Benefits of Disclosure of HIV Status to Infected Children and Adolescents: Perceptions of Caregivers and Health Care Providers

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The rate of disclosure of HIV status to infected children and adolescents remains low in developing countries. We used a mixed-method approach to determine the perceptions of caregivers and health care providers about the benefits of HIV status disclosure to infected children and adolescents and to assess the support needed by caregivers during disclosure. We recruited a convenience sample of 118 caregivers of HIV-infected children and adolescents for the quantitative component of the study and completed in-depth qualitative interviews with 10 purposefully sampled key informants, including health care providers and volunteer workers. The main benefits of disclosure included improved medication adherence and healthier, more responsible adolescent sexual behavior. The main supports required by caregivers during disclosure included biomedical information, emotional and psychological support, and practical guidelines regarding disclosure. We confirmed the importance of disclosure to HIV-infected children and adolescents and the need to develop culturally specific disclosure guidelines.

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It is estimated that about 3.3 million children younger than 15 years of age are living with HIV globally (Foundation for AIDS Research, 2013). Of this number, 88% live in Sub-Saharan Africa (Foundation for AIDS Research, 2013). In 2011 alone, a total of 330,000 children younger than 15 years of age were newly infected, 90% of whom lived in Sub-Saharan Africa (Joint United Nations Programme on HIV/AIDS, 2013a). In Ghana, an estimated 33,000 children were said to be living with the HIV infection in 2012 (Joint United Nations Programme on HIV/AIDS, 2013b).

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The World Health Organization (WHO, 2013) reported that access to treatment over the previous decade had improved quite significantly and would be expected to improve further with the planned global scale-up of antiretroviral therapy (ART), which, when fully implemented, would be expected to help avert at least an additional 3.0 million deaths (adults and children) in low-to middle-income countries (WHO, 2013). This has resulted in improved chances of survival for children with the infection. Many more children who would otherwise have died of the infection at infancy will now survive and live into adolescence and adulthood. Therefore, there is a need for discussion and formulation of the role, timing, methods, and benefits of telling these children their HIV diagnoses.

WHO (2011) and the American Academy of Pediatrics (1999) have recommended that, as part of their long-term management, children of school age should be told their HIV status, based on improved access to ART and the numerous benefits of disclosure of HIV status to infected children, such as improved adherence to medications, responsible adolescent sexual behavior, and improved psychological health of infected children. They further recommended that younger children should be told their status incrementally to accommodate cognitive skills and emotional maturity, in preparation for full disclosure (American Academy of Pediatrics, 1999; WHO, 2011).

Despite expanding access to ART and the numerous benefits of disclosure mentioned above, disclosure remains rare, especially in developing countries (WHO, 2011). This may be accounted for in part by the numerous challenges faced in resource-constrained settings, including high rates of HIV-related stigma and the heavy workloads of health care workers coupled with inadequate training in pediatric HIV counseling (Lowenthal & Marukutira, 2013). It may also be a lack of awareness of these benefits in caregivers in developing countries, but very few studies have been done in resource-poor areas on the benefits of disclosure.

Studies such as those by Myer, Moodley, Hendricks, and Cotton (2006) and Nostlinger and colleagues (2004) suggested that if health care workers had formal guidelines to rely on to enable them to provide adequate support to caregivers and their families on disclosure, the rate of disclosure to infected children would improve. In other studies (Abebe & Teferra, 2012; Oberdorfer et al., 2006), a majority of caregivers indicated they would like support from health care providers working with HIV-infected children during the disclosure process. In spite of the need for formal guidelines to aid the disclosure process, Ghana has not developed a national guideline to support health care workers in this critical function. Acknowledging this gap, WHO (2011) suggested that health care workers often lacked support and were, therefore, not well positioned to assist caregivers. "Health care workers are often without the support of definitive, evidence-based policies and guidelines on when, how, and under what conditions children should be informed about their own or their caregivers' HIV status" (WHO, 2011, p.10).

The objectives of our study were to determine the perceptions of caregivers about the benefits of disclosure of HIV status to HIV-infected children and adolescents and to assess the nature of support required by caregivers during the process of disclosure from the perspectives of both health care workers and caregivers.

Methods

Study Design

A cross-sectional study using a mixed-method approach (quantitative and qualitative) was adopted. The quantitative aspect of the study involved the administration of structured questionnaires to caregivers of HIV-infected children and adolescents, ages 4 to 19 years, attending the three hospitals that offered pediatric HIV care in the Lower Manya Krobo District of the Eastern Region of Ghana. The hospitals included the Atua Government Hospital, the St. Martins de Porres Hospital, and the Akuse Government Hospital. These facilities were selected because of their locations in an HIV-endemic area. Additionally, no studies could be identified that had been carried out in such a resource-deficient setting as Ghana. Our study was conducted over a period of 3 months from August to October 2014. In order to allay respondent fears of inadvertent disclosure of an infected child's status, children and adolescents