

## Caregiver's Perception Regarding Diagnosis Disclosure to Children Living with Human Immunodeficiency Virus in Resource-Limited Settings: Observational Study from India

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**Abstract :** Background: With a better understanding of HIV pathogenesis and availability of antiretroviral therapy more children are growing and entering in teenage group; informing children of their own HIV status has become an important aspect of long-term disease management. There is little evidence of how and when this type of disclosure takes place in a resource-limited setting. Methods: A cross-sectional study was conducted from June 2010 to May 2011 among a dyads of 156 HIV-infected children and their caregivers, those were visiting pediatric clinic at a tertiary care hospital in Delhi, India. The study protocol was approved by the Institute Ethics Committee. After taking written informed consent; pretested structured questionnaire was administered to caregivers during routine clinic visits. Information regarding socio-demographic characteristics, awareness of HIV infection status among children and their perception regarding disclosure was collected. Mean and frequencies were calculated and chi-square and logistic regression test were applied. Results: The mean age of children was  $8.4 \pm 3.45$  years. Among them 73.7% were male and 39.1% were orphans. Among 156 enrolled children, 74.4% (n=116) were of  $\geq 6$  years and were assessed for disclosure. Only 18.1% (n=21) children had been informed of their HIV status. Of those under 9 years, 6.4% knew their status, whereas 18.4% of 9-11 years and 35.5% of 12-14 years children knew they had HIV. Awareness among males (23.3%) was higher than females (3.3%). Both age and sex of child were significantly ( $p < 0.01$ ) associated with disclosure status. Other factors favoring disclosure were orphan-hood, non-perinatal mode of transmission (OR = 4.32; 95% CI 1.01-7.12), ART initiation (OR = 4.21; 95% CI 1.03-6.98), and caregiver educated beyond primary level (OR = 1.89; 95% CI 1.03-3.26). Repeated enquiry regarding the visit to clinic was the most common reason (66.6%) for disclosure. In 52.4% children disclosure was done with the involvement of other family members. 82.5% caregivers felt the age of  $> 10$  years is appropriate for disclosing the HIV infection status to the child. Conclusion: Detailed guidelines on disclosure are required focusing on children of school-going age with perinatal infection who are not on ART and with caregivers of low educational status.

**Keywords :** HIV, children, India, disclosure

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