Indian J Med Res 129, January 2009, pp 42-49

Demographic & clinical profile of HIV infected children accessing care at Tambaram, Chennai, India

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Received January 9, 2007

***Background & objectives*: Human immunodeficiency virus (HIV) is severely affecting the poorly educated and economically disadvantaged in Indian society. When children start developing clinical manifestations, needing treatment, they have to travel long distances for accessing care and support at tertiary institutions. This places an extra burden on patients, who are already struggling to cope with their illness. Sufficient data are needed for the government to evolve appropriate policy for providing care to the children affected with HIV. We undertook this study to present the socio-demographic characteristics, signs and symptoms, clinical profile, distance travelled and follow up pattern of HIV positive children who accessed care for the first time in a referral hospital at Chennai, India.**

***Methods*: Electronic medical records from patients diagnosed with HIV between 2002 and 2004 at the Government Hospital for Thoracic Medicine (GHTM) in Tambaram (Chennai) in India were analyzed to understand care-seeking behaviours. Demographic variables such as age, sex, education and occupation, data on clinical manifestations were examined together with geographic information.**

***Results*: At GHTM 1,768 new paediatric patients accessed care from 2002 to 2004. Children aged less than 5 yr were 49.9 per cent; 1115 children had (63%) tuberculosis. Significantly, 14.9 and 20.6 per cent children had extra-pulmonary TB and disseminated TB respectively. Lower respiratory infection (15.8%), *Pneumocystis carinii* pneumonia (15.20%), oral/oesophageal candidiasis (13.5%), wasting (6.1%) and diarrhoeal disorders (3.5%) were the common clinical manifestations. In all 47 per cent children traveled between 200-400 km from home and 14 per cent travelled over 400 km.**

***Interpretation & conclusion*: Our findings showed that tuberculosis should be regarded as the indicator disease for HIV infection in children, especially when they have clinical manifestations of progressive, non pulmonary and disseminated disease. The primary and secondary health care centres should have the trained capacity to diagnose and treat HIV disease and opportunistic infections so as the children to have much needed care and support nearer to their residence.**

Key words Access to care - children - clinical manifestations - GIS - HIV - HIV and TB - opportunistic infection

Human immunodeficiency virus (HIV) infection poses tremendous challenges to health globally. Over 90 per cent of the estimated 38 million people with HIV infection in 2003 lived in resource poor

settings. According to the recent estimate, driven by the expanded sentinel surveillance system, the Third National Family Health Survey and Behavioural Surveillance Survey[1], there are 2-3.1 million (2.47 million) people living with HIV / AIDS (PLHAs) in India at the end of 2006. Of these, 0.97 million (39.3%) are women and 0.09 million (3.8%) are children[2]. India has the second highest burden in the world after South Africa[3]. Based on the census data, the prevention of parent to child transmission (PPTCT) statistics and using 30 per cent vertical transmission rate, the estimated HIV positive children in the 2003 was estimated to be 55,145[4]. The universal access to comprehensive health services is focused to address six needs: voluntary counselling and testing, prevention of HIV transmission, prophylaxis against opportunistic infections (OI), diagnosis and treatment for OIs and neoplasms, anti retroviral therapy (ART), palliative care and health care infrastructure and capacity to provide quality care[5].

However, not much is known on access to care among HIV infected individuals. The HIV infected need to travel long distances to access care in tertiary care level hospitals. This results in enormous burden for the children living with HIV, who are entirely banking on the assistance of surviving parents, grandparents or guardians for care and support. The clinical profile of HIV infection in children has been reported from India and Africa[6-13]. However, large and reliable data are necessary to evolve appropriate national policy in managing children with HIV. The present study was carried out to present the socio-demographic characteristics, clinical profile, distances travelled and follow up pattern of HIV positive children who have accessed care for the first time in Government Hospital for Thoracic Medicine (GHTM), a referral hospital at Tambaram, Chennai, India.

Material & Methods

The GHTM at Tambaram, Chennai, India, is a tertiary care hospital for managing tuberculosis and HIV disease. As of 2004, 28,700 HIV infected individuals were seen at the hospital. In order to improve the quality of patient care an electronic medical record system, named TB and HIV Hospital Information System (T/HIS) was launched in December 2001. Patients are provided with unique patient numbers and have been tracked during the follow up visits. The Data collected at the out patient counters, inpatient services, laboratory, voluntary counselling and testing centre (VCTC) and ART facilities are linked for analyses. The unique family tree constructed for each patient provides significant information on HIV infection and living status of the children and their parents.

The diagnosis of HIV was established as per the guidelines of National AIDS Control Organization (NACO)[14] and the diagnostic algorithm was constant for the entire analysis. For children aged 18 months and above, HIV screening was done according to adult national testing strategies[14]. Two positive HIV antibody test results, done sequentially, in a clinically symptomatic child, suggestive of HIV infection, indicate HIV infection. However, in children below 18 months of age, HIV status was decided on the basis of two PCR tests. They were termed as "HIV positive" when 2 PCR tests were positive or otherwise they were termed as "HIV negative". PCR testing facility was not available at GHTM, Tambaram, and the test results of the reputed centres were taken into consideration, as and when the tests performed and results made available.

All children who accessed care at the GHTM, Chennai, from 2002 to 2004 were included in the study. All the children were subjected to chest radiography and tuberculin skin testing to detect tuberculosis. Sputum smear microscopy for acid fast bacilli (AFB) was performed from the sputum specimens obtained from children, who were found or motivated to expectorate. In very young patients, gastric aspirates were examined for AFB. The overall clinical features, radiological findings, enhanced tuberculin indurations (>5 mm to 1 TU of PPD) and sputum smear microscopies were taken into consideration for diagnosing primary and pulmonary tuberculosis. Clinical presentation, fine needle aspiration cytology (FNAC) of lymph nodes, enhanced tuberculin indurations (>5 mm to 1 TU of PPD), smear microscopy for AFB from all the aspirates and CSF, ultra sonography of abdomen and/or CT scan brain, wherever needed, helped in diagnosing extra-pulmonary tuberculosis. *Pneumocystis carinii* pneumonia was diagnosed predominantly on clinical-presentation of progressive dyspnoea, tachypnoea disproportionate to chest skiagram findings, low oxygen saturation (<60%) in pulse oxymetry and/or chest radiological features ranging from normal to ground glass opacity and diffuse nodular appearance. When the characteristic manifestations of oral candidiasis were found with odynophagia, the diagnosis of oesophageal candidiasis was applied.

Children with HIV were provided with one month co-trimoxazole prophylaxis and the needed opportunistic infection treatment on their monthly visits of their life-long follow up. Free ART was given to eligible persons living with HIV/AIDS as part of National AIDS Control Programme[15], from April 1, 2004. Under the National Programme, CD4 count / % was performed to screen the medical eligibility for ART in children. In infants <11 months, ART was initiated if CD4 count was < 1500 cells/mm^3 (<25%). For those children aged 12-35 months and 36-59 months, the eligibility criteria for ART were CD4 count <750 cells/mm^3 (<20%) and <350 cells/mm^3 (<15%) respectively. HIV positive children aged >5 yr received ART if their CD4 count was <350 cells/mm^3. The positive network of PLHA and NGOs assisted in their monthly visits. Railway travel concession was offered to children with tuberculosis co-infection and also to one of the accompanying persons.

Statistical analysis: As the number of visits made was a skewed distribution, log transformation was done to compute mean and then antilogarithm was taken. The mean number of visits made by the children according to distance categories was compared using Kruskal-Wallis test. Chi-square test for trend was used to test associations. Quartile ranges for number of children visited by districts were obtained to plot and study the changes in districts over time using Geographical Information System (GIS). The distance from Chennai to the other districts in Tamil Nadu and Andhra Pradesh was obtained from Indian Map Service atlas[16]. GIS was done using MAPINFO software[17]. Data were analyzed using SPSS 13.0[18].

The protocol of this study was approved by the GHTM Institution Review Board.

Results

The number of HIV paediatric patients seeking care at GHTM has increased dramatically over time. The total number of visits for both old and new patients was 77,303 in 2002, 115,113 in 2003 and 149,884 in 2004. The total numbers of children visited were 8623, 12073 and 11902 in 2002, 2003 and 2004 respectively. The number of new HIV positive children visiting in these years was 476, 562, and 730 respectively (Table I).

Children with HIV disease attending GHTM, Tambaram for the first time (new cases) were considered for the present analysis. Between 2002 and 2004 inclusive there were 1,768 new HIV positive children enrolled for services at GHTM. Most of the HIV positive children (49.9%) were in less than 5 yr age group. This proportion has remained remarkably steady over time. There were also a substantial number of older (5-9 yr) children. Eleven per cent of HIV positive children were aged over 9 yr, 81 (4.6%) were infants (Table I).

Girl children represented an increasing proportion of the new HIV infected individuals at the institution. In 2002, 182 (38.2%) girls accounted of new patients while that number increased to 328 (44.9%) in 2004. However, compared to population proportion, significantly (P<0.001) more male HIV positive children were brought to GHTM. Of the new positive children, 43.1 and 56.9 per cent were female and male respectively. Of the children who were over 5 yr of age, 64 (9.8%) were illiterate and majority of them 564 (86.4%) studied up to primary. Out of 194 children, who were aged over 9 yr, only 22 (11.3%) had secondary education. The age range of the children who have studied up to secondary was 11-14 yr; 17 per cent children, who studied up to primary, had aged 11-14 yr. Nearly two thirds were from the State of Tamil Nadu [1106 (62.6%)] and most of the remaining were from the neighbouring State of Andhra Pradesh [637 (36.0%)].

Parents and sibling HIV status: Nearly 38 per cent of these children had parents who were both positive for HIV infection. 24.5 per cent of the children whose mothers were positive for HIV infection but their fathers' HIV status remained unknown. For nearly 30 per cent of the children, HIV status of their parents was not known. 1.7 per cent of the children, whose mothers' HIV status was positive with their fathers showing negative result in HIV screening. Mothers of 1 per cent children were found to be HIV negative, though their husbands were infected with HIV. At least one sibling of 181 (10%) positive children also had HIV. Two more HIV seropositive siblings were found in the family of 7 (1%) children.

Comparison of HIV infected and non infected children: There were 5389 HIV non infected children who have accessed care at the GHTM during 2002 to 2004. Of these, 26 per cent children were over 9 yr old, while the figure for HIV infected children group was only 11.2 per cent. Nearly half of the HIV infected children were younger aged ≤4 yr, while this was 37.9 per cent in the HIV non infected children. These differences were

Table I. Socio-demographic characteristics of HIV positve children registered at GHTM, Tambaram, by year of visit

Characteristics	2002		2003		2004		Total	
	n = 476		n = 562		n = 730		n = 1768	
	No.	%	No.	%	No.	%	No.	%
Age (yr):								
< 4	251	52.7	295	52.5	336	46.0	882	49.9
5-9	173	36.3	209	37.2	310	42.5	692	39.1
>10	52	10.9	58	10.3	84	11.5	194	11.0
Sex[*]:								
Female	182	38.2	252	44.8	328	44.9	762	43.1
Male	294	61.8	310	55.2	402	55.1	1006	56.9
Education (age ≥ 6; n = 653)[**]:								
Illiterate	22	12.9	18	8.9	24	8.5	64	9.8
KG	-	-	3	1.5	-	-	3	0.5
Primary	143	84.1	176	87.1	245	87.2	564	86.4
Secondary	5	2.9	5	2.5	12	4.3	22	3.4
State of residence:								
Tamil Nadu	326	68.5	350	62.3	430	58.9	1106	62.6
Andhra Pradesh	138	29.0	204	36.3	295	40.4	637	36.0
Karnataka	7	1.5	4	0.7	2	0.3	13	0.7
Kerala	-	-	1	0.2	1	0.1	2	0.1
Puducherry	-	-	2	0.4	-	-	2	0.1
Others	5	1.1	1	0.2	2	0.3	8	0.5
Parents' HIV status:								
Both +ve	85	18.0	231	41.5	355	49.3	671	38.3
Father +ve Mother-ve	2	0.4	7	1.3	8	1.1	17	1.0
Father +ve Mother NK	23	4.9	23	4.1	37	5.1	83	4.7
Father -ve Mother+ve	1	0.2	9	1.6	20	2.8	30	1.7
Father NK Mother+ve	83	17.5	159	28.5	186	25.8	428	24.5
Both NK	279	59.0	128	23.0	114	15.8	521	29.8
Children in a family +ve:								
1	454	95.4	497	88.4	621	85.1	1572	88.9
2	17	3.6	62	11.0	102	14.0	181	10.2
3	5	1.1	3	0.5	7	1.0	15	0.8

*P<0.01; **P<0.001. NK, not known. Test: Chi square test for trend

statistically significant (P<0.001). The sex distribution was nearly similar in both the groups; 35.2 per cent of the HIV infected children were illiterate while this was 23.3 per cent in the HIV non infected children. Otherwise, nearly half of them studied up to primary in both groups.

The GIS by year of diagnosis by district is presented in the Fig. In Tamil Nadu, 20 per cent districts had more than 20 positive children visiting GHTM in 2002. This has become 28 and 30 per cent in 2003 and 2004 respectively. Similarly, in Andhra Pradesh, 15, 27 and 42 per cent districts had more than 20 positive children visiting GHTM in 2002, 2003 and 2004 respectively, showing increasing epidemic trend in the GIS.

Clinical diagnoses: Tuberculosis was the most common co disease found in 1115 (63.1%) of 1768 children examined and analysed. While tuberculosis was detected to the extent of 56.5 per cent in 2002 and 55.1 per cent in 2003, there was an increased occurrence of tuberculosis found in 534 children (73.2%) infected with HIV in 2004. Pulmonary TB, including primary and progressive primary types accounted for in 27.5 per cent of 1768 children. Disseminated TB, involving more than one organ was witnessed in just over 20 per cent patients. 264 children (14.9%) had extra-pulmonary TB, predominantly involving lymph nodes. *Pneumocystis carinii* pneumonia was the frequently diagnosed opportunistic infection in 268 (15.2%) children. Various forms of lower respiratory infections (15.8%) and pneumonia (1.6%) were found to cause

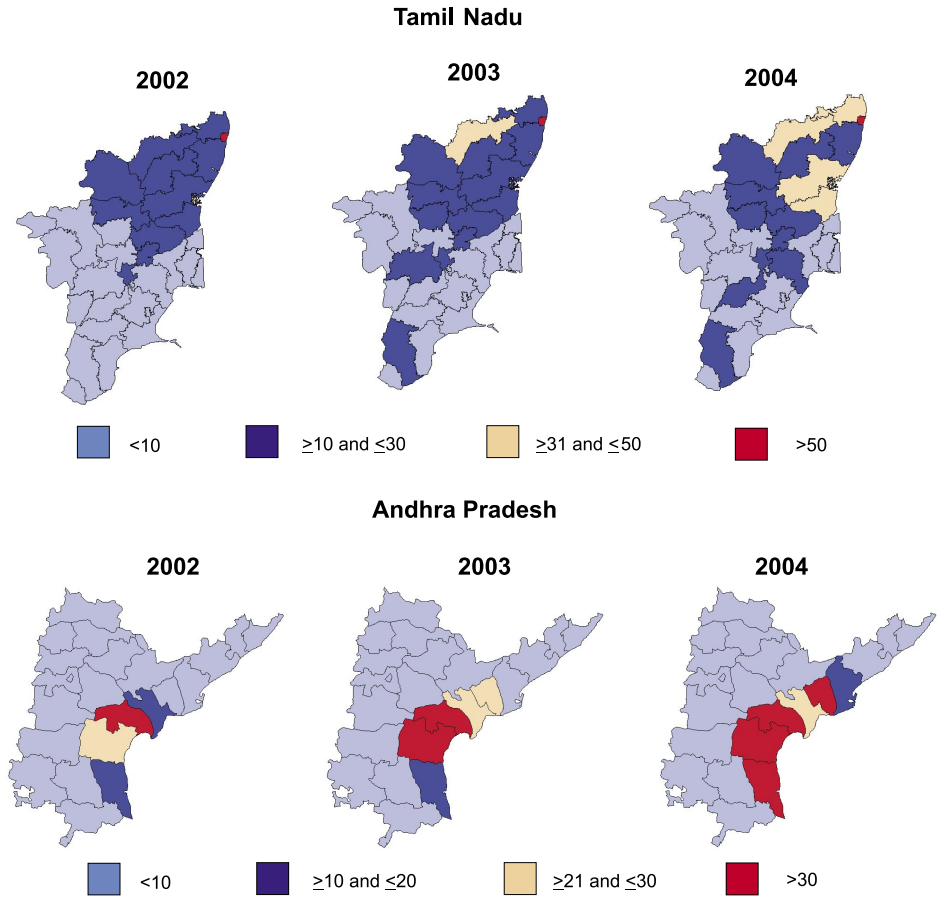

Fig. Raising trend in children accessing care at GHTM, Tambaram, Chennai from various districts of Tamil Nadu and Andhra Pradesh.

respiratory symptoms. Oral/oesophageal candidiasis (13.5%), wasting (6.1%) and diarrhoeal disorders, both acute and chronic (4.3%) were other clinical manifestations seen among them (Table II).

Distance travelled and number of visits: Of the 1768 HIV positive children seen between 2002 and 2004, a total of 47 per cent travelled from homes that were between 201 and 400 km from the hospital, while an additional 14 per cent came from over 400 km away. Once patients received initial services for HIV, they were expected to return on a regular basis (usually monthly) for follow up clinical assessments and to receive medications. Follow up rates were initially high but declined over time. Of those patients first seen in 2002, 87.1 per cent had at least one follow up visit within 6 months, 33 per cent had at least one follow up visit within 7-12 months, and 26.5 per cent had at least one within 13-18 months. The mean number of visits in the first six months for new patients living within 100 km of GHTM was on 3.6, while for those living more than 400 km away that number was 4.0. Among children who visited at least once in 13-18 months following their initial HIV diagnosis, the mean number of visits for those living within 100 km was 3.5 compared to only 2.7 for those living more than 400 km away.

Discussion

Data on prevalence of vertical transmission of HIV in the country are scanty[1]. However, the rate of perinatal transmission is reported to be 14 per cent at 6 wk of age and 24 per cent at 3-6 months[19]. In India, the estimated vertical transmission would be at the rate of 30 per cent and would expect to have 75000 infected neonates born every year[20]. In our study, the percentage of new HIV positive children, who were brought to GHTM during 2002 to 2004, was 4.4 per cent. Of them 4.6 per cent were infants. The sex ratio was 57:43.

Many of the HIV infected children were found to have tuberculosis when they attended for the first

Table II. Clinical profile of new HIV children from 2002 to 2004

Clinical manifestation	2002 (n = 476)	2003 (n = 562)	2004 (n = 730)	Total (n=1768)	
				Patients	Per cent
Tuberculosis:	269 (56.5)	312 (55.5)	534 (73.2)	1115 (63.1)	100
Pulmonary TB	157	109	220	486	43.6
Extra-pulmonary TB	17	115	132	264	23.7
Disseminated TB	95	88	182	365	32.7
Non tuberculous conditions:	207 (43.5)	250 (45.5)	196 (26.8)	653 (36.9)	100
Lower respiratory infection	73	103	104	280	42.9
Pneumocystis carinii pneumonia	124	91	53	268	41.0
Oral/oesophageal candidiasis	52	92	94	238	36.4
Wasting	29	43	45	108	16.5
Upper respiratory infection	7	21	23	51	7.8
Chronic diarrhoea	12	15	10	37	5.7
Pneumonia	10	9	10	29	4.4
Acute diarrhoea	4	12	9	25	3.8
Peripheral neuritis	4	4	3	11	1.7
Anaemia	3	0	8	11	1.7
Herpes zoster/Simplex	4	4	2	10	1.5
Hepatitis	5	2	3	10	1.5
Malaria	4	2	1	7	1.1
Oral hairy leukoplakia	1	1	2	4	0.1
Molluscum contagiosum	0	2	1	3	0.1
Lymphoma/non Hodgkin lymphoma	2	0	1	3	0.1
CNS HIV	2	0	1	3	0.1
Others	2	7	6	15	2.3

Values in parentheses show percentage

time at GHTM, Tambaram. TB was most common co-infection (63.1%) in our study. Other studies reported 43.4 per cent TB co-infection and 29.5 per cent pulmonary and extra-pulmonary TB from Mumbai[9,12]. However, the pulmonary TB was 27.2 and extra-pulmonary TB was 14.9 per cent in our study. The reported rate of pulmonary TB was 35 per cent in another Chennai study[10]. However, in Zambia, 68.9 per cent TB co-infection was reported[6]. TB should be regarded as the indicator disease for HIV infection and screening for HIV in all cases of disseminated TB is recommended[9].

The prevalence of recurrent/persistent lower respiratory tract infection (LRTI)[7] was 86.4 per cent and oral candidiasis was 36.4 per cent in 22 and 26.2 per cent[12] in 42 children. Merchant *et al*[9] reported that the prevalence of oral thrush was 14.73 per cent, which was similar to our report. LRTI was 15.8 per cent and oral/oesophageal candidiasis was 14 per cent in our study. The prevalence of wasting was 6.1 in our study, while failure to thrive ranged from 35.6 to 45.1 per cent[10,12]. The difference could be due to the definition of failure to thrive. Oral with or without oesophageal candidiasis was noticed in 13.5 per cent children. In our study, the chronic and acute diarrhoea was 2.1 and 1.4 per cent respectively, as against 15.08 and 21.4 per cent by others[9,13] which could be due to smaller sample studied by others.

Over 60 per cent traveled more than 200 km from GHTM: 35 per cent of the children come from the neighbouring State Andhra Pradesh. The reasons include: (*i*) facilities to treat and care for HIV may not be located near the home of many of these patients; (*ii*) many facilities that are available, are private and these patients cannot afford to pay for medicines required to treat infections or HIV-associated opportunistic diseases; (*iii*) health care providers at local clinics who do not have the resources to treat HIV refer them to GHTM; and

(*iv*) the prevailing stigma and discrimination in society drives the patients to seek remedy in a place away from his village or town to escape from the identification of his HIV status by friends and other local residents (GHTM, unpublished data).

Still some of those patients from farther away eventually either try and get care near home, stop seeking care from GHTM more quickly than those who live nearby as they feel better and no longer require treatment. Neither may be true. More likely the time and expense of visiting the hospital every month to receive medicines is simply too great a burden on the patients and their families, and as a result they forego care. The European Collaborative Study reported that more than 15 per cent of infected children will have progressed to category C or death by age 1 yr and nearly 50 per cent by 10 yr. Just fewer than 20 per cent of children will have evidence of severe immunodeficiency by age 1 and 75 per cent by 10 yr[21]. In our study, the portion of patients with 18 month follow up was 26.5 per cent. This programme have no system to contact these children, if they do not turn up for a long time.

Our study had some limitations and therefore cannot be extrapolated to HIV children in the general population. Only those symptomatic children infected with HIV, who were able to reach GHTM, Tambaram, were included in this study. Further, the analysed sample did not have an adequate number of children in <18 month group, as PCR facility is not available in this hospital. There is a possibility of attributing the high percentage of TB co-infection due to high 'referral. Though it may be true to a limited extent, it is not a limitation to project the higher rate of TB in the clinical profile of children in this study, as more than 50 per cent children attended with their known HIV status and/or of their parents' established HIV diagnosis.

This study clearly brought out three important pointers: (*i*) Tuberculosis was the most frequent clinical manifestation in HIV infected symptomatic children, like (*ii*) The family oriented approach in HIV screening adopted at GHTM, Tambaram, helped in identifying hitherto undetected HIV in children, and (*iii*) Adequate training of health care professional and creating an unstigmatised atmosphere in nearby primary and secondary health care settings would help children and their parents to access nearest health facility for care and support.

Given the problems with treatment adherence and the need for family support, it will be important that patients have facilities to receive medicines nearer to their homes and their relatives.

Acknowledgment

Authors thank Dr Thiagavalli Kirubakaran, Director of Medical Education, Chennai, Ms. K. Sujatha Rao, the Director-General of National AIDS Control Society and Ms. Supriya Sahu, the Project Director, Tamil Nadu AIDS State Control Society for the constant support and encouragement. We are grateful to Dr Meade Morgan, CDC GAP, Atlanta, Drs Dora Warren and Michael Friedman, CDC GAP, India, for the funding and for the help in writing the manuscript. We express our gratitude to all the doctors, nurses, laboratory staff and the data entry personnel for getting all the relevant information and also for compiling the data.

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