

Disclosure of the HIV Infection Status in Children

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ABSTRACT

Objective. To determine the perception of caregivers about the disclosure of the diagnosis of HIV infection in children.

Methods. Caregivers of fifty HIV-infected children were enrolled in the study after taking written informed consent. They were interviewed using a structured questionnaire. The questionnaire included information on the demographic details, questions about the disclosure status of HIV infection in children and perceptions about the disclosure of status to child.

Results. Only 7 out of the 50 children (14%) were aware of their HIV status while 43/50 (86%) were unaware; as reported by their guardians/ parents. Only 6 percent children (3/50) were given factual information about the disease while 68% (34/50) were given no information. Majority of caregivers felt mid-teenage as the appropriate age for disclosing the HIV infection status and that the parents were the appropriate persons to reveal the infection status (21/50, 42%).

Conclusion. There is need to develop and implement guidelines for disclosure of HIV infection status to HIV-infected children in resource limited settings. [Indian J Pediatr 2009; 76 (8) : 805-808] E-mail: rakesh_lodha@hotmail.com

Key words: HIV; Children; Disclosure

The number of children living with human immunodeficiency virus (HIV) infection and acquired immunodeficiency syndrome (AIDS) are on the rise. According to the current estimates by World Health Organization (WHO) there are 2.5 million children living with HIV or AIDS globally with approximately 0.1 million in India.¹ With advent of national programme for providing care and free antiretroviral therapy to children, the number of children living with HIV or AIDS and surviving to adolescent age group are bound to increase.

Studies have shown that 36 to 61% children with HIV infection are expected to live till 13 yr.² Hence disclosure of HIV infection status is emerging as an important issue. Though, there are established guidelines regarding disclosure of chronic illness³ including HIV⁴, the disclosure rate in HIV infected children older than 5 yr varies widely from 17 to 100%.⁵ It was also found that children suffering from chronic illnesses including malignancies were able to cope with the disease better with fewer psychosocial problems if they were appropriately informed.^{6,7} Likewise HIV infected children who were disclosed of their infection status had higher self esteem, lesser depression and greater adherence to antiretroviral/ prophylactic

therapy.⁸ Hence, pediatricians should anticipate the need for eventual disclosure of the infection status when attending to HIV infected children. The practices of disclosure may be affected by cultural background.

There are limited data on the disclosure of HIV infection status in children and the perception of caregivers about the same. We undertook this study to determine the perception of their caregivers about the disclosure of the diagnosis of HIV infection in children.

MATERIAL AND METHODS

The study was conducted in the Pediatric HIV services of a tertiary care centre in New Delhi, India between April and August 2007. Caregivers of fifty children were enrolled in the study after taking written informed consent for participation. Interview of caregivers (parents/ guardians) was conducted using a pretested structured questionnaire by a trained medical social worker. The questionnaire included information on the demographic details, questions about the disclosure status of HIV infection in children and perceptions about the disclosure of status to child. The information about the child's clinical and immunologic staging and therapy was extracted from the clinic records. Data was entered in Microsoft Excel and descriptive statistical analysis was performed.

The study proposal was approved by the Institute Ethics Committee.

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RESULTS

Caregivers of fifty children who were regularly attending the Pediatric HIV services were interviewed. The mean age of the children was 8.98 ± 0.42 yr. Of these 38 (76%) were boys and 12(24%) were girls. In four patients (8%) both parents had expired while in 11 children (22%) mother had expired and in 10 children (20%) father had expired. The HIV infection status of the mother was known in 34 cases of which 24 were infected (70.6%) and in case of fathers, 19 out of 36 (52.7%) whose status was known were HIV infected. For 39 children, parents were the informants [mother = 19/50(38%) and father = 20/50(40%)] while rest were as follows- grandparents 5/50 (10%), uncle 4/50 (8%) and legal guardian 2/50 (2%) (Table 1).

Only 7 out of the 50 children (14%) were aware of their HIV status while 43/50(86%) were unaware; as reported by their guardians/ parents. Parents had disclosed the status in 5 (10%) children while in 2 (4%) status was disclosed by other primary care takers. Only 6 percent children (3/50) were given factual information about the disease while 68% (34/50) were given no information. Majority of children (58%) were given no explanation for the repeated hospital visits, only 14% (7/50) were informed about hospital visits were for HIV infection and another 24% (12/50) were told that the visits were for routine health check up. Of the 47 children who were on antiretroviral therapy or cotrimoxazole or other medications, only five children (5/47, 10.6%) were told of

it being given for HIV infection, and here again majority being not given any information (21/47, 44.7%). Rest of them were given the following reasons for regular medicines- improving general health (3/47, 6.4%), associated physical ailments (3/47, 6.4%).

Responding to a query whether the HIV status should be revealed or not to the child, 44 % (22/50) favored disclosure. Majority of caregivers felt mid teenage as the appropriate age for disclosing the HIV infection status. Majority of the caregivers felt parents were the most appropriate to reveal the infection status (21/50, 42%) (Table 2).

DISCUSSION

Disclosure of the diagnosis of HIV infection or AIDS to a child is an emotionally charged and controversial issue. HIV infection, with advent of antiretroviral therapy, is now more of a chronic illness with need for regular follow ups and strict adherence to medications. But unfortunately its unique nature like relentless progression, associated social stigma, risk of person to person transmission and simultaneous affliction of multiple members of the same family make it different from other chronic diseases like malignancies.

The major observation in the present study was that

TABLE 1. Patient Characteristics (n=50)

| | |
|-----------------------------------|--------------------|
| Mean age of the children in years | 8.98 \pm 0.42 |
| Sex (n %) | Male 38/50 (76%) |
| | Female 12/50 (24%) |
| Clinical stage (WHO) | |
| I | 5 (10%) |
| II | 5 (10%) |
| III | 15 (30%) |
| IV | 25 (50%) |
| Immune stage (WHO) | |
| Mild | 7 (14%) |
| Advanced | 15 (30%) |
| Severe | 28 (56%) |
| Current therapy ART | 42 (84%) |
| Number of patients with | |
| Both parents expired | 4/50 (8%) |
| Mother expired | 11/50 (22%) |
| Father expired | 10/50 (20%) |
| HIV status of mother | |
| Positive | 24/34 (70.6%) |
| Negative | 10/34 (29.4%) |
| HIV status of father | |
| Positive | 19/36 (52.7%) |
| Negative | 17/36 (47.2%) |
| Informant | |
| Father | 19/50 (38%) |
| Mother | 20/50 (40%) |
| Grandmother | 5/50 (10%) |
| Uncle | 4/50 (8%) |
| Legal guardian | 2/50 (4%) |

TABLE 2. Responses of Caregivers to Various Questions Regarding Disclosure of HIV Infection Status to Children

| | |
|---|---|
| What has been told to children about the illness that they were suffering from? | Factual information 3/50 (6%) Other diagnosis told 13/50 (26%) No information provided 34/50 (68%) |
| What explanation has been provided to child for repeated hospital visit | For check up for HIV infection 7/50 (14%) For associated physical illness 2/50 (4%) For routine health check up 12/50 (24%) No communication in this regard 29/50 (58%) |
| What explanation for repeated/ daily medicine intake including ART | For HIV infection 5/47 (10.6%) For associated physical illness 3/47 (6.4%) For improving child's health 3/47 (6.4%) No explanation given 21/47 (44.7%) Others 15/47 (31.9%) |
| Does the child know about person to person transmissibility of HIV infection? | No 43/50 (86%) Not sure 7/50 (14 %) |
| Should infected children be told of the HIV status? | Yes 22/50 (44%) No 27/50 (54%) Not sure 1/50 (2%) |
| Appropriate age for HIV status disclosure | Not sure 8/50 (16%) 8 years 1/50 (2%) 10-12 years 5/50 (10%) 12-14years 5/50 (10%) 14-16 years 15/50 (30%) 16-18 years 12/50 (24%) After 18 years 4/50 (8%) |
| Who do you think is the best person for disclosing the HIV status to a child? | Doctor 5/50 (10%) Family members 8/50 (16%) Parents 21/50 (42%) Parents or doctor 8/50 (16%) |

Disclosure of the HIV Infection Status in Children

the disclosure rate in our services was low with only 14% of the children being aware of their infection status. Although majority of these children were on some medications were given factual information with 68% being given no information on the disease. Parents were the informants of the HIV infection status in majority (5 of the 7 informed) and majority of respondents also felt parents as the apt persons to disclose the status. The present data shows that majority of care givers felt mid-teenage as the right age for disclosure with almost 54% preferring the age of 14-18 yr. Only two percent agreed with age less than 10 yr as the right time. Though the disclosure rate was low, majority of caregivers interviewed felt the need for disclosure in the future.

Compared to the present data, the disclosure rates from other regions have varied from 17 % to 100 %.⁵ In a study from Thailand by Oberdorfer *et al*, the disclosure rate in 103 children and adolescents, only one third (30.1%) children in the age group 4-15 yr were aware of their infection status.⁹ Similarly in a study by Funk-Brentano *et al* only 17% were fully informed about their infection status in the age group of 5-10 yr and another 40% were partially disclosed of the same.¹⁰ Age was found to be an important determinant of HIV disclosure. In the study of Bor, all children who were 16 years old knew their HIV status whereas of those who were younger than 10 yr only 37% knew their status.¹¹ Similarly, in the study by Cohen, 95% of children older than 10 yr were aware of their status whereas only 30% of children aged 5-10 yr knew about their diagnosis.¹²

In agreement with the theory of child's cognitive understanding of illness, the age from 9 to 10 yr and older is considered to be the best time for HIV-infected children to know about their sicknesses as at this age children can understand about the complex causes of illness and its consequences.¹³ Moreover, the child consequently gains a better understanding about the need to adhere to the highly active antiretroviral therapy (HAART) regimen. In a study from Thailand the mean age of disclosure was 9.2 yr (SD 3.0; range 4-15 yr)⁹ which was much younger than the perceived ideal time for disclosure in the present study.

Regarding the disclosure pattern majority of caregivers use various methods of deception like telling a lie, selective disclosure or inaccurately explaining about associated illnesses like allergy, respiratory infections or just explaining the repeated visits as routine health check ups. Similar pattern of deception was reported in other studies.^{9, 10, 14} In majority of studies, care givers felt parents as the right persons to disclose the HIV status. In a study by Moodley *et al*¹⁵ in South Africa, 83% and by Apateerapong *et al*¹⁶ in Thailand, 59% felt caregivers should disclose the infection status which was similar to the present study results. The beneficial impacts of HIV disclosure included better adaptation, lesser psychological stress, higher self esteem and better adherence to antiretroviral

therapy.^{17, 18} This is also important in those children especially in adolescent age group who may be sexually active.

The common barriers to disclosure included negative psychological consequences⁹, stigma, emotional unpreparedness and lack of knowledge and communication skills¹⁹. Though there are established guidelines for HIV disclosure in children older than 5 yr in western countries⁴ there is lack of any such guidelines for resource limited setting like ours. With advent of national programme for care and treatment of a HIV infected children under the National AIDS Control Programme, more children are going to survive longer with HIV infection and disclosure of their infection status would be an important aspect in the holistic management of these children.

The limitations of our study include small sample size. We did not assess the impact of the disclosure status on the child's quality of life or psychosocial problems or adherence to therapy.

CONCLUSION

Though the need and importance for disclosure of HIV infection to the infected child has been recognized by the primary caregivers, its implementation is far from satisfactory. There is lack of consensus and knowledge regarding appropriate age for disclosure. There is a need to develop and implement guidelines for disclosure of HIV infection status to infected children in resource limited settings.

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