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 ±3.45 years. Among them 73.7% were male and 39.1% were orphans. Among 156 enrolled children, 74.4% (n=116) were of ≥ 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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