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# Impact of HIV/AIDS on HIV positive children at individual and family level: an institution-based cross-sectional study in Eastern India

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**Abstract:** *Background:* HIV infected children constitute a huge number. These children suffered from adverse consequences of HIV/AIDS. *Objectives:* In this context this study was conducted to elicit the impact of the disease on HIV positive children at individual and family level. *Methods:* This cross-sectional study was conducted at Paediatric Centre of Excellence in HIV Care, Kolkata among 202 HIV positive children. Data collection was done for a period of one year. Relevant information was collected by interview method and from Treatment cards of the HIV positive children. *Results:* Majority of the caregivers were mothers (64.6%).Two-third of the children (64.6%) belonged to upper lower or lower socio-economic class. About 29.2% of the children were thin while 36.6% were stunted. About two-third of the children were afflicted by one or more comorbidities. Both parents were HIV positive among129(67.2%) of the children. 36.9% HIV positive fathers had to change their job and 7.8% lost their jobs while 9.2% HIV positive mothers changed their jobs and 31.4% mothers had to work for a living. One-fifth of the children were AIDS orphans, while 27.6% lost their father due to AIDS. Most of the families reported decreased family income and increased expenditure (94.3% and 96.4% respectively) due to HIV/AIDS. School drop-outs were 14.0%. Discrimination experienced from family members (12.7%), neighbours (22.4%), school (29.2%) as well as health care workers (HCWs) (13.0%). *Conclusion:* HIV/AIDS children are in dire need of support, empathy and high quality health care.

**Keywords:** Impact of HIV/AIDS, Children, Social discrimination

## Introduction

Since its first detection, HIV/AIDS has spread over many countries infecting millions of people. HIV/AIDS is a major global threat today. In 2017 there were 36.9 million people living with HIV/ AIDS (PLHA) [1]. In the same year, 1.8 million people were newly infected with HIV; among them children (<15 years of age) were estimated at 1.8 lacs [1]. This incurable disease has a huge annual death toll (9.4 lacs in 2017) out of which 1.1 lacs were children [1]. The disease too has affected a substantial population of India. In 2015 there were 2.1 million PLHA in India; among them 6.5% were children [2]. The prevalence among adult population was .2% in 2017 with annual new infection in 88,000 population out of which 3700 were children [3]. The annual death toll in 2017 was 69000, among them 2600 were children [3].

The children living with HIV/AIDS go through multiple challenges and hardships. The impact of HIV/AIDS on children can be divided into three main areas-psycho-emotional impact, social impact and material impact.[4]Possibly the most important and the harshest direct consequence of AIDS for children is the loss of their family unit, particularly one or both parents, and with it their natural economic, social and emotional 'safety net'[4]. AIDS orphans are those children who have lost their mothers or both parents to AIDS before reaching the age of 15 years [5]. Globally the estimated AIDS orphans (0-17 years) were 12.2 millions in 2017 out of which were 9.3 lacs were Indian children [3]. Children living in India who lose parents to AIDS face terrible hardships [6]. Parental illness and death trigger

 

psychological distress to the children [7]. They are often forced to fend for themselves or take the responsibilities of siblings and/or ailing parents [7-8]. Some AIDS orphans are adopted by grandparents or other extended family-members, but many are left without any care or support.

Stigma and discrimination towards this disease and the diseased persons are still prevailing widely in the community despite efforts to reduce this social evil. These are caused by ignorance and fear of AIDS in the community and their moralistic and often judgmental views community members have about AIDS - equalling 'bad' with HIV-positive and 'good' with HIV-negative [4]. As a consequence of losing the family unit, as well as of stigma and discrimination, children end up having less access to education, health care and social services [4, 8]. HIV/AIDS results in an emergence of growing number of helpless children facing orphan hood, physical and sexual abuse, psycho-social distress, poverty, malnutrition and other diseases and above all stigmatization and discrimination [6-12].

Very few studies have been done on impact of HIV/AIDS on children especially in this region of our country. With this backdrop this study was designed and conducted to elicit the impact of HIV/AIDS on HIV positive children at individual and family level.

## Material and Methods

This was an institution-based cross-sectional study. It was conducted at Paediatric Centre of Excellence in HIV Care, Medical College and Hospital, Kolkata. This centre caters to patients hailing mostly from districts of South-Bengal, though there is no geographical demarcation for service for this centre. Study duration was one year (1st Nov 2016 - 31st Oct 2017).

*Inclusion Criteria:* HIV positive children (upto 14 years of age) of the above centre(new as well as follow-up patients) were included in the study.

*Exclusion Criteria:*

1. Those HIV positive children whose caregivers refused to give informed consent for the study.
2. Children who were brought by NGOs/ CBOs (As caregivers could not provide adequate information on the children they accompanied.)

Convenience sampling technique was adopted for the study. The patients availed services for six days a week in this centre. Any two days a week were selected for data collection. All children attending the clinic on those 2 days were included in the study, leaving out those who were incorporated in the exclusion criteria. During the one year period, 268 children were approached.

Applying exclusion criteria, 66 children were excluded from the study (refused to give consent=30, brought by NGO/CBO =36). At the end, 202 children were selected for this study. Interview was conducted on 192 caregivers i.e.10 caregivers brought two children each. Data was collected from the caregivers with the help of a pre-designed pre-tested structured schedule. Relevant secondary data from treatment cards of the children were also recorded.

*Ethical Clearance:* At the outset approval from Institutional Ethics Committees of Medical College & Hospital, Kolkata was obtained for this study. Informed consent was taken from the caregivers. During this process the caregivers were explained about the purpose of the study, about the right to refuse to participate in the study and also that in spite of refusing to join the study they would continue to receive the standard medical care from the centre. They were also assured about the anonymity and confidentiality of the information provided by them. There was no incentive for participation in the study.

*Statistical Analysis:* Data was entered in Excel spreadsheet and analysed using SPSS software (Version16.0).

## Results

Majority of the caregivers were mothers (64.6%); rest were close relatives or others. There was high prevalence of illiteracy among the caregivers (31.3%). Very few caregivers (1% only) had higher education i.e. graduation or above. Majority of the children (64.6%)

belonged to upper lower or lower Socio-economic class. The most common occupation of fathers were migrant workers (40.6%) while majority of mothers (61.0%) were home makers. The most common mode of transmission of the disease was mother-to-child (MTCT) (91.6%). More than half of the children were diagnosed with the disease by the time they were 5 years of age. Regarding the parents, 83.3% of fathers, 91.1% of mothers and 67.2% of both parents were HIV positive (Table 1).

**Table-1: Distribution of study subjects according to socio-demographic and medical characteristics (n=202)**

| Characteristics | | Frequency (%) |
|---|---|---|
| Gender | Male | 115(57.0) |
| | Female | 87(43.0) |
| Religion | Hindu | 155(76.7) |
| | Muslim | 47(23.3) |
| Age (Yrs) | <1 | 7(3.6) |
| | 1—5 | 34(16.8) |
| | 5—10 | 91(45) |
| | 10--14 | 70(34.6) |
| Primary caregivers | Mother | 124(64.6) |
| | Father | 36(18.8) |
| | Extended family members | 25(13.0) |
| | Others* | 07(3.6) |
| Education level of primary caregivers | Illiterate | 60(31.3) |
| | Below primary | 17(8.9) |
| | Primary completed | 54(28.1) |
| | Middle level | 30(15.6) |
| | Secondary level | 21(10.9) |
| | Higher secondary level | 8(4.2) |
| | Graduate or above | 2(1) |
| Socio-economic status (modified BG Prasad Scale 2017) | Upper class | 3(1.6) |
| | Upper middle class | 20(10.4) |
| | Lower middle class | 45(23.4) |
| | Upper lower class | 67(34.9) |
| | Lower class | 57(29.7) |
| Occupation of the parents** | **Of father** | |
| | Migrant worker | 78(40.6) |
| | Driver | 15(7.8) |
| | Service | 15(7.8) |
| | Business | 35(18.2) |
| | Labourers | 7(3.6) |
| | Others | 42(21.9) |
| | **Of mother** | |
| | Home maker | 169(61.0) |
| | Working(other than CSW) | 20(37.4) |
| | CSW | 3(1.6) |
| MTCT Prophylaxis measures | ARV medicine to mother and/or child | 10(5.4) |
| | Withheld breastfeeding | 10(5.4) |
| | Caesarean section delivery*** | 4(2.2) |
| | Any one measure taken | 14(7.6) |
| | No measures taken | 171(92.4) |
| Mode of transmission | Mother to child | 185(91.6) |
| | Blood transfusion | 12(5.9) |
| | Unknown/Probable unsafe injection | 5(2.4) |
| Age at diagnosis (Years) | <1.5 | 22(10.8) |
| | 1.5-5 | 84(41.6) |
| | 5-9 | 66(32.7) |
| | 9-14 | 30(14.9) |
| HIV +ve members in the family# n=192 | Father | 160(83.3) |
| | Mother | 175(91.1) |
| | Both parents | 129(67.2) |
| | Siblings | 29/80(36.2) |

# multiple response ,* Others include step-mother, foster-mother and mausi of CSW
**At the time of diagnosis of HIV infection in the child,
***though 33 children was born by Caesarean section delivery, only in 4 cases it was done as a prophylactic measure

At individual level, half of the children were immunosuppressed (CD4 Cell <25%). Regarding nutritional status, 29.2% children were thin and 36.6% were stunted. About 66.3% of the study subjects suffered from one or more comorbidities (Table 2). As a consequence of this disease, 36.9% HIV positive fathers had to change their job and another 7.8% lost job while 9.2% HIV positive mothers changed their job and 31.4% mothers were forced to work for a living. One-fifth of the children were AIDS orphans, while 27.6% lost their father to this disease.

In most of the families decreased family income and increased expenditure were found (94.3% and 96.4% respectively) following diagnosis of HIV/AIDS in the family. School drop-outs were among 14.0% of the children. Among those disclosed, the study subjects experienced discrimination from family members (12.7%), neighbours (22.4%), school (29.2%) as well as health care workers (HCWs)(13.0%) (Table 3).

**Table-2: Distribution of study subjects according to adverse effects of HIV/AIDS at Individual level. n=202**

| Characteristics | | Frequency (%) |
|---|---|---|
| Immunological status (CD4 Cell %) | =>25(No suppression) | 102(50.5) |
| | 15-24(Moderate Suppression) | 69(34.2) |
| | <15(Severe Suppression) | 31(15.3) |
| Nutritional status | **BMI-for-Age (Z score)** | |
| | Normal(+2 to -2) | 143(70.8) |
| | Thin(< -2 to -3) | 38(18.8) |
| | Severely thin(< -3) | 21(10.4) |
| | **Height-for-Age (Z score)** | |
| | Normal (+2 to -2) | 128(63.4) |
| | Stunted (< -2 to -3) | 55(27.2) |
| | Severely stunted (< -3) | 19(9.4) |
| Morbidity* | **HIV-TB coinfection**** | 39(19.3) |
| | Fever | 22(10.9) |
| | Cough | 29(14.4) |
| | Fever with cough | 29(14.4) |
| | Diarrhoea | 8(4.0) |
| | Scabies | 17(8.4) |
| | Others | 58(28.7) |
| | Any morbidity*** | 134(66.3) |
| School drop-outs status n=178 | Drop outs | 25(14.0) |
| | Continuing school | 153(86.0) |

*Multiple response; duration considered- last two weeks except TB
** 6 children on ATD, others had TB the in past since diagnosis of HIV infection
*** includes 6 children on ATD

**Table-3: Distribution of study subjects according to impact of HIV/AIDS at Family level**

| Impact of HIV/AIDS | | Frequency (%) |
|---|---|---|
| Death in the family due to HIV infection. n=192 | Father | 53(27.6) |
| | Mother | 31(16.1) |
| | Both parents | 7(3.6) |
| | Any member of family | 81(42.2) |
| Adverse consequences on occupation of parents | **HIV positive father** ( n=160) | |
| | Occupation changed | 59(36.9) |
| | Incapacitated to work | 10(7.8) |
| | No change of occupation | 91(56.9) |
| | **HIV positive mother** (n=175) | |
| | Occupation changed | 16(9.2) |
| | Forced to a living | 55(31.4) |
| | No change of occupation | 104(59.4) |
| Decreased family income due to HIV/AIDS. n=192 | Yes | 181(94.3) |
| | No | 11(5.7) |
| Increased family expenditure due to HIV/AIDS. n=192 | Yes | 185(96.4) |
| | No | 07(3.6) |
| Experience of discrimination following disclosure of HIV status | Family members | 20/157(12.7) |
| | Neighbours | 13/58(22.4) |
| | At school | 7/24(29.2) |
| | Health personnel | 6/46(13.0) |

## Discussion

Several adverse effects due to HIV infection among the children in this study were noted:

*Nutritional status:* At individual level,29.2% children were thin and 36.6% were stunted compared to 19.5% and 59.7% respectively as reported by a study from Hyderabad [13]. Another study from Gwalior found stunting among 76.2% under five HIV positive children and 60.1% among 6-18 years age-group while thinness was found in 20.6% of the older age-group children [14].

*Adverse consequences on occupation of parents:* At family level, this study shows 36.9% HIV positive fathers had to change their job, another 7.8% lost job due to this disease while 9.2% HIV positive mothers changed their job and 31.4% mothers were forced to work for a living following this disease. Compared to the above, another study from Kolkata reported 62.5% and 28.5% job loss for indoor and new HIV positive patients respectively [15].

*Death in the family due to HIV infection:* In the present study 19.7% children were AIDS orphans, while 27.6% lost their father. In comparison to the above finding another study from Zimbabwe reported 41.1% HIV positive children as AIDS orphans while a study from China found 15.0% of these children lost one parent 16-17]. In most of the families of HIV positive children decreased family income and increased expenditure were found in this study--the study from Kolkata echoed the same [15].

*School drop-outs status:* In the current study 14.0% school drop-outs were found compared to around 20% in the above mentioned study from Kolkata while another study from Karnataka reported only 74% children were attending school [15, 18].

*Experience of discrimination following disclosure of HIV status:* There were stigma and discrimination towards HIV positive children and their family members in the present study. In a study from Karnataka, 30.4% of family members expressed opposition, fear and shunning of the affected person as compared to 12.7% in the present study [18]. In consistent with the above findings, considerable stigma and discrimination from neighbours, community members even by family members were also reported by other studies [19-20]. Health care workers were not exceptional in this regard. In the present study 13% of HCWs showed discrimination towards HIV positive children. Widely prevalent stigma and discriminatory practices among HCWs towards PLWHA were reported by a study in Bangladesh [21], while other such studies from India also supported the above findings [22-23].

The study is not without its limitations. The sampling method should have been more robust, children from NGO/CBO should have been included and analysis for the predictors of each of the different impacts should have been done. This study among children in a AIDS Centre of Excellence in Eastern Region gives the impetus to researchers for further in-depth research work with longitudinal study design and a larger sample size on the pathetic condition of children with HIV/AIDS and its hazardous consequences.

## Conclusion

Thus this study supported by many other studies confirm the happening of some very unfortunate and adverse sequelae following the occurrence of the disease in a family with special reference to the little children who have a whole life time in front of them. However, the magnitude and types of after-effects may in different studies vary according to the differentials identified regarding the awareness of the community, health infrastructure and social support system etc.

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