

# Caregiver's Burden of Children Living with HIV on Antiretroviral Therapy at an Urban Setup

Shivangi Ashvinbhai Inamdar, JK Kosambiya<sup>1</sup>, Anjali Modi<sup>1</sup>

Department of Community Medicine, Medical College, Vadodara, <sup>1</sup>Department of Community Medicine, Government Medical College, Surat, Gujarat, India

## Abstract

**Context:** Availability of antiretroviral therapy (ART) has helped to decrease morbidity and increase the longevity of children living with Human Immunodeficiency Syndrome (CLHIV/CLHA). These children require the special involvement of family members for adherence to care and support programs. Long-term caregiving stress can result in physical, social, emotional, and medical consequences for both the caregiver and the CLHIV. This study explores the burden and needs for support among CLHIV caregivers. **Methods:** A cross-sectional study was conducted at an ART Centre of Tertiary level Health Care Institute among 126 caregivers of CLHIV pretested and piloted semi-structured questionnaire and Zarit Burden Interview Scale (ZBIS) were employed to assess study objectives. Descriptive statistics and caregiver burden scoring were calculated. ZBIS score of 22 and above were considered additional burden for caregivers. **Results:** Mean age of caregivers was  $34 \pm 7.15$  years. Among 126 CLHIV caregivers, 116 were female, while 110 had positive HIV serostatus. Ninety-seven percent disclosed their and the child's status to one or more family members. Mean caregiver ZBIS was  $25 \pm 7.08$  with 71.5% caregivers having mild-to-severe levels of burden. Around 85% of caregivers knew correctly about four routes of HIV transmission although 8.7% had misconception regarding HIV transmission. **Conclusions:** ZBIS assessment shows emotional, financial, and future of child-related burden among CLHIV caregivers. There were gaps in the knowledge about HIV transmission, care and support needs of the CLHIV. The acquisition of HIV from parents in CLHIV suggests the need of strengthening the prevention of parent-to-child transmission program in Indian settings.

**Keywords:** Caregiver's burden, children living with HIV, HIV

## INTRODUCTION

Globally, 1.8 million children are living with HIV (CLHIV).<sup>[1]</sup> Children (<15 years) account for 6.54% of HIV prevalence in India.<sup>[2]</sup> Existing research acknowledges that caregiving for CLHIV may be associated with physical, economic, and psychological stress along with social stigma and isolation.<sup>[3]</sup> This caregivers' burden may be responsible for care gaps, loss of uptake, and adherence of antiretroviral therapy (ART). The present study assesses the CLHIV caregivers' burden and needs of support in the Indian scenario where families are conventional social structures responsible for providing and caring during illnesses.

## METHODS

A cross-sectional study was conducted among 126 primary caregivers of CLHIV enrolled for care and support services at an ART center associated with a tertiary level health care institute in years 2016–2017.

Primary caregiver is, one who provides unpaid physical support such as helping in activities of daily living, shopping, food preparation, helping in administering medication, overseeing medical appointment, financial, and emotional support to people living with HIV/AIDS.<sup>[3]</sup>

The inclusion criteria were consenting adults taking care of a registered CLHIV, aged between 2 and 15 years, for 6 months or more. Primary caregivers of children who were on ART but transferred out, loss to follow-up, missed the doses of ART and died while on treatment were excluded from the study.

A pretested and semi-structured questionnaire was developed to collect information about the sociodemographic profile,

**Address for correspondence:** Dr. JK Kosambiya,  
A-6-B Poddar Residency, Canal Road, Surat - 395 007, Gujarat, India.  
E-mail: jkkosambiya@gmail.com

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sources of transmission, and caregiving burden of HIV-positive children. The Zarit Burden Interview Scale (ZBIS) was used along with the self-developed questionnaire for quantification of caregiver's burden ([https://dementiapathways.ie/\\_filecache/edd/c3c/89-zarit\\_burden\\_interview.pdf](https://dementiapathways.ie/_filecache/edd/c3c/89-zarit_burden_interview.pdf)). The study tools were piloted and validated before the data collection. The ZBIS is a multi-item (22 questions) five-point rated Likert-based scale designed to assess the subjective and objective burden of caregivers' in dementia or debilitating diseases. ZBIS five-point categories being never (0) points to nearly always (4) with the maximum score "88" and minimum score "0." The higher the score the greater the burden felt by the caregivers.

The Cronbach's alpha method was applied for estimating validation of Zarit scale in the present study. Cronbach's Alpha estimates the internal consistency of the items in a scale; or in simple language how accurately these multiple items/questions measure the concept or construct. Cronbach's alpha of the ZBIS in the present study was found to be 0.716.

According to Computer-based Management Information System data of the study center on, 245 children (0–15 years) were alive and on ART. Taking an allowable error of 30% due to lost to follow-up, missed, transferred out, death and nonresponse rate, 171 participants could be potentially recruited for the study. However, only 126 CLHIV were eligible according to the study inclusion criteria. The study was approved by the Human Research Ethics Committee of the institute. Written consent was taken from study participants and Unique ID was generated for each participant to maintain their confidentiality.

Data were entered in Microsoft Excel-sheet software 2016 and analyzed by the SPSS Inc. Released 2007. SPSS Windows, Version 16.0 Chicago, SPSS Inc. Measures of central tendency and variability were calculated.

Study variables were CLHIV caregiver's burden, sociodemographic characteristics, knowledge regarding HIV/AIDS, and HIV status disclosure. The primary outcome was assessing the caregiver's burden and knowledge about various routes of HIV transmission.

## RESULTS

A total of 126 caregivers were interviewed to complete the socio-demographics questionnaire and ZBIS details. The mean age of CLHIV was  $(9.42 \pm 3.49)$  years while the mean age of caregivers was  $34 \pm 7.15$  years with approximately 80% of caregivers  $\leq 40$  years of age. Ninety-two percent of CLHIV ( $n = 116$ ) were cared by their parents; mostly mothers ( $n = 109$ ). In the rest of the cases ( $n = 10$ ); seven and three were cared by female and male caregivers, respectively. Among 126 caregivers, 110 (87.3%) were having positive + HIV serostatus. Around 8% of caregivers did not get themselves tested for HIV as they are not parents and perceived themselves not at risk of having HIV. ZBIS mean scoring was  $25 \pm 7.08$  for the study participants. Three-fourth (71.5%) of

caregivers felt mild-to-severe level of burden while 96 (76.2%) worried about the child's future. Around 80% felt child dependency for daily routine activities; 40% felt financial burden; another 40% felt loss of control of their life, and 77% felt they could do more for the child [Table 1].

Out of 91 HIV-positive caregivers, 87 (96%) had disclosed their serostatus to some of the near relatives to avail help in caring of CLHIV. On the other hand; 107 (84.9%) caregivers had disclosed the HIV serostatus of CLHIV to others [Table 2]. Approximately 6% of caregivers had disclosed the child's status in school as some are getting scholarships from the school, 2.9% to their friends, and 1% to neighbors in fear of social rejection [Table 2]. Eighty-five percent of caregivers knew the first four causes (blood transfusion, mother- to child, sharing needles, and sexual contact) of HIV transmission; however, a quarter responded that they "Do not know" regarding other modes of transmission. Around 8.7% still had myths about HIV transmits by eating, hugging, and exposure to sneezing of HIV-positive individual. The remaining persons were counseled in detail about HIV transmission after the collection of data for the present study.

The majority of caregivers (93.7%) felt the need to get adequate knowledge from health care providers to provide appropriate care to the children. Approximately 80% and 90% required psychological or financial support while 34.1% required support from relatives and family members [Table 3].

## DISCUSSION

The present study observed that CLHIV were cared usually by their mothers. This finding was similar to the study done by Chauhan *et al.* and Lorenz *et al.* in India and Uganda, respectively.<sup>[4,5]</sup>

Out of the total 126 CLHIV study participants, 124 got vertical transmission of HIV infection through their parents and 17.5% were  $< 5$  years of age. These observations suggest the need of strengthening the cascade of prevention of parent-to-child transmission (PPTCT) of HIV program. Antenatal testing of all mothers at least once or if possible twice for HIV followed by adherence to ART and other care and support components of prevention programs is essential to eliminate new infections in newborns eliminate mother to child transmission. (EMTCT).<sup>[6]</sup>

In the present study, one-third of caregivers reported had no burden [Figure 1], though ZBIS shows emotional, financial, and future of the child-related worries [Table 1] which was similar to studies done by Asadullah *et al.*, Kidman and Thurman and Guo *et al.*<sup>[7-9]</sup> This may be because caring for own sick child is considered more as social responsibility in the Indian setting. HIV-associated social stigma and isolation may limit caregivers' willingness to seek assistance from formal agencies, for themselves or their families.<sup>[10]</sup> It was observed that caregivers had not disclosed positive serostatus and avoided seeking support from some relatives, friends, and neighbors. This acted

**Table 1: Distribution of caregivers burden according to Zarit burden interview scale categories (n=126)**

Question* (in relation to CLHIV's care only)	Never 0, n (%)	Rarely 1, n (%)	Sometimes 2, n (%)	Quite frequently 3, n (%)	Nearly always 4, n (%)
Child asks for more help	52 (41.3)	23 (18.2)	40 (31.8)	10 (7.9)	1 (0.8)
No time for self	95 (75.4)	9 (7.1)	16 (12.7)	5 (4)	1 (0.8)
Feeling stressed	49 (38.9)	15 (11.9)	42 (33.3)	17 (13.5)	3 (2.4)
Embarrassment	85 (67.5)	11 (8.7)	14 (11.1)	15 (11.9)	1 (0.8)
Anger	103 (81.8)	12 (9.4)	8 (6.4)	3 (2.4)	0
Relationship affected with others	112 (88.9)	3 (2.3)	5 (4)	6 (4.8)	0
Afraid about future	4 (3.2)	1 (0.8)	12 (9.5)	96 (76.2)	13 (10.3)
Dependency of the child on the caregiver	58 (46)	12 (9.6)	44 (34.9)	12 (9.5)	0
Feeling strained	109 (86.5)	8 (6.3)	6 (4.8)	3 (2.4)	0
Health suffered	96 (76.2)	7 (5.5)	18 (14.3)	5 (4)	0
No privacy	115 (91.3)	2 (1.6)	9 (7.1)	0	0
Social life suffered	100 (79.4)	10 (7.9)	10 (7.9)	6 (4.8)	0
Uncomfortable because of child	91 (72.2)	8 (6.3)	21 (16.7)	5 (4)	1 (0.8)
Expectations from caregiver only	11 (8.6)	7 (5.6)	100 (79.4)	7 (5.6)	1 (0.8)
Increased financial burden	16 (12.7)	8 (6.3)	31 (24.6)	55 (43.7)	16 (12.7)
Feels unable to care	109 (86.5)	1 (0.8)	13 (10.3)	3 (2.4)	0
Lost control life	38 (30.2)	5 (3.9)	30 (23.8)	51 (40.5)	2 (1.6)
Wished to have someone else to care	120 (95.2)	3 (2.4)	0	3 (2.4)	0
Uncertain about child	9 (7.1)	3 (2.4)	28 (22.2)	86 (68.3)	0
Feels can do more for child	0	0	5 (4)	106 (84.1)	15 (11.9)
Feels can do a better job at caring	0	0	4 (3.2)	99 (78.6)	23 (18.2)
Overall, burden of caring	121 (96)	5 (4)	0	0	0

\*The questions were asked to the caregiver in relation to what they felt while caring for the sick CLHIV. These questions were asked in detailed during the interview. Here for manuscript we have given short version of questions. CLHIV: Children living with HIV

**Table 2: Distribution of disclosure of serostatus of caregiver and child**

Categories	n (% cases)
Caregivers HIV serostatus (n=126)	
Positive	110 (87.3)
Negative	6 (4.8)
Not tested	10 (7.9)
Child's HIV serostatus disclosed or not (n=126)	
Yes	107 (84.9)
No	19 (15.1)
Disclosure caregiver's sero-status (n=91)*	
Family members	87 (96.7)
Relatives	64 (71.1)
Friends	4 (4.4)
Neighbors	1 (1.1)
Disclosure child's serostatus (n=107)*	
Family members	102 (97.1)
Relatives	68 (64.8)
Friends	3 (2.9)
Neighbors	1 (1)
School	6 (5.7)

\*Multiple options of disclosure were possible

as additional stress factor. Similar finding was observed in a study done by Madi *et al.*<sup>[11]</sup> and Grafström and Petersson.<sup>[12]</sup>

Around 15% of caregivers and 8.7% had misconceptions about HIV transmission and prevention of HIV infection. This is in

direct contrast to the findings that the majority of caregivers were positive for HIV and also caring for CLHIV more than 6 months. This was found in the study done by Meena *et al.*<sup>[13]</sup>

Based on the study findings, we recommend that the counseled be counseled about routes of transmission, care and support needs of CLHIV. There were few limitations of the present study. As the study was conducted at one urban setup generalizability to other setups, requires caution. Burden of caregivers who were lost to follow-up could not be assessed.

## CONCLUSION

Caregivers of CLHIV had emotional, financial, and future of child-related burden. There were gaps in the knowledge about HIV transmission and care and support needs of the CLHIV. Acquisition of HIV status from parents also suggests the importance of strengthening the PPTCT program in Indian settings.

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**Table 3: Need of support felt by the caregivers (n=126)**

Categories: Types of support	Yes, n (%)	No, n (%)
Knowledge about giving care to persons with HIV/AIDS	118 (93.7)	8 (6.3)
Psychological support to cope with the situation	103 (81.7)	23 (18.3)
Communication support	27 (21.4)	99 (78.6)
Religious/spiritual support	41 (32.5)	85 (67.5)
Social support	21 (16.7)	105 (83.3)
Economic support	113 (89.7)	13 (10.3)
Support from relatives	43 (34.1)	1 (65.9)

### Conflicts of interest

There are no conflicts of interest.

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