

## **Growth and nutritional status of orphaned HIV-infected children living in an institutional facility in India**

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## **Abstract**

Orphanhood is a tragic consequence of the HIV epidemic worldwide and often compounds pre-existing malnutrition and ill-health among HIV-infected children. As the number of HIV orphans overwhelms the capacity of extended biological families to care for these children, a viable option is to provide institutionalized residential care for these children. This study aims to understand the health status of HIV orphans in a well-structured model institutional facility in India using prospective longitudinal analysis of growth and nutritional status of these children. Eighty-five HIV-infected orphan children residing at Sneha Care Home, Bangalore, for at least one year, (between June 2008-May 2011) were included for analysis. Prevalence of anemia at entry into the home was 40%, with the cumulative incidence of anemia during the study period being 85%. At baseline, 79% were underweight and 72% were stunted. All children showed significant increase in weight (mean weight-for-age Z score change: -2.93 to -1.75,  $p < 0.001$ ) and height (mean height-for-age Z score change: -2.55 to -1.62,  $p < 0.001$ ) irrespective of ART status. These findings suggest that good nutrition even in the absence of ART can bring about improvement in growth. The Sneha Care Home model indicates that a holistic approach to combating HIV in severely malnourished orphan children is effective in improving nutritional status and may contribute towards optimal management of HIV orphans globally.

**Key words:** HIV, orphans, institutional facility, growth, nutrition, ART.

## **Introduction**

The HIV epidemic has devastating consequences on affected children particularly those who experience loss of one or both parents. Worldwide, it is estimated that there are 16 million children who have been orphaned by HIV (UNICEF, 2010). In India, over 31 million children are orphaned due to various causes including HIV (UNICEF, 2010). Current epidemiological data indicate that the number of children <15 years of age living with HIV infection is approximately 100,000 (UNAIDS, 2010) and additionally 50,000 infants are perinatally infected with HIV in India annually (NACO, 2010). Moreover, in India about 170,000 adult deaths per year (of the total 2.3 million adults living with HIV) can be traced to HIV (NACO, 2010-11). These data clearly lead one to infer that the burden of HIV orphans in India is substantial.

The adverse experiences of HIV-infected children often begin before the death of their parents. The period of parental illness results in loss of income, increased expenditure on medical needs, and general neglect of the affected children. Following parental death, the infected orphans are vulnerable to abandonment by the extended family, depression, abuse, increased malnutrition, lack of health care and schooling, and early entry into child labor (Williamson., 1997). The debate about the best way to meet an orphan child's needs is yet to be resolved. As the number of HIV orphans overwhelms the capacity of extended biological families to care for these children, a viable option is to provide institutionalized residential care (Foster et al., 1995; Foster and Williamson, 2000). While global policies recommend that institutionalized care be used as a last resort for orphaned children (Wakhweya A, 2008), there is evidence to suggest that well-structured orphanages can offer advantages for these children and can even lead to positive outcomes (Whetten et al., 2009; Wolff and Fesseha, 1999). Despite the high burden of pediatric HIV and adult deaths in India, there is a dearth of literature on the appropriate care of HIV-infected orphans in the country. This study aims to understand the health status of HIV orphans in a well-structured institutional facility in India by a prospective longitudinal analysis of growth and nutritional status of these children.

## Methods

**Study setting:** Sneha Care Home is a faith-based residential care facility for children infected with HIV who have lost one or both parents, and hail from a low-income background. The facility was established in June 2008 in a semi-rural setting within Bangalore district in Karnataka State, Southern India, which is one of the highest HIV-prevalence states in India. Sneha Care Home aims to meet the orphans' basic needs with a long-term goal to maintain the children's mental and physical health. The residential facility is built over an area of 3 acres with spacious dormitories, well-equipped classrooms, an on-site hospital, common dining hall, and playground for outdoor sports and recreation activities. Sneha Care Home incorporates a regular daily schedule for school, meals, sports, bedtime and entertainment. Specific responsibilities are given to children such as gardening, providing pet care, kitchen hygiene, and assistance with the very young children.

**Study design and subjects:** A prospective cohort study of all HIV-infected children residing at Sneha Care Home between June 2008 and May 2011 was conducted. Children were admitted into the residential facility at different times, and only those children who had been living in the home for one year or longer were included in the analysis.

**Data collection:** At the time of admission into the orphanage, socio-demographic information and family history were recorded. Baseline and regular medical examination of all children were performed by the pediatrician and recorded in the children's medical records.

**Anthropometry and Dietary Recall:** Weight was determined using a digital scale for children accurate to 0.1 kg. Stature was measured to the nearest 0.1 cm using a standard stadiometer. Z-scores were based on the National Center for Health Statistics reference data and computed using the Centers for Disease Control and Prevention Anthropometric Software program (version 3.1; CDC, Atlanta, GA, USA). A 24-hour dietary recall was obtained from an interview with the residential facility caregivers and child, conducted by a trained nutritionist. The quantity and size of each food portion was estimated using standardized containers as described previously (Bharathi et al., 2008) and subsequently analysed using the Indian Food Composition Tables to determine nutrient and caloric intake (Gopalan C, 1996). Dietary intake was compared with the Indian Recommended Dietary Allowance (RDA) and expressed as a percentage of RDA (Gopalan C, 1996).

**Laboratory parameters:** Hemoglobin was measured using automated blood analyzer (Sysmex XT-2000i, Sysmex Inc., Kobe, Japan) and CD4 T cell count was measured using flow cytometry (FACS Calibur, Becton Dickinson Biosciences).

**Definitions:** Children were diagnosed and classified according to clinical and immunological categories as per the WHO criteria (WHO, 2006). Age-stratified WHO criteria were used to define anemia (WHO, 2001). Weight-for-age Z score less than -2 SD, height-for-age Z score

less than -2 SD and weight-for-height Z score less than -2 SD were considered consistent with underweight, stunting and wasting respectively.

***Statistical Analysis:*** All data were entered into Epi Info (version 3.5.3) and subsequently analysed using SPSS software version 17.0 for Windows. Descriptive analysis was done for baseline values. Longitudinal change in growth parameters were analyzed for significance using repeated measures ANOVA. P value of <0.05 was considered significant.

***Ethical considerations:*** Written informed consent was obtained from the guardian of the children and Director of Sneha Care Home. Individual informed oral assent from children >8 years of age was taken. The study was approved by the Institutional Ethical Review Board at St. John's Medical College Hospital.

## Results

Between June 2008 and May 2011, 103 HIV-infected children were admitted into this institutional facility. Fifteen children, recently recruited in 2011 whose duration of stay at the facility was less than 1 year were not included in this analysis. Two children who were admitted in 2008 were relocated within 1 year of admission to a different facility for closer proximity to extended family members. Another child died due to accidental trauma within 4 months of admission into the facility. Thus a total of 85 children were included in the current analysis. The average duration of stay at the facility for these children was 22 months (range 12-36 months).

*Demographic and clinical details:* Of the 85 HIV-infected children included in the study, 60% (n=51) were boys (Table 1). Mean age was 9.2 years ( $\pm 2.1$ , range 4-14 years). Double orphans (those who had lost both parents) constituted 37% of all children, paternal orphans (those who had lost their father) were 42%, maternal orphans were 12% and the remaining 9% had parents who had either abandoned their child or were unable to take care of them. All deceased and living parents were infected with HIV. All children had documented HIV infection acquired by the perinatal route of transmission. The majority of the children (82%, 70/85) had mild disease (WHO clinical stage 1 and 2) while the remaining 18% had advanced disease (WHO clinical stage 3 and 4) (Table 1). The mean absolute CD4 count was 798 cells/mm<sup>3</sup> ( $\pm 497$ ), and mean CD4 percentage was 24% ( $\pm 8.9$ ). Severe immunosuppression (defined as absolute CD4 count < 250 cells/mm<sup>3</sup> or CD4 percentage < 15%) was seen in 14% of the children.

*Antiretroviral treatment and immunological status:* At baseline, 29% (n=25) children were on ART prior to admission into the orphanage. During the study period, 14 more children were initiated on ART based on national guidelines (NACO, 2006). Of these children 9 were initiated on zidovudine-based regimen while the other 5 children who had coexisting anemia were started on a stavudine-based regimen. At the end of this study period, 46% of the children (39/85) were taking regular ART (23 on zidovudine-based ART, and 16 on stavudine-based ART). Mean CD4 percentage increased from 24% at entry into the Home to 27% at end of the study period. Children who were not on ART had a steady level of mean CD4 (24% to 25%), while the steepest increase of CD4 was seen among those who were newly started on ART (17% to 30%).

*Growth and nutritional status:* At the beginning of the study period, mean weight-for-age Z score (WAZ) was -2.93 ( $\pm 1.28$ ), height-for-age Z score (HAZ) was -2.55 ( $\pm 1.03$ ) and weight-for-height Z score (WHZ) was -1.49 ( $\pm 1.63$ ) (Table 1). Overall, 79% (67/85) of children were underweight, 72% (61/85) were stunted and 27% (23/85) demonstrated wasting. *Time trends in growth:* All children showed significant increase in weight and height during the follow up period. Mean WAZ increased from -2.93 at baseline to -1.75 over 36 months ( $p < 0.001$ ). Similarly, HAZ also increased from -2.55 at baseline to -1.62 over 36 months ( $p < 0.001$ ). (Table 2). Among children taking regular ART, mean WAZ increased from -2.76 to -1.9 ( $p < 0.001$ ) and mean HAZ increased from -2.69 to -2.13 ( $p < 0.01$ ). A similar increase in

growth was seen among children who were not on ART: mean WAZ increased from -2.73 to -1.08 ( $p < 0.001$ ) and mean HAZ increased from -2.69 to -1.44 ( $p < 0.01$ ) (Figure 1A & 1B).

*Dietary intake:* All children were served meals from the same kitchen. A structured menu including local seasonal produce and non-vegetarian meals was followed on a regular basis. During the day, children received 3 meals and 2 snacks (8.00 am: breakfast; 11.00am: snack; 1.00 pm: lunch; 4.00 pm: snack and 8.00 pm: dinner). 24-hour dietary recall revealed that children  $< 7$  years received 75% recommended daily allowance (RDA) for energy, while older children received 93-107% of RDA for energy. All children received adequate ( $> 100\%$  RDA) amounts of both protein and fat. Iron intake was low in all age groups, ranging from 38% to 69% while the other micronutrients such as folic acid and vitamin B<sub>12</sub> intake were appropriate for age and gender. (Table 3)

*Anemia:* The prevalence of anemia at baseline was 40% (34/85). However, the cumulative incidence of anemia during the period of study was 85% (72/85). Unless other features were present, etiology of anemia was presumed to be nutritional and related to iron deficiency. Zidovudine-induced anemia was present in 7 children (30% of total on zidovudine; 7/23) and all recovered to having normal hemoglobin levels once their ART regimen was switched to a stavudine-based regimen. Management of anemia included iron supplementation and yearly anti-helminthic medications.

*Incidence of infections:* Pulmonary tuberculosis was seen in 8% (7/85) of the children residing in the facility. Three children had preexisting tuberculosis and was initiated on anti-tuberculous therapy prior to admission into the facility, while 4 children were diagnosed during their stay at the facility. All these 4 children were symptomatic within 3 months of admission into the facility. Other common infections included impetigo (31%), varicella zoster (24%), chronic suppurative otitis media (15%) and parotitis (13%). A majority (75%) of these children had these infections in the initial period (of less than 3 months) of admission into the facility.

## Discussion

We highlight the positive effects of a well-structured institutional setting on orphaned children who lacked proper home care. The results of our study indicate that despite a high baseline prevalence of malnutrition among orphaned HIV-infected children living in an institutional facility, appropriate attention to nutrition and a comprehensive approach to healthcare even in the absence of ART can bring about improvement in growth among these children.

Poor growth is a common phenomenon seen in HIV-infected children and is reported among 50%-69% of these children (Arpadi, 2000; Weigel et al., 2010). Similar studies done on Indian pediatric population have shown the prevalence of poor growth to range from 45% to 62% in HIV-infected children (Dhurat et al., 2000; Merchant et al., 2001; Shah et al., 2005). In these studies, children were recruited from the community and none were from orphanages. A recent study conducted on a mixed population (orphans and non-orphans) in southern India has found the prevalence of underweight and stunting to be 55% and 46% respectively (Shet et al., 2009). In our study population of orphaned children alone, we found, at entry into the institution, a higher prevalence of both underweight and stunting of 79% and 72% respectively. In resource-limited settings like India this impact of HIV on children and families is further compounded by the fact that many families live in communities which are already disadvantaged by poverty, poor infrastructure and limited access to basic services. Additionally, orphans tend to be at greater risk for infection, all of which threaten normal growth and nutritional status.

Our results also indicated that anemia was a prominent manifestation of HIV. Although baseline prevalence of anemia was only 40%, we found that during the study period, the cumulative incidence rose to 85%. Other Indian studies have shown anemia prevalence of 38% (non orphans) and 66% (mixed population, orphans and non orphans) in HIV-infected children (Dhurat et al., 2000; Shet et al., 2009). However, studies conducted on African HIV-infected children revealed anemia to be more common (prevalence range, 73% to 91%) (Adewuyi and Chitsike, 1994; Eley et al., 2002; Semba et al., 2001; Totin et al., 2002) although these studies included infants who are generally more vulnerable to anemia.

### *Role of Nutrition*

HIV is a catabolic disease, and is associated with high resting energy expenditure (Mulligan et al., 1997). Co-existing infections also consume a major proportion of the energy intake, thereby causing a net deficit in the energy balance of the body. Further, the tremendous food insecurity and lack of supportive environments associated with these children, all together orchestrate poor growth seen in HIV-infected children. Examination of nutrient intake among HIV-infected children revealed that energy intake was significantly reduced among growth-impaired children compared to those with normal growth (Arpadi et al., 2000, Johann-Liang et al., 2000). Systematic reviews have demonstrated the importance of adequate nutrition in

improving outcomes in HIV infection (Irlam et al., 2010; Mahlungulu et al., 2007). Further, studies have also reported that in HIV-infected children nutritional supplementation was associated with an increase in weight-for-age Z scores (Banerjee et al., 2010). In our study, all 85 children irrespective of their ART status had demonstrated a significant increase in age-related weight and height Z scores. All these children received age and gender appropriate nutrition along with additional nutrition supplements such as iron, when required. These results suggest that dietary support (both macronutrients and micronutrients) may have an independent role in improving clinical outcomes in HIV-infected individuals by reducing the incidence of HIV-associated complications thereby improving quality of life and ultimately reducing disease-related mortality.

ART has a definite impact on sustaining growth in children with HIV, although the optimal growth rate is not often reached with ART alone (Nachman et al., 2005; Weigel et al., 2010). It is noteworthy that the growth response in the first year of ART was less pronounced in children treated in Uganda than among children in the United Kingdom and Ireland, despite similar virological and immunological control, possibly reflecting the higher degree of background malnutrition among the Ugandan children (Kekitiinwa et al., 2008). Follow-up analysis on Indian children revealed that growth response over 18 months of ART was more significant among children with normal nutritional status compared with malnourished children (Bandyopadhyay and Bhattacharyya, 2008). Taken together it is possible to conclude that ART alone may not be sufficient to improve outcomes in children with HIV, and that other factors such as optimal nutrition and shelter are critical contributory factors for good outcomes.

### *Role of Institutional Care*

Management of HIV-infected children requires a holistic approach with equal amount of focus on providing ART and adequate nutrition supplementation as well as providing education and adequate psychosocial care. This study provides evidence that orphaned HIV-infected children can show remarkable improvement in overall growth and nutritional status when given the opportunity to reside in an institutional setting with adequate nutritional supplementation, medical care, schooling and psycho-social support.

The debate about the best way to meet an orphan's needs remains contentious and it is unclear whether these residential homes confer survival advantage over community-based programs. Some favor extended family or foster care while others suggest institutionalized settings are more advantageous. Several studies have concluded that institutional care in contrast to foster care is damaging to the development of infants and small children (Smyke et al., 2002; Tizard and Hodges, 1978; Tizard and Rees, 1975). Studies in Romania found that young children in institutions were more likely to have cognitive delays, poorer physical growth and negative behavior compared to those living at home. However this study also revealed that improving caregiving quality within an institution was associated with better outcomes (Smyke et al., 2007). Proponents of community care argue that institutional settings

are unable to provide the individualized attention found in households and also suggest that the low child-to-caregiver ratio and frequent change of caregivers are detrimental (Ahmad et al., 2005; Skuse et al., 1994).

On the other hand, there are several studies that show positive outcomes for institutionalized care of orphans where good caregiving and structural conditions are provided (Wolff et al., 1995; Wolff and Fesseha, 1998). Large numbers of orphans make it difficult for the extended family system to absorb these children. This is particularly important for the Indian setting where economic constraints are a major limiting factor. Some authors have noted that orphanages that make an effort to nurture the child-caregiver relationships and emphasize on providing visual, tactile, and auditory interactions tend to create favorable rearing environments (Hakimi-Manesh et al., 1984). A study of orphan children in Eritrea found that children aged 9-14 living in an institution with participatory decision making and a focus on self-reliance among its children had significantly fewer emotional and behavioural difficulties than children living in an institution that had a director-driven authoritarian-style of management (Wolff and Fesseha, 1998). Another study found that changing the organizational structure of the institution so that they provided the children with greater decision making and encouragement resulted in improvements in child emotional wellbeing (Wolff et al., 1995). Jelsma et al examined motor development of orphaned children with and without HIV and found that children in extended family care lacked stimulation compared to those in institutional settings (Jelsma et al., 2011). An assessment of an AIDS orphanage in China indicated that while most basic needs for food, shelter and clothing are met, other aspects such as integrated education, financial stability and administrative flexibility are important requirements for an improved psychological and health outcome among orphaned children (Zhao et al., 2009). Further, orphans from China and Botswana have reported the importance of uninterrupted access to food, shelter and schooling and also acknowledged that the living conditions in these institutions were better than the families they lived with after the death of their parents (He and Ji, 2007; Morantz and Heymann, 2010; Zhao et al., 2009). These data directly challenge the assumption that extended family homes are better options for childcare in resource-limited settings.

### *Sneha Care Home as a replicable model*

Sneha Care Home offers a multitude of services, including a value-based education, balanced meals, recreational activity, and routine pediatrician visits. Our data indicate that this model is beneficial for raising children as the children's health indicators improved over time. There may be several explanations for this finding. These children reside in a family-like setting under the supervision of trained staff. The experience of living with other HIV-infected children may help normalize the HIV disease burden and provide a constant source of social support. Adherence to ART is likely to be excellent as the children are supervised in taking their antiretroviral medication together. The staff at the institution have been trained to take care of HIV-infected children, to identify any minor ailments and bring them to the immediate notice of the pediatrician for evaluation of any intercurrent illnesses. The staff

members are encouraged to constantly improve the quality of life for these children and work with a system of core values that includes compassion, care, commitment, and competence. The children are also prepared for life in the real world as they are given an education that includes vocational training and lifeskills management.

This study is limited by the small sample size and short period of follow up. The current analysis is limited to growth, nutrition and profile of infections experienced by the children living in the Home, and has not considered psychosocial wellbeing or cognitive growth of the children. In addition, the institution is located in Bangalore, and although the children come from all over South India, the generalizability of the results is limited, and more such studies need to be conducted in other parts of India and the world for a better understanding of optimal management of HIV orphans. These limitations notwithstanding, the lessons learned from this study will serve as a springboard for improved insight into creating well-structured insitutionalized care. Long-term solutions will need to be crafted for orphan children since the impact of HIV will last for decades even after the epidemic begins to wane, and the Sneha Care Home model may serve as a replicable model for safe and appropriate care of orphaned HIV-infected children.

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