Revealing the HIV Status to Vertically Infected Children: A Critical Issue with Problems and Benefits

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Abstract

Most of the HIV infected children are unaware of the fact that they are suffering from a highly stigmatized disease. Non-disclosure, however, is mainly due to the parent’s own concerns. HIV is a threat to the mental health of the children and to inform the children about their HIV status is troublesome. Since antiretroviral therapy has significantly increased the survival rate of vertically infected HIV children, informing the children about their HIV status is advantageous for their overall health and welfare. In spite of the benefits seen from revealing the HIV status to the children, disclosing the HIV status to the child remains a difficult issue.

INTRODUCTION

HIV/AIDS is a bio-psychosocial disease, the results of which are far beyond its physical symptoms. It has continued to be a highly stigmatized disease due to its association with socially denounced activities i.e. prostitution and illicit drug use [1]. It has severely affected the mental health of children and families worldwide. Pediatric HIV infection is even more stigmatized due to peer pressure, which further adds to the increased risk of mental health problems in infected child.

Antiretroviral medicines have drastically decreased the number of HIV infected children born to HIV-infected mothers. Also the use of other medications preventing the opportunistic infections has resulted in decreased morbidity and mortality in HIV infected children [2]. These medications having benefit of longer survival have resulted in an increased number of vertically HIV infected children, who are surviving and getting in to their teen ages and beyond. Nonetheless, HIV-1 infection remains a threat to the child health, family functioning and societal acceptance and thus it poses problems of higher level of depression, anxiety, behavioral changes and functional impairment.

Mental health of the children affected by HIV-1 is at risk due to the burden of stigma, poverty and stress. They face a great family stress and conflict [3], difficulties in maintaining relationships due to stigma attached to it [4-7], depression, anxiety and social withdrawal [8,9]. For the HIV affected children (children who are not HIV positive but are living with HIV infected people), sickness or death of the parents may shift family responsibilities upon them at a younger age resulting in school dropout, emotional and behavior problems, risky survival strategies including indulging in sex for money, which is again responsible for initiating another cycle of risk of HIV infection [10-14].

Problems associated with revealing the status of HIV to the infected child

Due to stigma attached to it, many HIV infected children are not informed of the fact that they are suffering from an HIV infection [15,16]. The proportion of children who know their disease status is lower in low and middle income countries as compared to the industrialized countries [17,18]. The decision to inform the children about their HIV status is difficult and troublesome because issues related to misinformation and misperceptions are responsible for concealing the HIV status to the children [19]. Non-disclosure is mainly due to parent’s own concerns as well [20-22].

It is difficult for HIV infected biological parents to reveal the HIV status to their child, if they are the source of their child’s HIV infection. It may result in increasing the parent’s guilt feeling about their sexual risk behavior, drug use, infecting their own child and disclosure of their HIV status in the community [17,23]. Parents sometimes bothered about unintended disclosure of their HIV status by the child to others which may lead to ostracism and discrimination by family, friends and community [24]. There are other reasons also which influences concealing the HIV status by the parents to their children. The most common reason is fear of emotional trauma to the children. The other reasons include the thinking that the child is immature to understand and will be difficult for him to keep it a secret, and/or the child may be overwhelmed by the information while in many instances parents by themselves don’t understand how to begin with the discussion [25].
Benefits of revealing the status of HIV to the infected child

Discussing the illness with children and informing them about their HIV status is advantageous for the overall mental health of the children. It is also helpful in making psychological adjustment in the family [26]. Revealing the HIV status to the children does not leave a negative impact on the children; rather it is favorable for their well-being. Studies suggest that the children who were aware of their HIV status were found to be more confident and less depressed than those children who were unaware of their disease status [26,27]. In another study, it was reported that the children who were informed of their diseases showed positive psychological adjustments and had a sense of empowerment in their family [28].

Clinicians involved in HIV care have also supported the notion that revealing the HIV status to school going children is useful for their well being [29,30]. Revelation enhances faith, engages the children in taking responsibility of their own medical care, influences adherence to ART and promotes long term health and emotional well being [18,20,29]. Revelation also lessens the psychological suffering and dejection of the HIV infected biological parents of the infected child and helps them in improving their mental health compared to those parents who did not reveal the HIV status to their child [21]. WHO, AAP 1999 and International Centre for AIDS care and Treatment Programs have recommended revelation of HIV status to children who are more than 10 years of age [30].

A well organized discussion relating to a child’s HIV status may result into several benefits. Informing the child in an appropriate, socio-culturally sensitive way may be fruitful for their good mental health. The discussion should be carried out in a structured setting involving parents and health care team. Thus each one associated with it must be prepared to cope up with the child’s reaction to revelation. The child may or may not respond instantly and may have a delayed response [31].

CONCLUSION

In spite of the recommendations made and benefits seen from revealing the HIV status to the children, many HIV positive children remain unaware of their infection. Disclosing the HIV status to the children remains difficult issue in lack of proper environment. Therefore, in greater interest of welfare of an infected child it is imperative to provide a purposeful guidance, create proper environment and initiate a healthy discussion involving all the stakeholders before revealing the disease status to a child. Once the HIV status is revealed to HIV-infected child, the overall welfare of the child must be taken care by engaging and monitoring him/her activities. It would also be in greater interest of public health in terms of healthier growth of such children, which may be satisfying to parents and helpful to the society at large.

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