

# Burden Among Caregivers of Children Living with Human Immunodeficiency Virus in North India

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## Abstract

**Background:** Due to wider access to and free antiretroviral therapy (ART) program, the number of children dying due to acquired immune deficiency syndrome (AIDS)-related causes has declined and the nature and duration of human immunodeficiency virus (HIV)/AIDS caregiving has also dramatically altered. The care of children living with HIV/AIDS (CLHA) places a significant additional burden on the caregivers. **Aims:** This study was conducted to assess the perceived burden among caregivers of children living with HIV in North India. **Materials and Methods:** A hospital-based cross-sectional study among 156 CLHA-caregiver dyads in North India was conducted from June 2010 to May 2011. Data were collected by using a pretested structured interview schedule. The caregiver burden was measured with a 36-item scale adapted from Burden Assessment Schedule of Schizophrenia Research Foundation (BASS). Child characteristics, caregiver characteristics, caregiving burden, the knowledge of caregivers, and issues related to health care, nutrition, education, and psychological aspects were studied. **Results:** Caregivers had a mean age of  $35.9 \pm 10.2$  years. Women accounted for over three-fourth (76.9%) of the caregivers. Nearly two-third of them (65.4%) reported as living with HIV. The mean caregiver burden score was  $68.7 \pm 2.9$ . A majority of the caregivers reported either low or moderate burden. Standardized percentage score was high in the domains of physical and mental health, external support, patients' behavior, and caregivers' strategy and seemed to be comparatively less in the other domains such as support of the patient and taking responsibility. **Conclusions:** Caring of children is a universal practice but there is a need of special care for children living with HIV. The majority of caregivers who were usually the mothers perceived the burden and need to be assisted in caring for the child. Stigma and discrimination with HIV infection further increased the burden as caregivers did not disclose the HIV status to any near and dear one.

**Keywords:** Caregiver, children, human immunodeficiency virus (HIV), acquired immune deficiency syndrome (AIDS)

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## Introduction

Globally, in year 2011 an estimated 3.4 million children younger than 15 years of age were living with human immunodeficiency virus (HIV) with a majority of them in sub-Saharan Africa.<sup>[1]</sup> During the same year, children accounted for 7% (0.15 million) of all HIV infections and

14,500 new infections in India.<sup>[2]</sup> In the past decade, due to a wider access to and free antiretroviral therapy (ART) program, the number of children dying due to acquired immune deficiency syndrome (AIDS)-related causes has declined and the nature and duration of HIV/AIDS

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caregiving had also dramatically altered.<sup>[3]</sup> Generally, it is challenging to care for any sick child and it is particularly demanding caring for an HIV-infected child.<sup>[4]</sup> Although families play a significant role in supporting people living with HIV/AIDS (PLHA), particularly with an increasing number of children living with HIV/AIDS (CLHA), the demand for informal caregivers is growing.<sup>[5]</sup>

Caregivers are responsible for enabling HIV-infected infants, children, and adolescents to live and thrive in home-based rather than institutionalized communities of care. Caregivers of children with HIV face many challenges such as depression, fatigue, and exhaustion that are similar to the problems of those who care for children with other life-threatening diseases.<sup>[6,7]</sup> Diminished stamina and the physical demands of a HIV-positive child leave many caregivers without adequate time for self-care and counseling.<sup>[8,9]</sup> Moreover, HIV is associated with additional stressors such as social stigma and isolation that may limit the caregiver's willingness to disclose the infection and seek assistance from formal agencies for themselves or their families.<sup>[8]</sup>

Caregiver burden is a multidimensional phenomenon reflecting the physical, emotional, social, and environmental consequences of caring for an impaired family member.<sup>[10]</sup> The nonnormative experience of caring for someone with a terminal illness can be a major source of stress for these young adults.<sup>[11]</sup> For people of all ages, HIV/AIDS caregiving creates the emotional strain of dealing with an unpredictable and currently incurable disease.<sup>[12]</sup> Some caregivers who are free of HIV are burdened by fears of contracting HIV even when they know that there is little basis for concern.<sup>[13]</sup> A final source of burden is the stigma surrounding HIV infection. Community rejection of HIV-positive individuals because of their disease or the mode of transmission often extends to relatives and friends who provide care.<sup>[14]</sup> Rather than face stigmatization, some caregivers try to conceal their caregiving activities by withdrawing from social relationships. Those who do acknowledge their caregiving status may find it difficult to obtain support from familial or social networks.<sup>[11]</sup>

A progressive increase in caregivers' responsibilities in the course of HIV might require further adjustments in family, work, and social commitments. Over the past decade, many studies have focused on the negative consequences of caregiving, generally referred to as caregiver burden, caregiver stress, and caregiver strain but no study had particularly assessed the burden among caregivers of children living with HIV. A better understanding of the multiple factors associated with caregiver burden can help health care providers to develop tailored programs and specific interventions

to assist HIV-affected families and address the needs of both the CLHA and their caregivers. Therefore, this study was conducted to find the perceived burden among caregivers of CLHA in India.

## Materials and Methods

### Study design and settings

A hospital-based cross-sectional study was conducted at the All India Institute of Medical Sciences (AIIMS), New Delhi, India where approximately 200 children living with HIV/AIDS were enrolled for pre-ART care in 2010.

### Study population

Conveniently, all the eligible children (less than 15 years of age and receiving treatment and care for HIV/AIDS at AIIMS) and their caregivers were enrolled in the study. Children too sick to participate in the study and those diagnosed with HIV infection within the last 1 year were excluded from the study. A total of 156 caregivers were interviewed from June 2010 to May 2011 during their visit to the pediatric chest clinic at AIIMS Hospital.

### Ethical considerations

The study protocol was approved by the Institute Ethics Committee of AIIMS. A participant information sheet was provided to all the participant caregivers and written informed consent was obtained before interview.

### Operational definitions

A caregiver was defined as the person who spent most of his/her time directly caring for the child and accompanied the child to the hospital on the day of interview.

### Study instruments and data collection

Data were collected by a single investigator using a pretested structured interview schedule. Children-related data were collected from the record available and the caregivers were interviewed.

The caregiver burden was measured with a 36-item scale adapted from the Burden Assessment Schedule of Schizophrenia Research Foundation (BASS), which is a 40-item structured instrument to measure both objective and subjective burdens of caregiving.<sup>[15]</sup> The items are related to the changes that a caregiver faces in his/her everyday life and routine. Responses of all the items ranged from 1 (not at all) to 3 (very much). The instrument was developed and standardized for the Indian population and has been reported to have a good interrater reliability ( $k$  0.80) and satisfactory face validity in terms of the relevance of the items in measuring caregiver burden. The scale is composed

of nine domains: Spouse-related, physical and mental healths, external support, caregiver's routine, support of the patient, taking responsibility, other relations, patient's behavior, and caregiver's strategy. Four spouse-related questions were removed from the questionnaire as they were irrelevant to the study population. The total score of the adapted scale ranged 36–108. A score of 36 on the BASS indicated no burden, 72 indicated moderate burden, and 108 indicated extreme burden. Increasing scores indicated increasing levels of burden.

Apart from the caregiver burden, child and caregiver characteristics, caregiver knowledge regarding HIV/AIDS, and other child health care, nutrition, education, and psychological support-related issues were studied. With particular regard to caregiver characteristics, we examined the caregiver's gender, marital status, HIV status, education, occupation, income, and relationship with the child. Living setup of the child and his/her caregiver was also assessed. The questionnaire was translated in the local language (Hindi) and pretested.

### Statistical analysis

Data were analyzed by using the statistical package SPSS Statistics for Windows, Version 17.0 (Chicago, SPSS Inc.). For categorical and continuous variables, proportions and means, respectively, were calculated. The mean scores for various burden domains were calculated and the test of significance (*t*-test) was applied to find the association of burden with the caregiver's gender. Pearson correlation coefficient was reported to summarize the bivariate association for various burden factors. A *P* value of <0.05 was considered to be significant.

## Results

### Sociodemographic characteristics of the study population

A total of 156 caregivers were interviewed. Women accounted for over three-fourth (76.9%) of the caregivers. Caregivers had a mean age of 35.92 ( $\pm 10.18$ ) years, with most of them in the age range of 31-40 years. Nearly two-third of them (65.4%) reported as living with HIV. The mothers were caregivers for 72.4% of the children. For others, the father (16%), grandparents (3.2%), and other relatives were taking care. Approximately one-third of the caregivers were illiterate and the majority comprised homemakers. A majority of the caregivers had a monthly personal income of less than ₹5,000. Many of the caregivers were widows [Table 1].

### Perceived burden among caregivers

All the caregivers reported some or more burdens. The mean caregiver burden score was  $68.7 \pm 2.9$ . A majority

of them (82.1%) reported perceiving mild to moderate caregiving burden (low burden) and others (17.9%) reported moderate to severe burden (high burden) [Table 2].

**Table 1: Characteristics of caregivers of children living with HIV (*n* = 156)**

Characteristic	Frequency	Percentage (%)
Gender		
Female	120	76.9
Male	36	23.1
HIV-positive	102	65.4
Age (years)		
≤30	41	26.3
31-40	71	45.5
41-50	36	23.1
>50	8	5.1
Relationship with child		
Mother	113	72.4
Father	25	16.0
Grandparent	5	3.2
Other relation	13	8.3
Education		
Illiterate	49	31.4
Up to primary level	21	13.5
Up to middle school level	17	10.9
High school level	27	17.3
Intermediate	22	14.1
Graduate and above	20	12.8
Occupation		
Farmer	9	5.8
Driver	1	0.6
Homemaker	106	67.9
Domestic help	3	1.9
Self-employed/Professional	37	23.7
Personal income (₹)		
≤5,000	110	70.5
5,001-10,000	24	15.4
10,001-20,000	13	8.3
>20,000	9	5.8
Marital status		
Currently married	108	69.2
Widowed	46	29.5
Never married	2	1.3

**Table 2: Level of burden perceived by caregivers of children living with HIV (*n* = 156)**

Burden level	BASS score	Frequency	Percentage (%)
No burden	36	Nil	Nil
Mild to moderate burden	37-71	128	82.1
Moderate to severe burden	72-107	28	17.9
Extreme burden	108	Nil	Nil

Although there was some difference in the mean score burden among various categories, the caregiving burden did not significantly differ with the caregiver's gender, HIV status, marital status, education, occupation, income, living set up, and relationship with the child. Individual domain-standardized percentage scores indicated that the highest burden was in the domain of physical health and mental health (58.3) followed by external support (67.7), patients' behavior (74.5), and caregivers' strategy (72.5). Standardized percentage scores seemed to be comparatively less in the other domains such as support of the patient (21.1) and taking responsibility (23.8) [Table 3].

Nearly half of the caregivers did not receive any external support in caring for the children and many had not told about the HIV status of the child to their friends, relatives, and other family members.

Bidomain associations are summarized in Table 4. As expected, the caregiver burden was positively and significantly correlated to external support ( $r = 0.70$ ,  $P < 0.01$ ) and taking responsibility ( $r = 0.55$ ,  $P < 0.01$ ). Caregiver burden was also positively and significantly associated with physical health and mental health ( $r = 0.46$ ,  $P < 0.01$ ) and caregiver's strategies ( $r = 0.58$ ,  $P < 0.01$ ).

## Discussion

The present study assessed the perceived burden among caregivers of children living with HIV. The existing literature suggests that caregiving has tremendous adverse effects on the well-being of caregivers.<sup>[16,17]</sup> In the present study, a significant level of burden was perceived by all the caregivers. Over 17% of the caregivers in this study reported experiencing a moderate to severe burden.

The emotional stress on caregivers can be significant. The greater responsibility forces caregivers to stay emotionally and physically strong to support PLHA.<sup>[18]</sup> The demanding nature of caregiving for PLHA means that caregivers can face social isolation.<sup>[19]</sup> As in the present study, a few of the caregivers disclose the HIV status of the child to friends and relatives. This results in a lot of physical burden and mental stress but as HIV is associated with stigma and discrimination, nondisclosure acts as a safeguard against social rejection. In addition, HIV infection among the caregivers can put an additional strain on them. As almost two-third of the caregivers were infected with HIV in the present study, the stresses of declining health and the added burden of taking care of PLHA might contribute to psychological distress.

Contrary to other studies, we also found that the HIV status of the caregiver was not significantly associated

**Table 3: Sexwise distribution of caregivers by their perceived burden scores in various domains**

Factor	Domain score range		Mean score (SD)		
	(BASS)	(Reported)	Female	Male	Total
Physical health and mental health	7-21	8-15	11.7 (1.5)	11.8 (1.3)	11.8 (1.4)
External support	6-18	9-15	12.5 (1.2)	12.8 (1.6)	12.6 (1.3)
Caregiver's routine	4-12	7-11	8.4 (1.1)	8.6 (1.1)	8.5 (1.1)
Support of patient	4-12	7-10	8.1 (0.5)	8.2 (0.7)	8.1 (0.5)
Taking responsibility	4-12	7-12	9.0 (0.7)	9.0 (0.8)	9.0 (0.7)
Other relations	3-9	5-7	5.7 (0.4)	5.6 (0.4)	5.7 (0.4)
Patient's behavior	4-12	5-8	6.9 (0.6)	6.9 (0.6)	6.9 (0.6)
Caregiver's strategy	4-12	4-7	5.8 (0.4)	5.8 (0.6)	5.8 (0.5)
Total burden	36-108	61-75	68.5 (2.8)	69.1 (3.3)	68.7 (2.9)

**Table 4: Correlation among various domain scores of BASS**

Domains	1	2	3	4	5	6	7	8	9
Physical health and mental health	1								
External support	0.09	1							
Caregiver routine	0.03	-0.18*	1						
Support of patient	-0.16*	0.06	-0.16*	1					
Taking responsibility	-0.09	0.53**	-0.16*	0.09	1				
Other relations	0.28**	0.18*	0.13	-0.15	0.01	1			
Patient's behavior	-0.34**	-0.04	-0.09	0.08	0.14	-0.09	1		
Caregiver strategies	-0.05	0.54**	-0.02	0.11	0.55**	0.01	0.10	1	
Burden	0.46**	0.70**	0.22**	0.11	0.55**	0.40**	0.04	0.58**	1

\*Correlation is significant at the 0.05 level (2-tailed), \*\*Correlation is significant at the 0.01 level (2-tailed)



with caregiver burden as most of the caregivers perceived caring of the child as a routine practice.<sup>[20,21]</sup> A standardized percentage of individual domain scores indicates high burden in the domain of physical health and mental health. Though Indian families are very closely knit and perhaps the burden in external support domain is high as in most cases, the HIV status of the children was not disclosed to many by the caregivers. The mean burden score among female caregivers was similar to that of male caregivers.

As caring for children is a usual practice and is not perceived as burden by caregivers in Indian society, it is difficult to assess the burden in reality due to social desirability bias. Further, the persons coming to the hospital on the day of interview were defined as the caregivers but they may not have been the real caregivers. This is one of the early hospital based studies in India to assess the burden among caregivers of children living with HIV. Considering the limitations of present study, a large community based study is required to assess the burden among caregivers of CLHA on ground. Future HIV programs should take into account the caregiver's well-being while focusing on the well-being of CLHA.

## Conclusion

Caring the children is universal practice but care for children living with HIV results in significant burden for caregivers. A majority of the informal caregivers who were usually the HIV-infected mothers need to be assisted in caring for the child. Stigma and discrimination of those with HIV infection further increase the burden as caregivers did not disclose the HIV status to any near and dear one.

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## Conflicts of interest

There are no conflicts of interest.

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