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Quality of life (QOL) and caregiving responsibilities of children affected by HIV and AIDS (CAA) in Tamil Nadu, India

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Abstract
Estimates indicate that HIV affected children are fifty times the number of infected children. These affected (not infected) children are 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 and AIDS between the age group of 12 to 17 were interviewed in selected two districts (Coimbatore and Salem) in Tamilnadu. 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. Pediatric Quality of Life Inventory™ (PedsQL™) tool were used to assess the quality of life. Both descriptive and association analysis including Analysis of variance (ANOVA) were carried out. Results: Mean age of the respondent children was 14.5 (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 male children engaged in specific caregiving activities and more female children engaged in household activities ($P<0.05$). Quality of life of children (Physical health, Emotional health, peer relationships and school performance) who perform caregiving activities is lesser than those does not perform ($P<0.05$). Conclusions: Quality of life (QOL) of children living in HIV infected families are affected due to early caregiving and household activities. Need prioritization of policy and programmes towards.

Keywords: Children affected by HIV, Tamil Nadu, caregiving, quality of life.

Introduction
The number of people living with HIV/AIDS (PLHIV) 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. Orphaned 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]. Younger children were more likely to be engaged in routine activities spend more time in caregiving [4]. 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. [4]**.** This research focused to study on the intensity of caregiving responsibility of the HIV/AIDS Affected children and its influence over their quality of life includes physical health, emotional status, peer relations and school performance.

Methods
A cross-sectional study conducted among Children Affected by HIV/AIDS. Multistage sampling methodology was adopted to select the respondents. At first stage, two districts were selected by convenient sampling and at second stage, respondents were selected using simple random methodology. Districts were placed in ascending order based on HIV population [PLHIV registered in antiretroviral therapy **(**ART) center] and selected two districts (Coimbatore and Salem). List of PLHIV registered with PLHIV networks (Salem Positive network and Coimbatore positive network) in selected district was collected and screened

based on the in inclusion criteria and finalised the sampling frame.

Study setting
Study was conducted in Tamilnadu (Coimbatore and Salem). Data were collected during the month of December 2014-February 2015. HIV positive networks (Salem Positive network in Salem district and Coimbatore positive network in Coimbatore) in the selected districts were involved in study to select the respondents and get consent from the respondents.

Sample size
205 children affected by HIV/AIDS were interviewed. Both male and female children were included in the study. Children' school going rate (86.9%) [5] Was used to calculate sample size with precision of 5% with 95% CI.

Study tool
Semi-structured interview schedule was used for data collection. 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 seven sections such as physical health, mental well-being, academic performance, involvement in work outside home, household chores, caregiving, and quality of life using Pedsqol [10]. Tool was pre-tested with the respondents and validated and ensured the flow of the interview schedule before collecting the data.

Data collection methodology
Randomly selected respondents were approached with the help of Outreach worker of the PLHIV networks. Inclusion and exclusion criteria was followed to select the respondents. Major inclusion criteria for the study is "Children living with HIV-infected parent/s 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 and living with a HIV-infected father and/or mother were included in the study. Major exclusion Criteria was affected children' living with grandparents/relatives without infected members or living in residential care homes, orphanages and hostels.

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

Ethics
Bharathiar university doctoral committee has reviewed and approved the study and utmost care was provided to ensure ethics and confidentiality. Written informed consent was obtained from the parent or guardian and written assent was obtained from the respondents (children).

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. 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 (with or without siblings) only and 6 living with father (with or without siblings) only (3%) and 8 (4%) living with siblings and grandparents.
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.
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.
41.5% of the children living with the family where 2 family members in addition to the respondent child, 34.1% with 3 and above family members and 24.4% with only one member. HIV situation in the family: 61.5% of the respondent living with the only one HIV Infected members in the family whereas 34.6% living with 2 infected family members and 2.4% with 3 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 ART for their disease.

Table 1: Socio demographic details

Variable		Percentage (N=205)
Gender		
	Male	46.3
	Female	53.7
Type of living place		
	Rural/village	58.0
	Urban/Town	42.0
Parents	Mother Alive	93.2
	Father Alive	51.7
Education		
	Primary school(upto 5th standard)	3.9
	Middle school(6-8th standard) to	34.6
	Higher secondary (9-12th std)	49.3
	Diploma/certificate	7.8
	Graduate and above	4.4
Occupation	Private company employee	2.9
	Daily wage earner	5.9

	Agriculture	0.5
	Unemployed/at home	2.4
	Student	88.3
Number of family members in the family(except child)	one	24.4
	Two	41.5
	Three	26.8
	Four and above	7.3
Number of HIV infected family members in the family	One	61.5
	Two	36.1
	Three	2.4
Families with Positive members		
	Parents positive	94.1
	Siblings	5.9
ART taking HIV members in the family		
	Yes	91.7
	No	8.3

Caregiving activities (table-2) 60.5% the children performed caregiving activities to their ill parents or siblings. Among those performing caregiving activities, they spent almost an hour per day for caregiving activities (Number of hours spent on caregiving in the past 7 days: 5.5 median hours spent on caregiving activities in the last 7days (Mean-7.0 hrs, sd: 6.2). Children also spent 2 days in a week for caregiving activities depends upon the caregiving activities and the situation of parents/siblings illness (maximum 48 hrs and minimum 1 hrs in a week). Among those who perform caregiving 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/cloths of ill person /helping ill parents or siblings to take bath.

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

Quality of life children (Tables-3-9)

Quality of life of the children was assessed using the Pedsqol and was associated with the socio-demographic variables including the caregiving and household chores activities. Table-3 shows the mean score of quality of life in domain wise. Overall quality of life score was 73.62. Physical domain mean score was 75.56, emotional QOL domain score was 69.12, peer relationships QOL domain mean score was 76.12 and educational QOL domain mean score was 74.57. When compare with other scores, emotional quality of life score was very less and peer relationship quality of life score was high. Educational quality of life score and physical quality of life score was in between.

Table-4 shows the Correlation between quality of life scores and age were tested and it was found that there is positive correlation between age and physical & peer relationships. Over all QOL is also positively correlated to the age. Children performing household chores is having less overall score when compare with children not doing household chores ($p=0.08$). Children performing caregiving activities is having statistically less score when compare with children not doing household chores ($p<0.001$).

Association of quality of life with socio-demographic variables including caregiving activities (Table-5, 6, 7, 8, 9): Anova analysis was carried out to find out the mean variation of overall quality of life score among the socio-demographic variables. Male children have more overall QOL when compare with the female children. Children studied/studying middle class or less having almost equal score with the children studied/studying high school or above. Children are going for work is having less QOL score when compare with non-working children. Children performing household chores is having less qol score when compare with children not doing household chores ($p=0.08$). Children performing caregiving activities is having statistically less score when compare with children not doing household chores ($p<0.001$). Anova analysis was also carried out to find out the mean variation of quality of life score by Physical health, Emotional health, peer relationships and school performance among the socio-demographic variables. Physical health, Emotional health, peer relationships and school performance score was lower among who perform caregiving activities when compare with those does not perform ($P<0.05$).

Table 3: Quality of life

Variable	n	Mean(95% CI)
Physical QOL	205	75.56
Emotional QOL	205	69.12
Peer Relationship QOL	205	76.12
Educational QOL	187	74.57
Overall QOL	187	73.62

Table 4: Association of age with quality of life

Variable	N	Pearson's R value	P value
Physical QOL	205	0.322	0.000***
Emotional QOL	205	-0.009	0.985
Peer Relationship QOL	205	0.205	0.003***
Educational QOL	187	0.11	0.133
Over all QOL	187	0.219	0.003***

Table 5: Association of Overall Quality of life with socio-demographic variables and caregiving/household activities

Variable		N	Mean	95% Confidence Interval for Mean		P Value
				Lower Bound	Upper Bound	
Sex	Male	82	74.21	70.96	77.46	0.628
	Female	105	73.15	70.27	76.03	
Education	Middle school and less	76	73.84	70.63	77.05	0.868
	High school and above	111	73.47	70.57	76.36	
Work	Yes	10	66.63	55.45	77.80	0.125
	No	177	74.01	71.83	76.20	
Household chores	Yes	100	71.86	69.11	74.62	0.083
	No	87	75.63	72.29	78.97	
Care giving activities	Yes	110	70.53	68.00	73.06	0.001
	No	77	78.03	74.47	81.59	

Table 6: Association of Physical QOL with sociodemographic variables and caregiving/household activities

Variable		N	Mean	95% Confidence Interval for Mean		P value
				Lower Bound	Upper Bound	
Sex	Male	95	76.68	72.85	80.51	0.408
	Female	110	74.60	71.38	77.82	
Education	Middle school and less	79	73.69	69.74	77.65	0.236
	High school and above	126	76.74	73.57	79.91	
School going status	School going	188	74.88	72.32	77.45	0.070
	Drop out	17	83.09	74.27	91.91	
House hold chores	Yes	111	74.07	70.60	77.54	0.194
	No	94	77.33	73.83	80.83	
Care giving activities	Yes	124	73.59	70.35	76.83	0.05
	No	81	78.59	74.84	82.33	

Table 7: Emotional quality of life

Variable		N	Mean	95% Confidence Interval for Mean		P value
				Lower Bound	Upper Bound	
Sex	Male	95	71.16	66.92	75.40	0.174
	Female	110	67.36	63.77	70.96	
Education	Middle school and less	79	69.24	64.84	73.64	0.946
	High school and above	126	69.05	65.50	72.60	
School going status	School going	188	69.20	66.37	72.03	0.849
	Drop out	17	68.24	56.28	80.19	
House hold chores	Yes	111	66.44	63.08	69.81	0.036
	No	94	72.29	67.84	76.74	
Care giving activities	Yes	124	65.77	62.35	69.18	0.003
	No	81	74.26	69.84	78.68	

Table 8: Peer Relationship-quality of life

Variable		N	Mean	95% Confidence Interval for Mean		P value
				Lower Bound	Upper Bound	
Sex	Male	95	71.16	66.92	75.40	0.174
	Female	110	67.36	63.77	70.96	
Education	Middle school and less	79	75.57	71.79	79.35	0.730
	High school and above	126	76.47	73.14	79.79	
School going status	School going	188	75.98	73.36	78.61	0.717
	Drop out	17	77.65	69.21	86.08	
House hold chores	Yes	111	75.32	71.96	78.67	0.489
	No	94	77.07	73.30	80.85	
Care giving activities	Yes	124	73.63	70.66	76.60	0.014
	No	81	79.94	75.63	84.24	

Table 9: Educational quality of life

Variable		N	Mean	95% Confidence Interval for Mean		P value
				Lower Bound	Upper Bound	
Sex	Male	82	75.30	71.51	79.10	0.615
	Female	105	74.00	70.55	77.45	
Education	Middle school and less	76	76.18	72.26	80.11	0.299
	High school and above	111	73.47	70.13	76.81	
Household chores	Yes	101	72.57	69.45	75.70	0.091
	No	86	76.92	72.81	81.03	
Care giving activities	Yes	110	71.55	68.49	74.60	0.004
	No	77	78.90	74.68	83.11	

Discussion and conclusion

Majority of the children living with HIV infected family members are involved in caregiving 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 specific caregiving activities when compare with female children who were engaged in household activities when compare with the male children.

Girl children are more affected (low QOL) when compare with male children. As age increases, children learn to cope with their physical and peer relationship. More noticeably, children who were engaged in caregiving activities had low quality of life (Physical, emotional, Peer relationship and educational performance) which shows strong negative impact of early caregiving responsibility of children.

Overall children affected by HIV/AIDS are having less emotional QOL scores when compare with other domain scores. Children felt that it is quite stressful to care for adults who would be caring for them instead. They are often helpless and need psychosocial support /guidance from adults [6]. The mental health needs are tremendous among the affected children and further studies on mental health of children affected by AIDS will help in designing interventions to help children cope up with the stress of taking up an adult role at a tender age [5].

Peer relationship of caregiving children also affected. Peer relationship were significantly and positively associated with psychological resilience of children even after controlling for the potential confounding factors, such as children's age, gender, and socio-economic status. The main effects of positive peer relationship on psychological resilience were significant [6].

In terms of educational performance, affected children are studying higher class are managing their education when compare with children studying lesser class as children studied/studying middle class or less having less score with the children studied/studying high school or above. With age or time children develop resilience. Children performing household chores is also facing challenges to meet the educational requirements as they have less score when compare with children not doing household chores in addition to the caregiving activities. Children are undertaking time-consuming medical care and domestic tasks, with high burden in AIDS-sick households. Adult AIDS-sickness in the home seems to impact child education [7]. The main responsibilities of the children caring for parents on ART were intimate care and nursing, household duties, and income-generating activities. To conclude, there is an urgent need for to provide holistic support to the affected by HIV in particular, to consider the hardships and coping strategies of children who live with a parent on ART [6, 8, 9]. 'Children/Young Carers' are an important group to consider in policy and planning which government, civil society needs to provide due importance [7] as their overall quality of life is affected due to their caregiving responsibility.

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