence, the country has achieved reduction in the number of new infections from 8,039 in 2000 to 1,408 in 2013 and 1365 in 2021. The estimated number of annual AIDS deaths of all ages is projected to decrease and this decline is most likely due to the increase of the number of people on antiretroviral treatment.³

Since 2004, Nepal has been providing free-of-cost ART.⁴ The introduction of ART has reduced mortality and morbidity among people living with HIV/AIDS (PLWHA) and so they live longer. Thus, HIV/AIDS has become chronic diseases like diabetes and

hypertension. Chronic illness affects not only the lives of those suffering from disease but also those of family members who care for them.⁵ Care giving is usually carried out by family members who serve as primary caregivers, and by community members who are recruited and trained to provide service as formal caregivers. Family members and volunteers often help in household chores and assist with the care of the children of the sick people. It is evident that families play a major role of support for PLHIV in Indian society.⁶ The scenario is same in the context of Nepal as well. Caregiver burden may develop from providing care for patients with chronic illness. Caregiver burden is frequently overlooked by clinicians.⁷ Zarit et al. have defined caregiver burden as: "The extent to which caregivers perceive that care giving has had an adverse effect on their emotional, social, financial, physical, and spiritual functioning".⁸

To cope with stressful events for caregivers of AIDS patients, both the internal factors such as knowledge and external factors such as finance and friends are very much necessary.⁹ Sometimes HIV caregivers can be seen as "guilty by association" and are forced to share the same stigma of rejection, loss of friends and harassment that the PLHIV might experience. Due to this demanding role, caregivers could begin to experience feelings of guilt, anger, depression or despair.⁶

In Nepal, most people cannot afford paid caregivers and rely on family members to take care of the sick. Whether driven by love or duty, the caregivers continue to care for their chronic patients against all challenges. Furthermore, when patients suffer from chronic, debilitating diseases, the burden on caregivers becomes overwhelming in a resource limited country like Nepal.¹⁰

Study done in Nigeria revealed that caregivers experienced high level of burden (physical, emotional, social and financial) as a result of the care they rendered to PLWHA.¹¹ Study done in northern part of Thailand also found that level of caregiver burden was strongly and independently associated with depression.¹²

The general well-being of PLWHA is greatly influenced by care of family members. Various studies have highlighted the need of counselling the caregivers on how to deal with PLWHA in the family. Majority of national HIV programs all over the world mainly focus on PLWHA and caregivers are always on the shade. Likewise, there are numerous research on experience of the caregiver documented for many illnesses but the research examining burden among caregivers of people living with HIV/AIDS is limited. Moreover, in context of Nepal nominal research has been

conducted on burden and depression among caregivers of HIV/AIDS to researcher's knowledge. So, the researcher aims to fulfill this gap in assessing burden and their liability for developing depression among caregiver's of PLHIV/AIDS. The purpose of the study was to assess caregiving burden and depression and their relationship among the caregivers of PLHIV/AIDS.

METHODS

Study design, setting and population

This study was a hospital based descriptive cross sectional study. The study was conducted in ART centre of Kaski district, i.e. Pokhara Academy of Health Sciences which is situated in Ramghat, Pokhara Lekhnath Metropolitan city. Kaski ART centre was established in 2006, where services are utilized by people living with HIV/AIDS of whole Kaski district as this is the only ART centre available here. So, patients are treated here in in-patient basis as well whenever they have serious problems. The researcher selected this setting with the expectation of covering wide range of population. Caregivers providing care to patients who attended ART unit of Pokhara Academy of Health Sciences for ART were the study population. At the time of study, there were 1001 people living with HIV/AIDS taking ART from ART centre. The study population consisted of caregivers aged 18 years and above and who had been taking care of the patient for at least three months were included in the study. Face to face interview was carried out separately with the caregivers in the waiting area after taking written informed consent from them. The primary caregivers were included in the study.

Sample size and sampling method

ART center of Pokhara Academy of Health Sciences was selected purposively for the study. Non probability consecutive sampling technique was used for selecting the subject. All the caregivers attending ART unit for one month time period were included in the study. The total sample size was 238.

Measurement of variables

In this study, dependent variables included burden and depression. Independent variables were caregiver's age, gender, educational status, marital status, occupation, family income, family type, relation with patient, HIV status, health problems and PLHIV/AIDS related variables as age, gender, duration of illness and WHO staging.

Zarit Burden Inventory (ZBI) is a 22-item questionnaire with a five-item response set ranging from "never" to

“nearly always.” Zero to 20 points mean little or no burden, 21 to 40 points mean mild to moderate burden, 41 to 60 points mean moderate to severe burden, and 61 to 88 points mean severe burden. ZBI has been successfully used in many studies. The validity and reliability of ZBI has been measured by previous studies¹³. The cronbach’s alpha was found to be 0.93 and the intra-class correlation coefficient for the test-retest reliability of the ZBI score was 0.89.¹³

The Beck Depression Inventory (BDI) is a validated 21-item questionnaire assessing the probability of depression, with scores ranging from 0 to 63; a score of 21 is highly suggestive of clinical depression. The reliability scores of BDI was found to be 0.88 in the Nepalese context.¹⁴

Data collection tools and techniques

Data was collected by interviewing the caregivers by direct face to face in a separate room by the researcher herself and the co-investigators. Each interview took around 20-25 mins. Data collection period was of one month from August 18, 2019 to September 18, 2019. Structured interview schedule was used for data collection which included information regarding socio demographic characteristics of caregivers and people living with HIV/AIDS. Standard tool ZBI and BDI was used to determine burden and depression among caregivers of HIV/AIDS respectively.

Data analysis

Collected data was checked, organized, coded and entered in Epi-data V.3.1 and was exported to SPSS version 16.0 for analysis. The data were analyzed by using descriptive statistics such as frequencies, percentage, mean, standard deviation. For inferential analysis, the dependent variables were kept continuous and Man Whitney U and Kruskal Wallis H test was used to assess the difference in caregiver’s burden and different socio-demographic variables of caregiver’s and PLHIV/AIDS. Similarly, Kruskal Wallis H test was used to identify the difference in caregiver’s depression with burden level. Spearman rank correlation coefficient was used to determine the correlation between burden and depression. The level of significance was considered at 5% with $p < 0.05$ and 95% confidence interval.

Ethical considerations

The study was carried out after obtaining ethical approval from Nepal Health Research Council (Ref. No. 3329) and Institutional Review Committee of Pokhara Academy of Health Sciences. Prior to data collection, written informed consent was taken from the participants with information of nature of the study and their role in research. The

objective of the study, confidentiality and autonomy were declared before starting the survey.

RESULTS

Out of 238 caregivers of PLHIV/AIDS, 57.56% were in the age group of 31 to 40 years with the mean age and standard deviation 38.86 ± 11.31 . Regarding gender, 50.84% were female, 46.64% had completed secondary school, 84.45% were married, 33.6% were from upper caste group, 84.90% were Hindu and 41.20% were homemakers. About 33.20% caregivers were wives, 56.70% had surplus income, 71.40% were from nuclear family, 65.10% were HIV positive caregivers and 91.60% caregivers had no any other health problem. (Table 1) Regarding PLHIV/AIDS, 28.02% were from 31 to 40 years age group where mean age was 38.47 ± 14.00 . Among the total respondents, 52.90% were female, 66.80% were in WHO third stage and 34.00% had duration of illness from 5 to 10 years.

Table 1: Background characteristics of caregivers of PLHIV/AIDS (N=238)

Variables	Characteristics	Frequency	Percentage (%)
Age (in Years)	≤30	60	25.21
	31-50	137	57.56
	Mean±SD (38.86±11.31)	>50	41
Gender	Female	121	50.84
	Male	117	49.16
	Illiterate/ No formal schooling	43	18.06
Educational status	Basic	64	26.90
	Secondary	111	46.64
	Higher	20	8.40
Marital status	Married	201	84.45
	Unmarried/Widow/widower/Separated	37	15.55
	Wife/Husband	149	62.61
Relation with patient	Close relatives	36	15.12
	Mother/Father	29	12.19
	Son/Daughter	24	10.08
Family type	Nuclear	135	56.72
	Joint	82	34.46
	Extended	21	8.82
HIV status	Positive	155	65.12
	Negative	83	34.88

The study found 54.62% had little or no burden, 36.14% had mild to moderate burden, 9.24% had moderate to severe burden among caregivers of PLHIV/AIDS with mean burden score 22.98 ± 12.15 . The study depicted 54.62% had minimal depression, 15.14% had mild depression, 16.80% had moderate depression and 13.44% percent had severe depression among caregivers of PLHIV/AIDS. (Table 2)

Table 2: Caregiving burden and depression level among caregivers of PLHIV/AIDS (N=238)

Level of burden	Frequency	Percentage (%)
Little or no burden	130	54.62
Mild to moderate burden	86	36.14
Moderate to severe burden	22	9.24
Level of Depression		
Minimal or no depression	130	54.62
Mild depression	36	15.14
Moderate depression	40	16.80
Severe depression	32	13.44

There was statistically significant difference in burden of caregivers with regard to gender, occupation, and family income, relation with patient and HIV status. On the other hand, no significant difference in burden score was found in terms of caregiver’s age, educational status, ethnicity, religion, family type and health problem (Table 3).

Table 3: Difference in caregiving burden among caregivers related variables (N=238)

Variables	Characteristics	Frequency	Caregiving Burden Score			P-value
			Median	Q1	Q3	
Age (in years)	≤ 39	132	21.0	14	30	0.901
	>39	106	20.5	15	29	
Gender	Male	112	19.0	14	27	0.005*
	Female	126	23.0	16	33	
Educational status	Illiterate	21	29.0	18	32	0.059
	Literate	217	20.0	14	29	
Marital status	Married	201	20	14	29	0.062
	Single	37	27	16	33	
Occupation	Employed	105	18.0	12	27	0.001*
	Unemployed	133	23.0	16	31	
Family income	Sufficient	103	23	16	34	0.001*
	Surplus	135	19	13	27	
Family type	Nuclear	170	21.0	13	28	0.213
	Joint & Extended	68	19.5	15	31	
Relation with patient	Family members	202	21	16	30	0.039*
	Closed relatives	36	16	12	29	
HIV Status	Positive	155	21	16	31	0.024*
	Negative	83	17	12	29	
Health problems	Present	20	23.5	13	33	0.540
	Not present	218	21	15	29	

*Significant at p value<0.05 based on Man-Whitney U test

Similarly, there was statistically significant difference in burden of caregivers with regard to age and gender of PLHIV/AIDS. (Table 4)

Table 4: Difference in caregiver’s caregiving burden with background variables of PLHIV/AIDS (N=238)

Variables	Characteristics	Frequency	Caregiving Burden Score			p-value
			Median	Q1	Q3	
Age in years	≤ 38	106	23.5	16	32	0.048*
	>38	132	19	14	27	
Gender	Male	117	23.0	16	33	0.006*
	Female	121	19.0	14	27	
Duration of illness in Years	≤ 6	137	20.0	14	30	0.7
	> 6	101	21.0	15	29	
WHO staging	1 st	34	21	13	34	0.806^
	2 nd	44	21	14	30	
	3 rd and 4 th	160	21	15	29	

*Significant at p value<0.05 based on Man-Whitney U test, ^Kruskal Wallis test

The study depicted there was significant difference in caregiver’s depression with burden level. (Table 5) In addition, there is moderate positive correlation between caregiver’s caregiving burden and depression. (Table 6)

Table 5: Difference in caregiver’s depression with caregiving burden level (N=238)

Variables	Frequency	Caregivers Depression Score			P-value
		Median	Q1	Q3	
Little or no burden	130	7	3	13	<0.001**^
Mild to moderate burden	86	18	11	24	
Moderate to severe burden	22	32	23	38	

*Significant at p value<0.05, ^Kruskal Wallis test

Table 6: Correlation between caregiver’s caregiving burden and Depression (N=238)

Outcome variable	Burden	p-value
Depression	0.631#	<0.001**

Spearman rank correlation coefficient, **significant at p value<0.001

DISCUSSION

The present study assessed the burden among caregivers of people living with HIV/AIDS. The existing literature suggests that care giving has tremendous adverse effects on the well-being of caregivers. In this study, a significant level of burden was perceived by all caregivers. About 36.1% of the caregivers reported experiencing mild to moderate burden and 8.4 percent reported a moderate to severe burden. Various other studies have depicted similar findings.^{12,15,16}

There was significant difference in burden of caregivers with regard to gender, occupation, family income and relation with patient and HIV status in the study. The difference between the groups was found to be statistically

significant. On the other hand, no significant difference in burden score was found in terms of caregiver's age, educational status, ethnicity, religion, family type and health problem.

There was significant difference in burden of caregivers with regard to gender. Female caregivers had high burden in comparison to male. Similar finding was obtained in a study done in Mysuru.⁶ This might be linked with the fact that female are more prone to stress and are more emotional and have weak coping mechanism.

Caregivers burden was found to be significantly higher in caregivers who are unemployed than employed. Employed caregivers are engaged in job and therefore they might have less time in thinking and worrying.

The median score for caregiver's burden differed significantly in terms of family income. Those from medium class have high caregivers burden than that from high class. The finding of the study was in line with the study done in China.¹⁷ This implies caregivers perceived more burden of caregiving if they have economic problem.

Caregivers who are from the family members scored higher caregiver burden than others, the finding was consistent to a study done in China.¹⁷ This could be because family members have the overall responsibility of caring and maintaining the health of PLWHA rather than other relatives.

Caregiver's burden was found to be significantly higher if the caregiver had also HIV positive status. The finding of the study was supported by a study done in Thailand.¹² This could be because HIV positive caregivers themselves have their own disease related stress and top of that care giving their partners further may add additional burden to them. However, another study found no any significant association of burden with HIV status of caregivers.¹⁶

The median score for caregiver's burden differed significantly in terms of age of PLWHA. Caregiver's burden was high in <38 years age PLWHA. Caregiver's burden was found to be significantly higher in case of male PLWHA. No significant difference in burden score was found in terms of duration of illness and WHO staging of PLHIV/AIDS.

The present study found that there was significant difference in caregiver's depression with regard to burden of caregiving. This finding is in consistent with other studies.^{12,16} Spearman rank co-relation was used to assess the correlation between caregiver's burden and depression which is found to be positive correlation with correlation coefficient value 0.631 which is moderate correlation.

Similar finding was revealed by other studies.^{16,18} The finding implies those caregiver's who are having more burden are more likely to develop depression or vice versa.

Because of the cross sectional nature of the study, causal relationship could not be established. Self-reported measure of burden and depression in the study might not present the exact picture. Social support might be an important variable which might affect the study result but was not included in this study.

CONCLUSIONS

The study concluded that burden and depression among caregivers of PLHIV/AIDS is alarming. Statistically significant difference in burden score of caregivers was found in terms of gender, occupation, family income, relation with patient, and HIV status. Similarly, caregiver's burden was found to be high in case of male and age ≤ 38 years of age PLWHA. Regarding depression, significant number of caregivers had depressive symptoms. Caregiver's burden was significantly correlated with depression. Therefore regular screening program among caregivers for depression should be conducted in ART unit on periodic time interval and counseling program should also be run on regular basis.

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AUTHORS' CONTRIBUTION

BG contributed to conceptualization, design, literatures review, data collection, and analysis and manuscript development. AP contributed to conceptualization, data analysis and manuscript editing. RS contributed to data collection and manuscript preparation. SB contributed to data collection and manuscript preparation. All authors reviewed and approved the final manuscript.

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