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Clinical and psychosocial profile of HIV orphans in Northern Karnataka – a longitudinal study

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ABSTRACT

Background **India currently has an estimated 220,000 children infected by HIV/AIDS and is home to the largest number of AIDS Orphans only next to South Africa in the world. The pandemic not only deprives Orphans of their rights to enjoy a good or a normal childhood, but it also has deleterious effects on their chances of survival or well-being. Thus the future of these children orphaned by the AIDS epidemic addresses a key social issue. Hence this study was done with the objectives, to assess the Demographic profile, Clinical profile and psycho-social profile of HIV Orphans.**

Methods **A Longitudinal study on 82 HIV orphans in the age group 5 to 15yrs was conducted after obtaining informed consent from their caregivers for duration of one year from at Anti retroviral therapy (ART) centre KIMS, Hubli. Clinical profile was assessed by WHO staging of HIV, Child Behavior Checklist (CBCL) was used to assess Psycho-Social Profile. Chi-square test, paired t test are the tests of significance for qualitative and quantitative variables respectively.**

Results **Mother to Child was the most common mode of transmission in majority of cases i.e 97%. Among the orphans 60% of them were deprived of mother's care i.e Double orphans and maternal orphans. Majority of subjects i.e 29 (35.4%) were in stage 2 of WHO clinical staging. 27(32.9%) were in mild immunosuppression at 350 to 499 Absolute lymphocytic count and CD4% in the range of 20 to 25% in 26(31.7%). A statistically significant increase of psychosocial problem in orphans was observed during the follow-up.**

Conclusion **It can be concluded that during the follow-up Psycho-social problems increased in Orphans significantly.**

Keywords: HIV Orphans, Psycho-social profile, Child Health behavior checklist (CBCL)

INTRODUCTION

Joint United Nations Program on HIV/AIDS (UNAIDS) defines an orphan as a child under 15 years of age who has lost their mother (maternal orphan) or both parents (double orphan) to HIV/AIDS[1,2]. With the above definition it is projected that the figure of 13 million in 2000 is expected to rise to 24.3 million in 2010 and 40 million by 2020[3]. At present children less than 15 years accounts for one in six AIDS related deaths worldwide and one in seven new HIV infections majority through vertical transmission[4]. According to UNAIDS and World Health Organization (WHO) HIV estimate, there are 2.5million children living with HIV and 1.66 billion are orphaned due to

AIDS in 2009[5]. India stands next to South Africa in the world with largest number of AIDS orphans and has 220,000 children infected by HIV/AIDS[6]. In India, Maharashtra accounts to 18,121 HIV-positive children, closely followed by Andhra Pradesh with 17,720 infected children and Karnataka at the third place with 11,000 children[7,8] . India is expected to become the next epicenter of the AIDS orphan crisis. This escalating AIDS crisis is leaving an unprecedented number of children orphaned with little or no adult protection and care. Given the long incubation period between infection and the onset of symptoms, the epidemic impact will linger for decades even if the rate of new infections is brought under control. The orphan crisis is also likely to have an impact on the country's economic and social fabric[9]. In this regard this attempt has been made to determine demographic, clinical and psycho-social profile of HIV Orphans.

MATERIALS AND METHODS

A one year longitudinal study was carried out in Anti Retroviral Therapy (ART) centre of Karnataka Institute of Medical Sciences (KIMS) Hubli, Karnataka from 1st June 2010 to 30th May 2011. All the HIV positive children aged between 5 to 15 yrs who has lost either of the parents or both of them attending the Pediatric High Risk Clinic were included in the study. A preformed and structured questionnaire was used to obtain data on demographic profile, clinical profile and psycho-social profile after obtaining informed consent. A sample of 82 subjects was selected as per the inclusion criteria during the initial six months of the study period. Later all the study subjects were followed up at 6 months interval. Clinical status was assessed according to WHO Clinical Staging for HIV Infection in Children. Psycho-social profile was assessed using Child Behaviour Checklist scale[10,11]. The analysis of the data was carried out by EPI info version 7. Chi square test was applied for qualitative data and Paired t test were applied for quantitative data. P value less than 0.05 was considered as statistically significant.

RESULTS

Table 1 depicts 53 (64.7%) of the Orphans were Males and 29 (35.3%) were Females. The Mean age of Orphans was 10.11± 3.13. 33 (40.2%) were Paternal Orphans, 25 (30.5%) were Double Orphans and 24 (29.3%) were maternal Orphans. Among the Orphans mother was the care provider in majority of subject's i.e 40.2%. Both the parents were seropositive in most of the subjects i.e 67 (81.7%) and only mother was seropositive in 13 (15.09%) of cases.

As per the WHO clinical staging majority of subjects i.e 29 (35.4%) were in stage 2 and the least was observed in stage I i.e 12 (14.6%) at the first visit. During follow-up majority 35 (42.7%) were in stage 2 and least in stage IV i.e 4 (4.9%). Most of the study subjects i.e 27(32.9%) reported 350 to 499 Absolute lymphocytic count and 26 (31.7%) reported 20 to 25 CD4% during first visit and after 6months during follow-up majority 34 (41.5%) reported >500 Absolute lymphocyte count and 43 (52.4%) reported CD4% > 25% (**Table 2**).

In **Table 3** a statistically significant increase of psychosocial problem in orphans was observed during the follow-up.

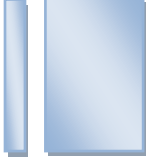

Table 1 Socio Demographic Profile of HIV orphans

Socio-Demographic Profile		Cases n=82	%
Age	6-10yrs	44	53.6
	11-15yrs	38	46.4
Sex	Male		
	Female		
Orphan status	Paternal Orphans	33	40.2
	Double Orphans	25	30.5
	Maternal Orphans	24	29.3
Caregiver	Mother	33	40.2
	Father	21	25.6
	Grandparents	18	22
	Others	7	8.5
	Orphanage	3	3.7
Sero-Positivity of Parents	Both Positive	67	81.7
	Mother Positive Father Negative	13	15.9
	Mother Negative Father Positive	2	2.4
Education	Primary	61	74.4
	Secondary	6	7.3
	Not Going to School	15	18.3
Mode of Transmission	Mother to Fetus	80	97.6
	Not Known	2	2.3

Table 2 Clinical Profile of HIV orphans

Clinical Profile		First Visit	Follow-up
		Cases n=82 (%)	Cases n=82 (%)
WHO Clinical Staging			
Stage	I	12 (14.6)	26 (31.7)
	II	29 (35.4)	35 (42.7)
	III	23 (28)	17 (20.7)
	IV	18 (22)	4 (4.9)
Absolute Lymphocyte Count			
> 500	Normal	18 (22)	34 (41.5)
350 to 499	Mild	27 (32.9)	30 (36.6)
200 to 349	Advanced	24 (29.3)	12 (14.6)
< 200	Severe	13 (15.9)	6 (7.3)
CD4%			
>25%	Normal	25 (30.5)	43 (52.4)
20% to 25%	Mild	26 (31.7)	23 (28)
15% to 25%	Advanced	18 (22)	10 (12.2)
<15%	Severe	13 (15.9)	6 (7.3)

Table 3 Psychosocial Profile of HIV orphans

Psychosocial Parameters	Orphans (n=82)	Scores		t test	p value
		Mean	Std. Deviation		
Depression	First visit	1.93	1.163	0.280	0.0001
	Follow up	2.45	1.079		
Withdrawal	First visit	2.66	1.642	0.342	0.0001
	Follow up	3.28	1.317		
Social Problems	First visit	2.88	1.527	0.3716	0.0001
	Follow up	3.48	1.279		

DISCUSSION

AIDS epidemic has affected children globally and India. HIV infection can directly affect children, in the absence of prevention; a mother can pass the virus to her baby during pregnancy, delivery, and breastfeeding. Subsequently Children can also be infected through contaminated blood during transfusions or by sexual abuse. But the consequences of the AIDS epidemic on children go well beyond these infection risks. Orphaned children are vulnerable by themselves due to the loss of care of parents. Orphans whose mother or father or both died of HIV/AIDS are vulnerable to stigmatization and discrimination. Those circumstances aggravate the risk of poor nutrition, psychosocial development, schooling, health care and loss of property[12,13]. In the study it was observed that 53 (64.7%) of the Orphans were Males, 29 (35.3%) were Females. The study was in accordance with Malabika Sarker et al study in Uganda, where majority 53% were male and 47% were female[14]. Similarly Ramesh R Pol et al, in Hubli observed that majority of Children with HIV were males, constituting 63.38% (2/3) of the cases[15].

The study showed that 33 (40.2%) were Paternal Orphans, 25 (30.5%) were Double Orphans and 24 (29.3%) were maternal Orphans. i.e 60% of Orphans has lost their mother who is the primary caregiver for children. These children are more likely to suffer from psycho-social problems. The observation was in accordance with the study by Malabika Sarker et al[14], in Uganda, where majority 70% were Paternal Orphans, 21% were Double Orphans and 9 % were Maternal Orphans. The study differs from Lucie D. Cluver et al, in South Africa among 425 AIDS Orphans, 58.6% were Maternal Orphans, 16.5% were paternal Orphans and 24.9% were Double Orphans[16].

Most common mode of transmission of HIV among children in the study was vertical transmission i.e in 97%. This was in accordance with Ramesh Pol et al[15] study in Hubli, where Sixty seven children (94.37%) had acquired infection by perinatal transmission and in 5.63% the mode of transmission was not known. Similar observation was made by Sunil Gomber et al, in Delhi, where 90% of infection was transmitted by mother to child[17].

WHO clinical Staging: It was observed that 41 (50%) of Orphans were in stage I and II. The study differed from Anita Shet et al., where 69% of children belonged to stage 1 and 2. 31% of children had advanced disease i.e stage III and stage IV[18]. The study also differed from Biobele et al study, among 272 HIV children in Nigeria, where majority 70.6% of them were in clinical stage 3 and 4 and 29.4% were in clinical stage 1 and 2[19]. Similar observation was made by Sunil Gomber et al and Sebi Das et al., where majority of children presented at stage 3[17,20]. During the follow up it was observed that 61 (74.4%) were in stage I and II this can be attributed to the regular ART visits and treatment.

Immunological Criteria: In the study it was observed that 30.5% had no evidence of immunosuppression, 44 (53.7%) had mild to advanced immunosuppression and 13 (15.9%) had severe immunosuppression. This was in accordance with Anita Shet et al study, where 34% had no evidence of immunosuppression, 44% had mild-to advanced immunosuppression and 22% of children were severely immunosuppressed[18]. The observation differed from Sebi Das where 59% had no immunosuppresion 14% mild, 17% advanced and

10% with severe immunosuppression[20]. The study also differed from Sunil Gomber et al were among 33 children, 28 (85%) had advanced and severe Immunosuppression[17].

Psychosocial profile: In the study it was observed that psychosocial problems in orphans like depression, withdrawal problems and social problems were significantly increasing with the follow-up even though there was improvement in the clinical status. A number of cross-sectional studies have found that chronically ill children are at increased risk of psychosocial problems. These children have been reported to have lower self-esteem, poorer body-image and more problems in psychological well-being, behavior and social adjustment than those without chronic conditions[21]. Capaldini et al, and Tate et al, found that HIV-positive patients live a longer life because of medical and social advances like ART, but treatment programs have not been able to eradicate the virus and cure the disease. As a result, patients are living longer with a chronic condition that continuously presents social, physical, and psychological challenges[22,23]. Constance A. Nyamukapa et al in their study found that Orphans had more psychosocial distress than did non Orphans [24]. Renee van Gelder et al in their study found that orphaned children living within the extended family system experienced significant psychosocial problems than children living with their parent(s) or in an orphanage [25]. The study by Atwine B et al., in rural Uganda, observed high levels of psychological distress in children who had been orphaned by AIDS, anxiety, depression and anger were more found to be more common among AIDS Orphans than other children[26]. In a study by Lucie Cluver et al, it was observed that AIDS-Orphans had significantly more psychological problems. They had more problems than children orphaned by other causes, and more than non-Orphans. AIDS-orphaned children were more likely to be depressed, have post-traumatic stress, consider suicide, have peer relationship problems, and show behavior problems than other children. These differences persisted independently of factors such as age, gender, migration and living in formal or informal dwellings[27].

CONCLUSION

The study concludes that among the orphans studied 60% of them were deprived from mother's care. Majority 97.6% of children acquired infection from Mother. During the follow-up Psycho-social problems increased in Orphans at a significant level. Informer bias cannot be ruled out because the caregivers who were questioned knew the HIV status of children and information may be over exaggerated.

Since millions of children have already lost at least one parent as a result of AIDS epidemic, and many more are likely to lose parents over the next few years. There is an urgent need to help, care and protect these children. There is also a need to prevent HIV infection in adults, so that the number of children orphaned in the future is minimized. Hence problems of HIV orphan a key driver for countries to plan and strategize by

1) Strengthening of Positive network of people living with HIV/AIDS.
2) Social assistance for caregivers and orphans
3) Strengthening of the IEC activity more in rural areas, with focus towards eliminating the stigma & discrimination.

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