

## Caregiver Burden among Adults Caring For People Living With HIV/AIDS in Mysuru

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### ABSTRACT

National Aids Control Organization (NACO) annual report 2016-17, as per the India HIV Estimation 2015 report, adult (15-49 years) HIV prevalence in India was estimated at 0.26% in 2015. In 2015, adult HIV prevalence was estimated at 0.30% among males and at 0.22 % among females. The number of people living with HIV (PLHIV) in India was estimated at 21.17 Lakhs in 2015 compared with 22.26 Lakhs in 2007. They may have a large psychological, physical and social impact on infected individuals and their families. People living with HIV rely on relatives for emotional support and economic assistance. Family or caregivers experience enormous physical emotional burden while caring for such relatives. The present investigation aims at finding out the level of burden and whether gender and domicile has any influence on burden in caregivers. The sample consists of 80 caregivers (40 male 40 female) they were selected from K R Hospital ART centre, Mysore. Result reveals that female caregivers experience high burden compare to male caregivers and rural caregivers have high burden compare to urban caregivers. The study discusses the implications for the need of intervention for the caregivers of HIV to improve their mental health.

**Keywords:** *Burden, People Living With HIV/AIDS.*

The introduction of Highly Active Antiretroviral Therapy (HAART) has reduced mortality and morbidity among people living with HIV/AIDS (PLHIV) and so they live longer. Lim and Zebrack (2004) said that HIV has become a chronic illness like Chronic Kidney disease and Diabetes. 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.

Pearlin, Mullan, Semple and Skaff (1990) according to caring for loved ones can have positive or negative consequences. Caregivers can get personal satisfaction by helping to

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reduce the suffering of their relatives. The negative aspect of care giving has been described as caregiver burden or stress. George and Gwyther (1986) say that caregiver burden is used to describe the physical, emotional and financial toll of providing care. Zarit et al. (1986), defined that 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”. Northfield and Nebauer, (2010) according to documented caregiver burden in the context of cancer, dementia and stroke. In India family caregivers provide bulk of care to PLHIV. There are hardly any publications about caregiver burden among adults caring for PLHIV in India.

National Aids Control Organization (NACO) annual report 2016-17, as per the India HIV Estimation 2015 report, adult (15-49 years) HIV prevalence in India was estimated at 0.26% in 2015. In 2015, adult HIV prevalence was estimated at 0.30% among males and at 0.22 % among females.

The states estimated in 2015, Manipur has shown the highest estimated adult HIV prevalence of 1.15%, followed by Mizoram (0.8%), Nagaland (0.78%), Andhra Pradesh & Telangana (0.66%), Karnataka (0.45%), Gujarat (0.42 %) and Goa (0.40%), Tripura, Tamilnadu have shown as estimated adult HIV prevalence greater than the national prevalence (0.26%), while Odisha, Bihar, Sikkim, West Bengal have shown an estimated adult HIV prevalence in the range of 0.21-0.25%.

The number of people living with HIV (PLHIV) in India was estimated at 21.17 lakhs in 2015 compared with 22.26 lakhs in 2007. Children account for 6.54% while females contributed around 40.5% of total HIV infection. Undivided Andhra Pradesh and Telangana have the highest estimated number of PLHIV (3.95 lakhs) followed by Maharashtra (3.01lakhs), Karnataka (1.99 lakhs), Gujarat (1.66 lakhs), Bihar (1.51 lakhs), and Uttar Pradesh (1.50lakhs). These seven states together account for 64.4 % of total estimated PLHIV. They face a large psychological, physical and social impact on infected individuals and their families.

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. People living with HIV rely on relatives for physical and emotional support such as to administer medicines, transport the person to their medical appointment, cook meals, carrying, lifting and bathing of patients, staying awake at night to attend to patients who are in the terminal stages of their illness. Family members and volunteers often take on 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.

A system of support is crucial for individuals living with HIV to strengthen their coping strategies when dealing with this disease. This support is often provided by informal caregivers who give individuals living with HIV with physical, emotional and spiritual care

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in dealing with the effects of PLHIV on their daily lives. These informal caregivers include parents, siblings, spouse, children and friends.

According to Treudley (1946), "Burden on the family" refers to the consequences for those in close contact with a severely disturbed psychiatric patient. Grad & Sainsbury (1963) and Hoenig & Hamilton (1966) developed the first burden scales for caregivers of severely mentally ill patients, and a number of authors further developed instruments trying to distinguish between "objective" and "subjective" burden. Objective burden concerns the patient's symptoms, behavior and socio-demographic characteristics, but also the changes in household routine, family or social relations, work, leisure time, physical health. Family caregivers face changes in their life that affect their daily routines. Such changes may involve their financial wellbeing relationships with others and their own physical and mental health. This effect on the family member has been referred to as caregiver burden, strain, role fatigue, role overload or caregivers stress (Schale and Faria 1997).

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. Not only does it require physically caring for someone you love at home, but it also means facing your own concerns about the diagnosis and eventual outcome of the disease. Most people fear an AIDS diagnosis in spite of the fact that the disease can generally be treated.

Chandran et.al. (2016) studied that caregiver Burden among Adults Caring for People Living with HIV/AIDS (PLHIV) in Southern India. 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 the study. The mean age of caregivers was  $36.09 \pm 10.18$  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 PLHIV 155 (43.1%) had Stage 2 disease. Mean CD4 count of the patients was  $405.2 \pm 240$  cells/ $\mu$ L. In our study 80(24.4%) caregivers had moderate to severe burden and 36(10%) had very severe burden. Physical domain of QOL showed maximum score of  $60.28 \pm 13.08$ , while a minimum score of  $51.88 \pm 14.20$  was seen in social domain. With increase in caregiver burden, the mean QOL scores decreased which was statistically significant.

## METHODOLOGY

### *Aim*

- The main aim of our study was to assess the caregiver burden among the family members of PLHIV

### *Objectives*

1. To study the level of burden in caregivers of People living with HIV/AIDS

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2. To find out whether gender has any influence on burden in caregivers
3. To find out whether domicile has any influence on burden in caregivers

### *Sample*

The sample consists of 80 caregivers (40 male and 40 female) of registered PLHIV who attend ART centre KR Hospital Mysore. Sample ranges from 30-50 years.

### *Tools*

The Burden assessment schedule developed by Sell, H., Thara, R., Padmavathi,S., Kumar (1998) was adopted in this study. This scale is a 20 item questionnaire consist 5 factors which include impact on well being, marital relationship, appreciation for caring, relation with others, perceived severity of the disease with 4 items in each category. Higher scores indicate greater burden experienced by the care-giver.

### *Procedure*

After establishing rapport with the subjects, the researcher told the purpose and nature of the study, they were asked to fill the information schedule. Then they were given appropriate instructions and administered the Burden assessment schedule. Whenever they had doubt in understanding any item the test administrator clarified their doubts in their local language.

### *Statistical Analysis*

Data collected was analyses using SPSS Version 19 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 AND DISCUSSION**

*Table 1 shows the Descriptive statistics of Burden, the mean SD of gender and domicile*

<b>GENDER</b>	<b>DOMICILE</b>	<b>Mean</b>	<b>SD</b>	<b>N</b>
MALE	URBAN	24.62	2.692	21
	RURAL	25.53	2.590	19
	Total	25.05	2.650	40
FEMALE	URBAN	36.89	3.985	19
	RURAL	43.05	3.905	21
	Total	40.13	4.983	40
Total	URBAN	30.45	7.042	40
	RURAL	34.73	9.457	40
	Total	32.59	8.559	80

Table no. 1 indicates the mean SD scores of descriptive statistics score of Burden in gender and domicile. The mean and SD value for urban male is 24.63 and 2.69. The mean and SD scores for rural male is 25.5 and 2.59. The total mean and SD for male is 25.05 and 2.6. The

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mean and SD scores for urban female is 36.8 and 3.9. The mean and SD scores of rural female is 43.05, 3.9. The total mean and SD scores for female is 40.13 and 4.98. The total mean and SD scores for both male and female in urban is 30.45 and 7.04. The total mean and SD scores for both male and female in rural is 34.73 and 9.45. The total mean and SD scores for both the gender and both the domicile is 32.59 and 8.55 respectively.

**Table No.2 shows mean, SD scores and F values of Burden in male and female caregivers of PLHIV**

DOMAIN	GENDER	N	MEAN	SD	F	P
Burden	Male	40	25.05	2.650	392.961	.001*
	Female	40	40.13	4.983		
	Total	80	32.59	8.559		

\*  $p > 0.01$  highly significant

Table no.2 indicates the mean, SD scores and F values of male and female caregivers. In burden of care domain, the mean and SD values for male caregiver are 25.05 and 2.65; female caregivers are 40.13 and 4.98 respectively. In total burden domain the mean, SD of male and female caregivers are 32.5 and 8.5 respectively. Further the F and P values are 392.9 and .001 which is highly significant. This shows that female caregivers have high burden compare to male caregivers of people living with HIV/AIDS.

**Table no. 3 shows mean, SD scores and F values of Burden in urban and rural caregivers of PLHIV**

DOMAIN	DOMICILE	N	MEAN	SD	F	P
Burden	Urban	40	30.45	7.042	22.061	.000*
	Rural	40	34.73	9.457		
	Total	80	32.59	8.559		

\*  $p > 0.01$  highly significant

Table no.3 indicates that mean SD scores and F values of urban and rural caregivers of PLHIV. In burden of care domain the mean SD of urban and rural caregivers are 30.4, 34.7 respectively. The SD scores of urban and rural caregivers 7.04, 9.4 respectively.

In total burden domain the mean, SD of urban and rural caregivers are 32.5 and 8.55 respectively. Further the F and P values are 22.06 and .000 which is highly significant. This shows rural caregivers have high burden compare to urban caregivers of people living with HIV/AIDS.

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*Table no. 4 shows F and P values for interaction effect of gender and domicile on burden of care in caregivers of PLHIV*

DOMAIN	INTERACTION	MEAN SQUARE	F	P
Burden	Gender* Domicile	137.238	12.179	.001

$p > 0.01$  highly significant

Table no.4 indicates F and P values for interaction effect of gender and domicile on burden of care in caregivers of PLHIV. Interaction effects of gender and domicile are found highly significant, with value of F and P is 12.17, .001 values which indicate highly significant interaction effects between gender and domicile on burden.

The overall result reveals that female caregivers experience high burden compare to male caregivers and rural caregivers have high burden compare to urban caregivers. The burden of caring for the sick weighs disproportionately on women not only because they are the main providers of care in homes, but also because many have lost their male partners or have never been married, men rarely assist with care giving because they are usually involved in formal or informal activities to earn an income for the family (Olagoke Akintole 2004). Barbara J. Messinger (2008), reported that urban caregivers experienced less burden this may be due to Rural caregivers perceive a lack of specialized health care and a greater sense of social isolation, and a lack of social support. The study indicates the need of intervention for the caregivers of PLHIV to improve their mental health. It is necessary to provide accurate and useful sources of educational information for both patients and Caregivers.

### CONCLUSION

1. The female caregivers having higher burden compare to male caregivers of people living with HIV/AIDS.
2. The rural caregivers having higher burden compare to urban caregivers of people living with HIV/AIDS.
3. The interaction effects having highly significant difference between gender and domicile on caregivers' burden of people living with HIV/AIDS.

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### REFERENCES

- Barbara, J., Messinger., (2008) Impact of Dementia Care giving on the Caregiver in the Continuum of Care. *Annals of long term care*.
- Burden C, Quite NRS. A practical guide to caring for caregivers. *Am Fam Physician*. 2000;62:2613–20.

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- George LK, Gwyther LP. Caregiver well-being: a multidimensional examination of family caregivers of demented adults. *Gerontologist*. 1986;26:253–59.
- Karin, J Faison., Sandra, H Faria., Deborah Frank (1999). Caregivers of Chronically Ill Elderly: Perceived Burden. *Journal of community health nursing* 243-253.
- KSAPS (2010) Karnataka state Aids prevention Society consolidated on ART Report October 2010 Bangalore:
- Lim J, Zebrack B. Caring for family members with chronic physical illness: a critical review of caregiver literature. *Health Qual Life Outcomes*. 2004; 2:1–9.
- NACO (2009-10) New Delhi: National Aids Control Organization, Ministry of Health and Family Welfare, Govt of India.
- NACO (2016-17) New Delhi: Annual report National Aids Control Organization, Ministry of Health and Family Welfare, Govt of India.
- Northfield S, Nebauer M. The caregiving journey for family members of relatives [6] with cancer: how do they cope? *Clin J Oncol Nurs*. 2010;14:567–77.
- Olagoke Akintola (2004). A gender analysis of the burden of care on family and volunteer caregivers in Uganda and South Africa, Health Economics and HIV/AIDS Research Division (*HEARD*)
- Pakenham, K. I., Dadds, M. R., Terry D. J (1995). Caregiver's burden and adjustment to HIV. *AIDS Care*; 7:189–203.
- Patricia Engler., Bradley Anderson., Debra Herman., Duane Bishop., Ivan Miller., Paul Pirraglia., Jumi Hayaki., Michael Stein(2006) Coping and Burden among Informal HIV Caregivers. *American psychosomatic society*
- Pearlin LI, Mullan JT, Semple S, Skaff MM. Caregiving and stress process: An overview of concepts and their measures. *Gerontologist*. 1990;30:583–94.
- Rigby H, Gubitz G, Phillips S. A systematic review of caregiver burden following stroke. *Int J Stroke*. 2009; 4:285–92.
- Sarah Biel-Cunningham., (2003). The Support Needs of Caregivers,
- Shim SH, Kang HS, Kim JH, Kim DK. Factors Associated with Caregiver Burden in Dementia: 1-Year Follow-Up Study. *Psychiatry Investig*. 2016; 13:43-49.
- Terri, L. Wilder., (2000). Caring for the caregivers. *AIDS Survival Project*
- Walter Kipp ., Thomas Matukala Nkosi., Lory Laing., Gian, S Jhangri., (2006). Care burden and self-reported health status of informal women caregivers of HIV/AIDS patients in Kinshasa, Democratic Republic of Congo, *Aids care*: 18 694-7)
- Zarit SH, Todd PA, Zarit JM. Subjective burden of husbands and wives as caregivers: a longitudinal study. *Gerontologist*. 1986. 26:260-66.

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