International Journal of Multidisciplinary Research and Development
Online ISSN: 2349-4182 Print ISSN: 2349-5979
www.allsubjectjournal.com
Volume 2; Issue 11; November 2015; Page No. 343-346

Children affected by HIV/AIDS are at vulnerable due to caregiving activities to their HIV-infected family members--findings from cross-sectional study in Tamilnadu, India

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Abstract
Background: Estimates indicate that affected children are fifty times the number of infected children. These affected (not infected) children were under noticed by the policies in HIV related interventions even though they take more responsibility to take care of their infected family members. Methodology: Cross-sectional descriptive study was conducted with Children Affected by HIV/AIDS in 2014-15. Multistage sampling methodology was adopted to select the respondents. 205 children affected by HIV /AIDS between the age group of 12 to 17 were interviewed in selected two districts (Coimbatore and Salem) in Tamilnadu. Bharathiyar university doctoral committee has approved the study and written consent from parents/guardians and assent from the child were obtained. A semi-structured interview schedule was used to collect the information on children caregiving responsibilities and its related issues. Both descriptive and association analysis were carried out. Results: Mean age of the respondent children is 14.5 years (SD: 1.59) and 53.9% female children and 58.75 living in rural; Overall 59% of the children perform caregiving activities to the infected family members and siblings; 42% of the children perform both caregiving and household activities. More (give the proportion) male children engaged in caregiving activities and more (give the proportion) female children engaged in household activities ($P<0.05$). Children who performed care giving activities missed food in the last 7 days, had illness in the past 30 days and missed schools in the last 30 days significantly more when compare with those not involved in care giving activities($p<0.05$). Conclusions: Affected children engaged in care giving activities were vulnerable and often missed food, got illness and missed for school. Special focus needs to be given for the childen who provides care to the infected family members.

Keywords: Children affected by HIV, Tamil Nadu, caregiving, vulnerable

Introduction

The number of people living with HIV/AIDS in India is estimated to be 2.0 - 3.1 million, giving a national adult prevalence of 0.36 percent. According to national estimates, women account for almost 39 percent of all HIV infections. It is estimated that 70,000 children below the age of 15 are infected with HIV in India and 21,000 children are infected every year through mother to child transmission [1,2]. However, these figures do not reveal that the number of children affected by HIV/AIDS is far larger than those infected. For every child who is infected, there are apparently another fifty who are affected – have an HIV positive parent or have been orphaned by AIDS [3]. Some of the HIV high prevalence states in India such as Karnataka, Tamil Nadu, Andhra Pradesh, Maharashtra, Manipur and Nagaland are grappling with increased numbers of children infected and affected by HIV and AIDS. There are a large number of children who are often left to fend for themselves in this context. They first lose one, or both, parent(s) to the illness and are later confused due to their stigmatization. In paradigmatic cases, these children, considered single orphans, live with their widowed mother after having lost their father to the infection. These children are forced to give up their property rights after the death of their father and sometimes their education in order to care for their ailing mother and siblings. An alarming consequence of this is a child-headed household where "the very young end up looking after the very old" [3]. These children are also undertaking time-consuming medical care and domestic tasks, with high burden in AIDS-sick households [4]. A number of social factors determine children's ability to cope with these responsibilities, including the caregiving children's access to nutritious food, social and emotional support, assistance from community health workers, and adequate healthcare knowledge. [5]. This research focused on the intensity of care giving responsibility of the HIV/AIDS Affected children and its influence over their physical health and academic performance.

Materials and Methods

A cross-sectional study conducted among Children Affected by HIV/AIDS. Multistage sampling methodology was adopted to select the respondents. At the first stage, two districts were selected by convenient sampling and at the second stage, respondents were selected using simple random methodology. Districts were placed in ascending order based on HIV population (PLHIV registered in ART center) and selected two districts (Coimbatore and Salem) using convenient selection. List of PLHIV registered with PLHIV networks was collected and screened based on the in inclusion criteria and finalised the sampling frame. Major inclusion criteria for the study is "Children living with HIV-infected father and/or mother and /or siblings" that were considered at the first level of screening to finalise the sampling frame of the study. Both male and female

children, who are between the age of 12 to 18 years, residing in Tamil Nadu, and living with a HIV-infected father and/or mother were included in the study. Major exclusion Criteria was HIV/AIDS affected children's living with grandparents/relatives without infected members and HIV/AIDS affected children's living in residential care homes, orphanages and hostels. Respondents were approached with the help of Outreach worker of the PLHIV networks and written informed consent was obtained from the parent or guardian and written assent was obtained from the respondents (children).

Children school going rate (86.9%) [6]. was used to calculate sample size with precision of 5% with 95% CI. 205 respondents were interviewed using semi-structured interview schedule. The study tool has two parts. First part of the tool is on socio-economic conditions that were administered with the parent of the child as it has some questions related to HIV status. The second part of the tools was administered with the children. The second part of the tool consists of five (5) sections such as physical health, mental well-being, academic performance, involvement in work outside home, household chores and caregiving. Tool was pre-tested with the respondents and validated and ensured the flow of the interview schedule before collecting the data. Data was collected during the month of December 2014-February 2015.

Researcher used Statistical Package for Social Science (SPSS) 20 for the statistical analysis of univariate (distribution and summary statistics) and bivariate (t-test for continuous variables and chi-square test for categorical variables).

Findings/results

Socio-demographic status of the respondent: Table-1: Mean age of the children is14.63 (sd:1.6). 53.7% are Female Children, and the remaining 46.3% are male children. 93.2% of the children' mother alive and only 51.7% of the children' father alive. 58% of the children from Village/rural and 42% are from Urban/town. The respondents' family living in the same place around 16 years (median year). 100 (49%) are living with both father and mother and 91 (44%) are living with mother only and 6 living with father only (3%) and 8 (4%) living with infected siblings. In terms of education, 3.9% of the children studied upto primary, 34.6% studied middle school, 49.3% studied high school and senior secondary school, 7.8% studied diploma/certificate and 4.4% studied graduate and above. In terms of occupation, 88.3% are school going are studying, 5.9% are daily wage earner, 2.9% working in private company and 2.9% are staying at home or involved in small agricultural works.

Table1: Socio demographic details

Variable		N	Percentage
Gender			
	Male	95	46.3
	Female	110	53.7
Type of living place			
	Rural/village	119	58.0
	Urban/Town	86	42.0
Parents	Mother Alive	191	93.2
	Father Alive	106	51.7
Education			
	Primary school(upto 5th standard)	8	3.9
	Middle school(6-8th standard) to	71	34.6
	Higher secondary (9-12th std)	101	49.3
	Diploma/certificate	16	7.8
	Graduate and above	9	4.4
Occupation	Private company employee	6	2.9
	Daily wage earner	12	5.9
	Agriculture	1	0.5
	Unemployed/at home	5	2.4
	Student	181	88.3
Number of family members in the family(except child)	One	50	24.4
	Two	85	41.5
	Three	55	26.8
	Four and above	15	7.3
HIV infected family members in the family	One infected family member	126	61.5
	Two infected family member	74	36.1
	Three infected family member	5	2.4
Families with Positive members			
	Parents positive	193	94.1
	Siblings	12	5.9
ART taking HIV members in the family			
	Yes	188	91.7
	No	17	8.3

41.5% of the children living with the family where two family members in addition to the respondent child, 34.1% with 3 and above family members and 24.4% with only one member. In terms of HIV situation in the family, 61.5% of the respondent

living with only one HIV Infected members in the family whereas 34.6% living with two infected family members and 2.4% with three infected family members. Of the infected family members, only 5.9% are siblings and the remaining 94.1% are parents. Among those infected family members, 91.7% are taking Anti-Retroviral therapy treatment (ART) for their disease.

Caregiving activities of children

Table-2: 60.5% the children performed caregiving activities to their ill parents or siblings. Among those performing care giving activities, they spent almost an hour per day for care giving activities (Number of hours spent on caregiving in the past 7 days: 5.5 median hours spent on care giving activities in the last 7days(Mean-7.0 hrs, sd:6.2).Sometimes, children need to spend more 2 days in a week for care giving activities depends upon the care giving activities and the situation of parents/siblings illness (maximum 48 hrs and minimum 1 hrs in a week).Among those who perform care giving activities, 56.5% were supporting adherence to medication as they were engaged in giving medicines on time to ill person; 46.8% were feeding the ill person/s; 48.4% were taking/accompanying the ill parents/siblings to hospital;13.7% were engaged in cleaning bedsores/bed of ill person /helping ill parents or siblings to take bath (4% were also engaged in cleaning bedsores/bed of ill person; 12.1% were also helping the ill parents/ siblings to take bath/bathing).

Table-2: Care giving activities

Variable		n	Percentage
Care giving activities			
	Yes	124	60.5
	No	81	39.5
Median hours spent on care giving in the last 7 days		124	5.5
Types of care giving activities	Giving medicines on time to ill person	70	56.5
	Feeding the ill person/s	58	46.8
	Taking/accompanying them to hospital	60	48.4
	Cleaning bedsores/bed of ill person	5	4
	Helping the ill person/s to take bath/bathing	15	12.1

Table 3: Care giving activities across demographic groups

Variable		N	Caregiving(Yes)	P value
Total		205	60.55	
Sex				
	Male	68	54.8	<0.01
	Female	56	45.2	
Working				
	Yes	20	16.1	0.001
	No	104	83.9	
Missed food in last 7 days	Yes	38	76.3%	<0.05
	No	167	56.4%	
Illness in the last 30 days	Yes	33	78.8%	0.014
	No	172	57.0%	
Missed schools in last 30 days	Yes	35	88.6%	
	No	153	52.3%	0.000

Physical health: 18.5% of the children missed having food atleast once in the last 7 days. Reason for missing food was mainly parent/s was too sick to cook (24.2%); sick (18.4%), loss of appetite (18.4%) and family did not have enough money to buy food (5.3%). In the past 30 days, 16.1% of children also had illness such as fever (n=27); diarrhoea, injuries allergy and cold (n=4) and stomach pain (n=2).

School performance: 8.3% were dropped out of school and the reason was poor grades (23.5%); household chores as thier parents are sick (6%); I had to take care of my sick parents/siblings as my parents are ill(6%),unable to pay fees/buy note books/uniforms (11.8%), had to support my family financially by working (70.6%); Among school going, 4.3% were repeated class (failed) and of those failed, 75% (6) were failed due to poor grades and 25% (2) failed due to missed promotional examinations. Among school going, 18.7% of the children missed schools in the past 30 days and the reason for missed schools were household chores as their parents were sick (42.9%), caregiving to their sick parents/siblings (20%) and not feeling well/fever (31%). Children were self-rated their performance as poor/average (19.1%) and good/very good (80.9%).

Work for money: 10.7% of the children were engaged either part time or full time job and reasons for were support their family income as their parents are sick (72.7%) and not interested to study (27.3%)

Association between care giving activities with socio-demographic status of the children

Socio-demographic variables (sex, working status, type of place where they live), physical health variables (illness, missed food) and school variables (education, school going status, missed schools) were analysed to see the association with care giving activities. Male children were involved more in care giving activities when compare with female. Children who performed care giving activities missed food in the last 7 days, had illness in the past 30 days and missed schools in the last 30

days significantly more when compare with those not involved in care giving activities.

Discussion and conclusion

This study attempted to describe the psychosocial issues of children affected by HIV/AIDS especially living with the PLHIV parents and or siblings in Tamilnadu. The majority of the affected children were female and living in rural areas. Their families are living in the same place for quite a long time (around 16 years). Nearly half of them are living with infected parents (both infected mother and father) and almost half of them living with the infected mothers. Around 4% of the children were living with only infected siblings. Around 89% of the children were also school going and doing care giving activities. Around 40% of the affected children are living in the family where more than one infected family members (parents and or siblings) living. Most of their family members were on Antiretroviral treatment (ART) for HIV.

The study indicates that majority of the children living with HIV-infected family members are involved in care giving activities and household activities as full time or part time in addition to their routine children school and social life. They take care of both infected parents and infected siblings. More male children were engaged in care giving activities when compared to female children whereas more female children were engaged in household activities when compared to the male children. A significant difference was observed between children living in rural and urban as well.

The majority of the children were engaged in care giving activities and most of them were supporting their infected family members for taking medicines on time, taking/accompanying to hospitals. The study data revealed that there is an association between care giving and missing food and getting illness. Some of the children were also engaged in cleaning bedsores/bed of ill person which is putting the children in high-risk situation to get ill if they are not following the universal precautions.

Impact on education of female children in HIV households, the study points out that due to limited resources, the girls are more likely to be withdrawn from schools than boys as they are expected to take care of their younger siblings and household chores [7]. Moreover study findings revealed that children involved in caregiving activities missed school which may reduce their academic performance. All children bereaved and mentioned that it is quite stressful to care for adults who would be caring for them instead. Children are helpless and need psychosocial support /guidance from adults [5].

The main responsibilities of the children caring for parents on ART were intimate care and nursing, household duties, and income-generating activities. A number of social factors determine children's ability to cope with these responsibilities, including the care giving children's access to nutritious food, social and emotional support, assistance from community health workers, and adequate healthcare knowledge. The level and consequences of the children's care giving activities as well as their ability to cope were heavily influenced by: 1) the dynamics of their parent's health condition while on antiretroviral (ARV) medication, and 2) the context in which the child sought social and economic resources. There is an urgent need for education on home-based care services to look holistically at people's needs and resources at the household level, and, in particular, to consider the hardships and coping strategies of children who live with a parent on ART [8, 9]. Study also has some limitation as it didn't collect information on whether children follow any precautionary measures while involved in cleaning bedsores/bed and helping them to take bath. In-depth study on this aspects may provide more light on this or children involved in care giving activities need to be educated on universal precautions. Study also didn't attempt to know the HIV knowledge of the children as some of the children may not know the parents/siblings HIV status. Special study on this also would light more on this and provide strategies. Even though the definition o f children affected by HIV/AIDS include non-infected children, under prioritization for services, large numbers of children who are not affected less focused and can also be ignored [10]. Thus this study insists on focus on affected children especially who involved in caregiving activities to reduce the vulnerability and access services in par with normal children.

Acknowledgement

I am grateful to Bharathiyar University and Bishop Appasamy Arts & Science College for providing opportunity to carry out project under PhD course. I thank very much to the Doctoral committee of Bharathiyar University, Department of social work for the guidance and approval of the study. I sincerely thank my Phd guide Ms. Estar Rani for her continuous tireless guidance and support on this. I also thank my working organization India HIV/AIDS Alliance for supporting me to carry out this study. I also thank the Salem positive network and Coimbatore positive network and their staff who supported me on data collection. My sincere thanks go to the respondents (parents and children) for their participation in the study. I also thank my friends and family members for their continuous support and motivation to complete this study.

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