Brief Report

Debunking Common Barriers to Pediatric HIV Disclosure

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Summary

As HIV-positive children continue to gain more access to antiretroviral therapy and survive into young adulthood, caregivers face the difficult process of disclosing a child's HIV status to that child. Although disclosure has many proven benefits for mental health, psychosocial development, caregiver well-being, treatment adherence and future planning, such a process is still often met with resistance. This article discusses the main reasons given for delaying or avoiding disclosure of a child's HIV status. Each barrier to disclosure is discussed and debunked as an insufficient reason to delay the positive benefits that the disclosure process has shown to produce. HIV disclosure is a critical and multifaceted issue in children. Such a process has been shown to best involve a multi-disciplinary support team that assists caregivers in continually adapting the disclosure discussion to meet the developmental needs and understanding of each individual child over time.

Key words: HIV/AIDS, disclosure, adolescents.

Introduction

As more HIV-positive children gain access to antiretroviral therapy (ART) and survive into adolescence, caregivers face the difficult process of disclosing a child’s HIV status to that child [1]. There exists important evidence of the multiple benefits of disclosure for both children and their caregivers. Studies have shown that disclosure has positive effects on children’s mental health, contributing to improved self-esteem, decreased problematic behavior and less psychological distress [2, 3]. Likewise, studies have found that the mental health of caregivers may benefit from disclosure practices, with disclosing parents reporting less psychological distress and depression compared to non-disclosing parents [3, 4]. Additionally, disclosure has been shown to increase a child’s adherence to ART [5, 6], which is important for reducing opportunistic infections and preventing drug resistance [7]. Disclosure may also play a role in preventing the spread of HIV by decreasing vulnerability to risk behavior [8]. Social support and open communication regarding a child’s diagnosis gain special importance during puberty when adolescents must make decisions about sexual activity, drug experimentation and future planning. These choices are given added complexity for the HIV-positive adolescent and should be made with an appropriate understanding of one’s infection status.

Barriers to Disclosure

Although disclosure has many proven benefits for mental health, psychosocial development, caregiver well-being, treatment adherence and disease prevention, such a process is often met with resistance. Understanding the major barriers to disclosure is necessary to prepare HIV-positive children for the future [9–15].

Child is too young

It is often assumed that children are ‘not old enough’ to comprehend the nature of a terminal illness. This assumption has been challenged by pediatric cancer studies showing that children were aware of the seriousness of their illness long before it was disclosed to them [16–18]. Children may interpret others’ behavior toward them as meaning that they are ill (crying relatives or distress shown by parents). They also learn by overheard conversations. In recent studies, caregivers of HIV-infected children did not perceive how much these children understood about their illness [12, 19]. The literature on childhood diseases indicates that a lack of disclosure certainly does not equate with a lack of illness awareness and that shielding a fatal prognosis may actually be harmful because children are not able to openly discuss their anxieties.
**Do not want to upset the child**

Many caregivers share the desire to ‘protect’ children from harmful information that might lead to negative psychological consequences. However, studies have concluded that children will feel the psychosocial stress of a serious illness whether disclosed to or not [19, 20]. In fact, non-disclosure may even contribute to poor psychosocial adjustment [19, 21]. Silencing disclosure to not ‘upset a child’, although well-intentioned, may likely have the reverse effect.

**Child is not asking questions**

Caregivers often cite the excuse that children are ‘not ready’ for disclosure because they have not been asking questions. Children may decide not to ask questions about their illness for several reasons [22]. Many children, especially in sub-Saharan Africa, have already seen family members die and can associate their own infection with the disease that took the lives of these relatives. By not putting forth the specific question ‘Do I have AIDS?’, children can remain with the hope that their suffering is due to something else. Living in a state of uncertainty allows people to linger in what has been called the ‘subjunctive mode’, where a different reality remains possible [23]. Additionally, it is an expectation in many cultures that children will not ask questions. Because children are at the bottom of the societal hierarchy, it is often inappropriate for a subordinate to question anyone in a superior social position [24, 25]. Simply because children are not asking direct questions about HIV does not mean that they are not ready to begin discussing their illness.

**Fear of parental disclosure**

HIV presents unique concerns regarding disclosure compared with other childhood diseases because disclosing a child’s HIV usually involves disclosing the status of other family members as well. HIV is often associated with deviant sexual and drug-related behaviors, and parents may fear having to explain to their children how they became infected and the rejection and blame that could result [26]. There is evidence, however, that concealing a diagnosis may actually result in increased psychological distress and depression for parents [3, 4]. It is important for health care providers to emphasize the benefits of disclosure and to address such parental fears throughout the disclosure process [27].

**Child cannot keep a secret**

Caregivers may avoid disclosure because they fear that children might accidentally reveal the diagnosis of other family members [28]. The anticipated negative consequences related to stigma may delay or prevent disclosure. While these fears are very real, they should not override the multiple benefits of disclosure and open communication with children. As previously pointed out, parents may be quite surprised by how much their child already knows. Education and other policies to reduce stigmatization surrounding HIV/AIDS should continue to be emphasized, and appropriate support systems for parents should be identified to assist them throughout the disclosure process.

**Caregiver does not know how to initiate the disclosure process**

Caregivers often struggle with the issues of when and how to begin the disclosure process. The prevailing view in pediatrics is that an HIV diagnosis should be shared with children at the appropriate developmental level and become progressively more detailed over time [20, 29–32]. Starting with younger children, the discussion should be centered on a general understanding of health and illness which then becomes a more focused conversation about HIV/AIDS in adolescents. Professional support by healthcare and social service providers in preparing families and more formal guidelines for both families and providers have been suggested as important means to improving disclosure to HIV-positive children [29, 33].

**Conclusion**

As HIV-positive children become young adults, understanding their diagnosis and the nature of the disease gain increasing importance. Issues such as treatment adherence, self-esteem, bereavement, behavioral problems and a fear of illness and death cannot be adequately addressed without disclosure. It is important for health care and social service providers to understand the major barriers caregivers face in initiating such a process. Disclosure is a critical and multifaceted issue that should involve a multidisciplinary support team to address the developmentally evolving needs of each individual child over time.

**References**