

ROLE OF CARE GIVERS IN THE TREATMENT OUTCOME OF PAEDIATRIC ART

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ABSTRACT

Objective: To compare the outcome of HIV positive children in relation to their care givers and to emphasize the need for the rehabilitation and supportive measures.

Methods: A Retrospective record based study of 472 HIV positive children on ART registered at Regional Pediatric ART Center, Niloufer Hospital, Hyderabad from December 2021 to May 2022. These children were categorized into 3 groups based on their care givers i.e, Parents, Relatives/Single parent and NGO organization. We have compared the WHO clinical stage, drug adherence, nutritional status, Socioeconomic status, opportunistic infections and CD4 counts in relation to the care givers.

Result: Out of 472 cases HIV positive children on ART, 153(32.4%) were taken care by parents, 185(39.2%) were taken care by either single parent or relatives and NGO's were care givers for 134(28.4%) children. Most of the NGOs are taking care of male children. CD4 counts decreased in children cared by single and grand parents group compared to both parents or NGO's. Opportunistic infections also significantly more number in single parent/grandparent. Moderate and severe malnourished children more number seen in caregivers of single/grand parents. Significant. Drug adherence of (80-95%)is seen in single/grand parents. Children of single /grand parents are more into stage III & IV classification. Study reveals that outcome overall is better when both parents are there followed by care by NGOs. It is seen that loss of one or both parent leads to poor outcome among children with HIV.

Conclusions: Our study has shown significant difference between the HIV positive children care taken by N.G.Os, both parents, single/grandparents in terms of Education, Nutritional status, immunological, psychological, OIs, drug adherence, cd4count status, mainly the socio

economical support. It indicates that the extended family is getting overwhelmed by the added responsibility of these orphans.

Keywords: ART, HIV, caregivers

INTRODUCTION :

Worldwide 2.8 million children and adolescents were living with HIV in 2018.¹ Pediatric HIV/AIDS is a significant cause of childhood morbidity and mortality.^{2,3} In the year 2013, there were 3.2 million children living with HIV all over the world and 240,000 children became newly infected.⁴

Globally an estimated 15.2 million children under the age of 18 have lost one or both parents to AIDS⁵. The number of children in India orphaned by AIDS is more than 2 million according to UN estimates. The death of parent has a great impact on the child in all the aspects. One out of three children had lost at least one biological parent and one of nine had lost both. Most children are cared by relatives, NGOs, single parent mainly mother.⁶

Globally, only half (52%) of children living with HIV are on treatment, as compared to adults (76%) are receiving antiretrovirals, according UNAIDS Global AIDS Update 2022.⁷ In 2020, at least 300,000 children were newly infected with HIV, or one child every two minutes. That same year, 120,000 children and adolescents died from AIDS-related causes, or one child every five minutes⁸

Hence UNAIDS, UNICEF, WHO and partners have brought together a global alliance to ensure that no child living with HIV is denied treatment by the end of the decade (2030) and to prevent new infant HIV infections.⁷

India HIV Estimation 2019 adult (15–49 years) HIV prevalence was 0.22% (0.17–0.29%). Nationally, 20.52 thousand pregnant women who required ART to prevent mother-to-child transmission of HIV⁹. India has estimated 145,000 children <15 years of age who are infected by HIV/AIDS, and about 22,000 new infections occur every year accounting for 7% of all the new HIV infections.⁹ More than 90% of the HIV infections in children are the result of maternal-to-child transmission (MTCT).¹⁰ The MTCT rate ranges from 20% to 45% in the developing world.¹¹ It ranges from 15% to 30% in nonbreastfeeding populations.¹¹ This is because breastfeeding has an additional 5%–20% risk of postpartum transmission. With adequate antiretroviral (ARV) prophylaxis, MTCT risk can be reduced to <2%.¹² However, these approaches are not always possible in developing countries wherein 95% of vertical transmission occurs.¹³

‘Double orphans’ – children who have lost both mother and father ¹⁴. They are especially vulnerable to poverty, exploitation and abuse.

HIV and AIDS affect virtually every aspect of child development and jeopardize the enjoyment of children’s rights. They undermine health and schooling, Endangering nutrition and health, reinforce marginalization and deprivation, Deepening gender inequality, Damaging psychosocial development, Isolating and excluding, and place the burdens of loss, fear and adult responsibility onto the shoulders of children.¹⁵ Guided by the best interests of the child, “parents or, where applicable, the members of the extended family or community, ... legal guardians or other

persons legally responsible for the child” have a responsibility to provide “appropriate direction and guidance in the exercise by the child” of his or her rights, as well as to ensure the upbringing and development of the child. The State is required to “render appropriate assistance to parents and legal guardians ... in the performance of their child rearing responsibilities.”¹⁶

Finally stigma and discrimination prevent children from accessing basic services (health, education, social protection) and need to be effectively addressed.

Hence the study is to look into outcome of treatment in children depending upon type of care givers.

AIM OF THE STUDY

- Assess the treatment outcome of HIV positive children in terms of opportunistic infections, CD4 count, nutritional status in relation to care taker.

SAMPLE:

Complete enumeration of 472 HIV positive children aged 0-18 yrs on ART attending Regional Pediatric ART Center, Niloufer (Maternal & Child health care hospital) Hyderabad from December 2021 to May 2022 were enrolled in the study.

SAMPLE UNIT:

Regional Pediatric ART Center, Niloufer (Maternal & Child health care) hospital, Hyderabad, Telangana.

DESIGN:

Retrospective follow up study.

MATERIALS AND METHODS:

This was a retrospective study was done at Regional Pediatric ART Center, Niloufer Hospital, Hyderabad. In this study we have enrolled 472 HIV +ve children in the age group of 0-18 yrs who are taking ART since 1yr. We compared the quality of life of children in relation to care giver. Care givers were divided in to three groups

1. Both parents.
2. Single parent/Grand parents
3. NGO organization.

Information was obtained regarding baseline characters like age at registration, gender was collected and was divided according to relation to the subject. Data regarding of WHO clinical stage, initial and current CD4counts and, Incidence of opportunistic infections and nutritional status by anthropometric parameters, were obtained from patient’s records. Adherence to ART was determined by questioning the primary caregiver, pill count and noting whether the patient

comes back for follow-up on the assigned date. Socioeconomic status of care givers was determined as per modified Kuppuswamy scale.

Results

Table 1: Types of care givers for children on ART

CARE GIVERS	n(%)
Parents	153(32.4)
Relatives/single Parent	134(28.4)
NGO	185(39.2)
Total	472(100)

There is lack of studies which compare outcome of treatment based on type of caregivers. Out of 472 HIV positive children on ART, 153 were taken care by parents, 134 children had lost one or both parents and NGO's were care givers for 185 children. The number of children orphaned is very large. Most children were in age group between 5-15 years.

Figure 1: Age classification of CLHA

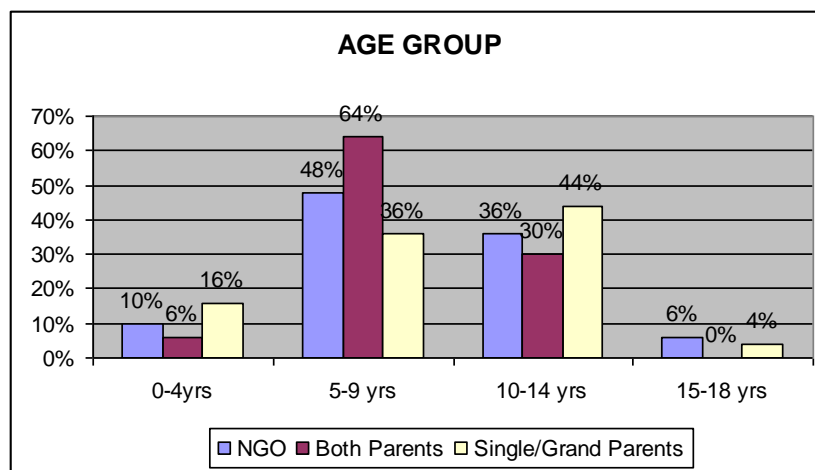


Table 2: Baseline characteristics of children on ART in relation to caregivers

	Both Parents N=153	Single/Grand Parents N=134	NGO N=185	P value
Age in years	n(%)	n(%)	n(%)	
<5	9(6)	22(16)	19(10)	0.0081
5-10	89(58)	50(37)	91(49)	
>10-15	51(33)	60(45)	69(37)	
>15	4(3)	2(2)	6(4)	
Gender				
Male	104(68)	83(62)	141(76)	0.0211
Female	49(32)	51(38)	44(24)	

SES of caregivers				
Lower	6(4)	27(20)		0.0000
Upper lower	73(48)	78(58)		
Lower middle	46(30)	23(17)		
Upper middle	28(18)	6(5)		
Upper	_NIL	NIL		

There is more number of male children compared to female children. It is seen that NGO s catered more to male children compared to female children. The numbers are of concern which might be due to negligence of female child.

It is seen that most single parent or relatives giving care to these children belong to lower socio economic background. Upper lower and lower class are significant in single /grand parent group. Lower socio economic status might be one of the reason in lesser care and poor outcome of children living with HIV.

Figure 2: Gender distribution

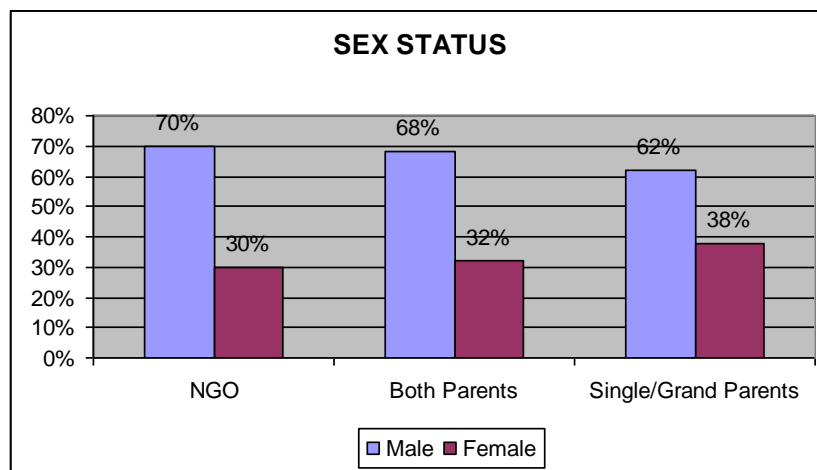


Table 3: WHO Clinical staging of the CLHA

	Both Parents N=153	Single/Grand Parents N=134	NGO N=185	Total N= (472)	P value
CLINICAL STAGE	n(%)	n(%)	n(%)		
I	58(38)	35(26)	48(26)	141(30)	0.0003
II	71(46)	55(41)	104(56)	230(49)	
III	21(14)	29(22)	26(14)	76(16)	
IV	3(2)	15(11)	7(4)	25(5)	

Children with HIV were classified according to the WHO classification of clinical staging. Majority of children were in clinical stage 1 or 2.

Children of single /grand parents are more in III & IV stage. It might be due to poor adherence to treatment or lack of quality care from single/grand parents.

Figure 3: Drug adherence according to type of caregivers

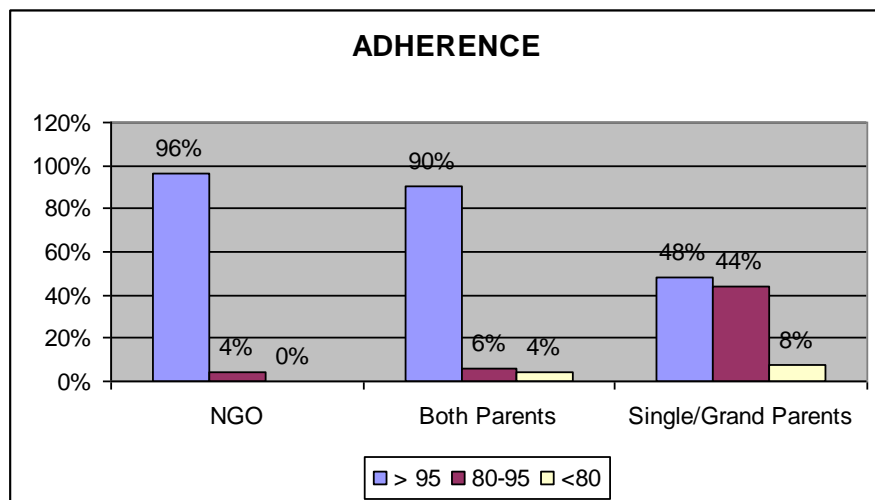


Figure 4: Nutritional status of the children

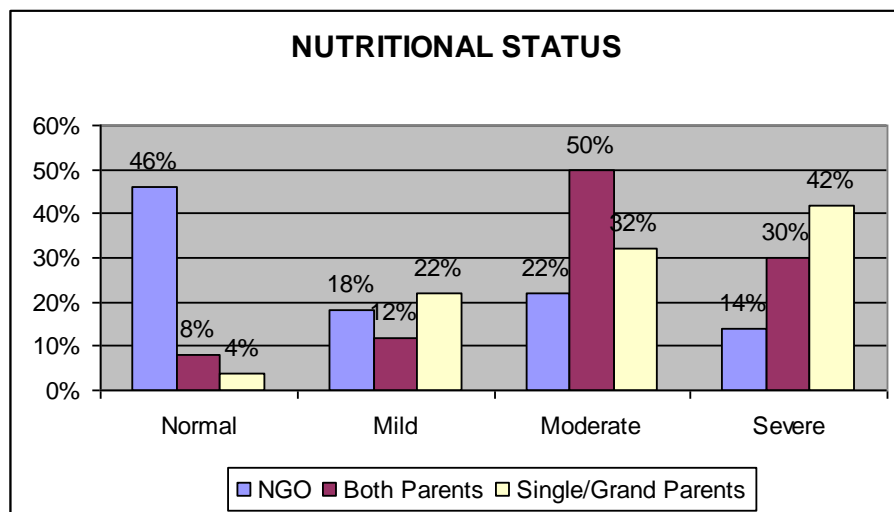


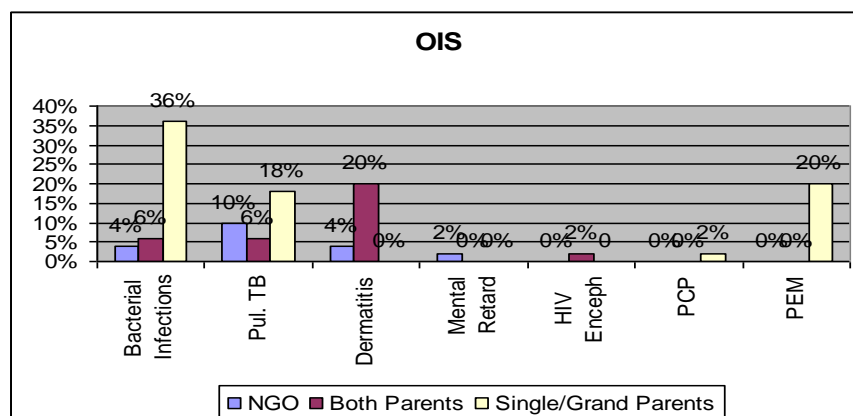
Table 4: Treatment outcome of CLHA based on type of care givers.

	Both Parents N=153	Single/Gr and Parents N=134	NGO N=185	P value
Opportunistic Infections:	n(%)	n(%)	n(%)	n(%)
Bacterial Infections (soft tissue infections, Otitis media, Sinusitis, UTI, etc.)	9(6)	48(36)	48(26)	0.0021

Pulmonary TB	9(6)	11(8)	19(10)	
Dermatitis	31(2)	17(13)	35(19)	
Encephalitis	3(2)	5(4)	2(1)	
PCP	3(2)	4(3)	4(2)	
Pneumonia	33(22)	41(31)	33(18)	
Herpes Zoster	16(11)	17(13)	17(9)	
Candidiasis	32(21)	29(22)	29(16)	
Diarrhea	47(31)	49(37)	59(32)	
CD4 Counts				
Increased	125(82)	64(48)	141(76)	0.0000
Decreased	28(18)	70(52)	44(24)	
Drug Adherence				
>95%	138(90)	64(48)	177(96)	0.0000
80-95%	9(6)	60(44)	8(4)	
<80%	6(4)	10(8)	0(0)	
Nutritional Status				
Normal	12(8)	54(4)	85(46)	0.0000
Mild malnutrition	18(12)	30(22)	33(18)	
Moderate malnutrition	77(50)	43(32)	41(22)	
Severe malnutrition	46(30)	57(42)	26(14)	

Study shows that treatment outcome was better among children with both parents and children living with NGOs. Opportunistic infections were more common among children with single parent. CD4 count decreased among 52% of children with single parent which was more compared to other group. Similarly drug adherence was low among children with single/ grand parents. Nutritional status was better among children living in NGOs compared to other two groups. There was significant difference in treatment outcome across different care givers.

Figure 5: Opportunistic infections among CLHA



Discussion and Conclusion:

There are many studies evaluating the treatment outcome of ART in children but there is lack in studies in terms of outcome related to care givers. Care givers play central role in giving physical, economic and emotional support. Hence there is need for such studies.

As seen from the study female child negligence is apparent. Parents are the best care providers for children. In HIV death of one parent or both parents puts great burden on single parent or relatives. Overall the outcomes are bad in children cared by single parent or cared by relatives. In this aspect NGO s provide better care than relatives. In a study more than one-half of the caregivers, 69.0% (78), were biological parents of the child, while 31.0% (35) were other relations that typically comprised other extended family members.¹⁷

To conclude in our study out of 472 children (PLHA's) 32.4% were taken care by partents, 28.4% were by single parent / guardian and 39.2% were by NGO's

- Our study has shown significant difference between the HIV positive children care taken by N.G.Os, both parents, single/grandparents in terms of Education, Nutritional status, immunological, psychological, OIs,drug adherence, cd4count status, mainly the socio economical support. It indicates that the extended family is getting overwhelmed by the added responsibility of these orphans.
- There is a need to study this problem in the community and provision of community help to the needy should be priority.
- Need for special attention to female children affected by HIV.
- Need of care and support programmes which would ensure retention and improve the quality of life of the children living with HIV

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