

# Caregiver Burden among Adults Caring for People Living with HIV/AIDS (PLWHA) in Southern India

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## ABSTRACT

**Introduction:** In India, family caregivers provide bulk of care to People Living With HIV/AIDS (PLWHA). Caregiver burden refers to the physical, emotional and financial hardships associated with providing care to a diseased individual. Attending to the needs of PLWHA can place a significant burden on family members. This may adversely affect their Quality of Life (QOL).

**Aim:** The main aim of our study was to assess the caregiver burden and QOL among the family members of PLWHA in Southern India. We also determined the impact of caregiver burden on QOL.

**Materials and Methods:** This facility based cross-sectional study was carried out at Kasturba Medical College (KMC) Mangalore. The study was conducted over a period of 18 months starting from October 2013. A total of 360 caregivers participated in our study. The data were collected by face-to-face interview. Caregiver burden was assessed using the Zarit Burden scale and WHOQOL-BREF scale was used to assess the QOL of caregivers. The collected data was entered and analysed using SPSS version 11.5. A p-value of less than 0.05 was considered statistically significant.

**Results:** The mean age of caregivers was 36.09± 10.18 years. Most of the caregivers were females 279 (77.5%). Majority of caregivers 184 (51.1%) belonged to Middle/Lower Middle socioeconomic class (Kuppuswamy class III). Majority of PLWHA 155 (43.1%) had Stage 2 disease. Mean CD4 count of the patients was 405.2± 240 cells/μL. In our study 88(24.4%) caregivers had moderate to severe burden and 36(10%) had very severe burden. Physical domain of QOL showed maximum score of 60.28±13.08, while a minimum score of 51.88 ± 14.20 was seen in social domain. With increase in caregiver burden, the mean QOL scores decreased which was statistically significant.

**Conclusion:** Our study highlights the need to counsel the caregivers on how to deal with PLWHA in the family. Family care plays a major role in the general wellbeing of PLWHA. Majority of national HIV programmes all over the world focus mainly on PLWHA. National programmes should immediately address the mental health issues of caregivers thereby reducing caregiver burden. More studies on this topic have to be conducted in developing countries.

**Keywords:** HIV, QOL, Zarit scale

## INTRODUCTION

The introduction of Highly Active Antiretroviral Therapy (HAART) has reduced mortality and morbidity among people living with HIV/AIDS (PLWHA) and so they live longer. HIV has become a chronic illness like Diabetes and Chronic Kidney disease. Chronic diseases not only affect the lives of those suffering from the illness but also affect the lives of family members who take care for them [1].

Caring for loved ones can have positive or negative consequences. Caregivers can get personal satisfaction by helping to reduce the suffering of their relatives. The negative aspects of care giving has been described as caregiver burden or stress [2,3]. Caregiver burden is used to describe the physical, emotional and financial toll of providing care [4]. 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" [5]. Studies have documented caregiver burden in the context of cancer, dementia and stroke [6-8]. In India family caregivers provide bulk of care to PLWHA. There are hardly any publications about caregiver burden among adults caring for PLWHA in India.

## AIM

The main aim of our study was to determine the care giver burden and quality of life among the primary caregivers of PLWHA in Southern India.

## MATERIALS AND METHODS

**Study Design and Setting:** This facility based cross-sectional study was done at the infectious disease centre of Kasturba Medical College (KMC), Mangalore. KMC Mangalore is a tertiary care referral hospital of Southern India.

## Sample Size, Sampling Technique, Study Duration and Study Population:

The sample size was calculated based on expected proportion of 'moderate to severe' or 'severe' caregiver burden among the relatives of PLWHA as 66% based on previous study [9], considering absolute precision as 5% and 95% confidence interval, sample size was calculated to be 360. The study was conducted over a period of 18 months starting from October, 2013. The investigator interviewed the caregivers of PLWHA who accompanied them to the hospital. Study participants were selected by non probability sampling. Caregivers (spouse, parent, sibling or children) in the age group of 18–60 years who provided care to the patient for at least 6 months of duration were included. Caregivers suffering from any obvious debilitating co-morbid conditions or depression were excluded from the study. The study protocol was approved by the Institutional Ethics Committee of KMC Mangalore.

**Data Collection:** The study subjects were made to understand the details of the study and only after obtaining written informed consent from them the subjects were enrolled for the study. A face-to-face interview was conducted at the study site for the collection of the data. The interviews lasted for 30 minutes. Data was collected using a semi-structured proforma which included sociodemographic and clinical details of the care givers and patients. The socioeconomic status of caregivers was assessed using Modified Kuppuswamy Socioeconomic Status Scale. Caregiver burden was assessed using the Zarit Care Giver Burden scale [10] and the WHOQOL-BREF Questionnaire was used to assess the QOL of caregivers [11]. The scoring was done in accordance with the guidelines given in the respective instruments. Zarit burden scale consists of 22 questions. Caregivers were asked to respond to a series of questions about the impact of the patients' disabilities on their life. Items were answered on a 5-point likert

Caregiver profile	n (%)
<b>Gender</b>	
Female	279(77.5)
Male	81(22.5)
<b>Marital status</b>	
Married	328(91.1)
Widowed	17(4.7)
Single	15(4.2)
<b>Age (years)</b>	
≤ 30	127(35.3)
31 – 40	127(35.3)
41 – 50	70(19.4)
> 50	36(10)
<b>Relation with the patient</b>	
Wife	235(65.3)
Husband	57(15.8)
Son	24(6.7)
Mother	20(5.6)
Daughter	18(5)
Sister	6(1.7)
<b>Socio-economic status</b>	
Upper	5(1.4)
Upper middle	71(19.7)
Lower middle	184(51.1)
Upper lower	100(27.8)
Lower	0 (0)
<b>HIV status</b>	
Positive	134(37.2)
Negative	226(62.8)
<b>Treatment (HAART)</b>	
Yes	101(28.1)
No	259(71.9)
<b>Patient profile</b>	
<b>Gender</b>	
Male	252(70)
Female	108(30)
<b>Age (years)</b>	
≤ 30	51 (14.2)
31 – 40	177(49.2)
41 – 50	54(15)
> 50	78(21.7)
<b>WHO Staging</b>	
Stage 1	57(15.8)
Stage 2	155(43.1)
Stage 3	89(24.7)
Stage 4	59(16.4)

**[Table/Fig-1]:** Demographic and clinical profile of caregivers and patients.

scale (never, rarely, sometimes, quite frequently, or nearly always). Using these scores, the level of burden was categorized into little (0–20), mild to moderate (21–40), moderate to severe (41–60) or severe (61–88) burden [10].

WHO's QOL scale (WHOQOL-BREF) to assess quality of life in this study. The WHOQOL-BREF questionnaire contains 26 items including two items (global scores) i.e. overall QOL and general Health and 24 items of satisfaction that are divided into four domains: physical health, psychological health, social relationships and environmental health. Each item is rated on a 5-point Likert scale. The four domains have a score range of 4–20 that was transformed to 0–100 scale [11,12].

## STATISTICAL ANALYSIS

Data collected was analysed using SPSS Version 11.5 statistical software. For continuous variables, the mean and standard deviation were calculated while for categorical variables, we calculated proportions. For comparison of QOL in each domain with caregiver burden, statistical test ANOVA was used. The p-value <0.05 was considered to be significant.

## RESULTS

**Sociodemographic details of caregivers:** A total of 360 caregivers participated in the study. The mean age of caregivers was 36.09 ±10.18 years. Majority of them 184(51.1%) belonged to Lower Middle socioeconomic class. Among the caregivers 279 (77.5%) were females and 328 (91.1%) were married. In our study majority of caregivers 235 (65.3%) were wives of PLWHA [Table/Fig-1].

**Sociodemographic and Clinical Details of Patients:** The mean age of PLWHA was 40.83 ± 10.62 years and majority 177 (49.2%) belonged to the age group of 31 – 40 years [Table/Fig-1]. The mean duration of disease was 4.33 ± 2.38 years. Majority of PLWHA 155 (43.1%) had Stage 2 disease. Mean CD4 count of the PLWHA was 405.2±240 cells/μl.

**Caregiver Burden and QOL:** The mean Burden score was 32.98 ± 17.94. In our study 136 (37.8%) subjects reported 'little or no burden', 100 (27.8%) reported mild to moderate burden, 88 (24.4%) reported moderate to severe burden and 36 (10%) subjects reported severe burden [Table/Fig-2]. The quality of life scores among the caregivers was 60.28 ± 13.08 in physical domain, 59.69±11.93 in psychological domain, 51.88 ± 14.20 in social domain and 56.83±11.33 in environmental domain [Table/Fig-3]. The QOL scores among caregivers had a negative correlation with caregiver burden and the finding was statistically significant in all the four domains (p< 0.001).

Burden (score range)	n (%)
Little/No Burden (0– 20)	136(37.8)
Mild to Moderate (21–40)	100(27.8)
Moderate to severe (41–60)	88(24.4)
Severe (61–88)	36(10)

**[Table/Fig-2]:** Extent of caregiver burden.

## DISCUSSION

In our study 88(24.4%) caregivers had moderate to severe burden and 36(10%) had very severe burden. Physical domain of QOL showed maximum score of 60.28±13.08, while a minimum score of 51.88±14.20 was seen in social domain. With increase in caregiver burden the mean QOL scores decreased which was statistically significant.

Caregiving includes assistance with activities of daily living, medical care (e.g. medication management, accompanying patients to hospital), and providing emotional and financial support [13]. Studies have shown that illness of a close relative causes distress and compromises caregiver health [14,15]. Caregiving has features of a chronic stress experience [16]. Risk factors for caregiver burden include female gender, low educational status, residing with the patient, depression, social isolation, financial stress, higher number of hours spent in caregiving and lack of choice in being a caregiver [13,17]. These risk factors are derived from non-HIV studies but the same risk factors can be applied to HIV population as it is a chronic treatable disease. The issue of caregiver burden is significant in the context of HIV since the diagnosis is often withheld from the society due to fear of stigma and hence caregivers may experience more burden. In a study done in Africa among caregivers of orphaned HIV children caregiver economic vulnerability and those struggling with their own AIDS-

Domain	Burden	n	Mean QOL Score±(SD)	p-value
Physical	Little/No Burden	136	61.79 ± 11.35	p<0.001
	Mild to Moderate	100	62.96±11.46	
	Moderate and Severe	124	56.45±15.14	
	Total	360	60.28± 13.08	
Psychological	Little/No Burden	136	65.23±7.41	p<0.001
	Mild to Moderate	100	61.38±10.34	
	Moderate and Severe	124	52.25±13.32	
	Total	360	59.69 ± 11.93	
Social	Little/No Burden	136	54.90±10.56	p<0.001
	Mild to Moderate	100	54.92±15.58	
	Moderate and Severe	124	46.10±14.82	
	Total	360	51.88± 14.20	
Environmental	Little/No Burden	136	61.12±7.65	p<0.001
	Mild to Moderate	100	57.84±12.27	
	Moderate and Severe	124	51.31±11.73	
	Total	360	56.83 ± 11.33	

**[Table/Fig-3]:** Comparison of quality of life (QOL) in each domain with caregiver burden

related illness felt most overburdened [18]. In a study done in Botswana caregivers caring for PLHIV experienced burdens of physical, emotional, financial or social nature [19]. While providing care to PLWHA the entire focus of doctors is on the patient and demands of caregivers are often overlooked.

In a study done in Thailand [9] using the Zarit scale, 217 (53%) of caregivers experienced moderate to severe burden and 55 (13.4%) severe burden. In the same study 1(0.2%) experienced little or no burden. In a study done in Nigeria, 93(36%) caregivers had moderate to severe burden and 51(20%) had severe burden [20]. In the same study 4 (18.8%) experienced little or no burden while providing care. Caregiver burden was low in our study when compared with the Nigerian study. In a study done in Africa 41(11.4%) had moderate to severe burden and 2(0.6%) had severe burden [21]. In a study done among caregivers of orphaned HIV children 40% of orphan caregivers had a high level of caregiving burden [18]. They used 12-item Zarit Burden Interview in their study. In a study done in USA, 27% of informal caregivers had a high caregiver burden. They used Caregiver Strain Index (CSI) to assess burden in their study [22].

## LIMITATION

Our study had some limitations. Our study design was cross-sectional; therefore, causal interpretations cannot be established. It was a single centre study so the results may not be generalized. We did not assess the role of caregiver co-morbid illness on caregiver burden in our study. We used self report method to screen for caregiver depression in our study.

## CONCLUSION

Our study has significant implications for future HIV studies in our country. Family care plays a major role in the general wellbeing of PLWHA. Our study highlights the need to counsel the caregivers on how to deal with PLWHA in the family. Majority of national HIV programmes all over the world focus mainly on PLWHA. National programmes should immediately address the mental health issues of caregivers thereby reducing caregiver burden. Caregiver support groups must be established in hospitals. Physicians dealing with PLWHA must screen the primary caregivers for caregiver burden by using appropriate scales. Physicians must take the help of technology, nurses, social workers and psychologist to reduce caregiver burden. Financial support must be provided to caregivers via National programmes. More studies on this topic have to be conducted in developing countries so that the extent of problem can be defined.

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