



Disclosure of HIV Status to Perinatally Infected Adolescents in Urban Uganda: A Qualitative Study on Timing, Process, and Outcomes

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Disclosure of HIV status to children and adolescents living with HIV remains a challenge in pediatric HIV care. Many of the current disclosure guidelines from national and international bodies recommend that perinatally infected children be informed of their HIV status prior to adolescence, but rates of disclosure in both high- and low-income countries remains low. The applicability of the recommendations to low-income countries remains largely unknown, as few studies have explored the disclosure process in these settings. Our purpose was to explore disclosure experiences of HIV-infected adolescents in Uganda. Disclosure was a largely one-time event conducted by health care providers. The average age at disclosure was 13 years. Disclosure elicited a diverse array of positive and negative reactions, including suicidal ideation; reactions were closely associated with participant age, gender, knowledge about HIV, and health status at time of disclosure. Interventions to promote locally effective, process-oriented approaches to early disclosure are needed.

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Antiretroviral therapy (ART) has dramatically reduced HIV mortality (Lima et al., 2009), prolonging the survival of HIV-infected children into adolescence and young adulthood. The United Nations Joint

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Programme on HIV/AIDS (UNAIDS, 2013) has estimated that 3.3 million children are living with HIV globally, and 90% live in sub-Saharan Africa. In 2012, approximately 2.1 million adolescents (ages 10-19 years) were living with HIV worldwide; of these, 100,000 to 150,000 (5%) were living in Uganda (United Nations Childrens Fund, 2014). This adolescent population includes the maturing cohort of children perinatally infected with HIV. Despite advances in HIV care, numerous psychosocial challenges remain regarding the disclosure of HIV diagnostic status to infected children and adolescents.

Not all adolescents living with HIV are fully aware of their diagnosis; a continuum of experiences characterizes the manner in which their HIV status was revealed, including nondisclosure, partial disclosure, and full disclosure (Funck-Brentano et al., 1997; Pinzon-Iregui, Beck-Sague, & Malow, 2013; Wiener, Mellins, Marhefka, & Battles, 2007). Adolescents who are aware of their HIV status are more engaged in health care decision-making, and have higher self-esteem, improved access to social support, and better relationships with their parents/caregivers (Committee on Pediatrics AIDS, 1999; Funck-Brentano et al., 1997; Instone, 2000). Nondisclosure and partial disclosure have been associated with inadequate knowledge about HIV, poor adherence to ART, poor psychosocial adjustment, and poor coping responses (Abadía-Barrero & LaRusso, 2006; Instone, 2000); confusion and mistrust between the child, parents/caregivers, and health care providers (Abadía-Barrero & LaRusso, 2006); and increased risk of secondary HIV transmission (Bakeera-Kitaka, Nabukeera-Barungi, Nöstlinger, Addy, & Colebunders, 2008). Nondisclosure reinforces HIV stigma and isolation among HIV-infected persons (Tsai et al., 2013), violates adolescents' human rights to know, and undermines their emerging autonomy as young adults (De Santis & Colin, 2005).

Despite evidence of substantial benefits of disclosure, caregivers and health providers face significant challenges in disclosing an HIV diagnosis to infected children and adolescents. In both low- and high-resourced countries, rates of disclosure to children and adolescents remain varied, but they are lower in low-resourced countries compared to high-resourced countries (Pinzon-Iregui, Beck-Sague, &

Malow, 2013). In addition to the differences in disclosure rates between low- and high-resourced countries, there are marked disparities in age at disclosure, as disclosure typically occurs later (generally delayed to 12 years or later) in low-resourced countries (Pinzon-Iregui et al., 2013).

Barriers to disclosure include caregiver concerns about a child's cognitive ability to understand the full implications of an HIV diagnosis, the psychosocial impact of disclosure, and the child's ability to maintain confidentiality about their status; fear of stigma and discrimination; caregiver desire for the child to live a normal childhood; parental guilt about infecting the child; discomfort talking about HIV; and fear of anger, blame, rejection, or loss of respect (Domek, 2010; Funck-Brentano et al., 1997; Pinzon-Iregui et al., 2013; Mellins et al., 2002; Miah, 2004; Rwemisisi, Wolff, Coutinho, Grosskurth, & Whitworth, 2008; Wiener et al., 2007).

There is a need for successful strategies to facilitate disclosure of HIV status to infected children and adolescents (Pinzon-Iregui et al., 2013). A majority of existing studies on disclosure have focused on parental barriers to disclosure and the outcomes of disclosure; few have explored how parents are prepared and counseled to disclose to their children (Gachanja, Burkholder, & Ferraro, 2014). Only one study has explored the actual practice of disclosure in Africa (Lowenthal et al., 2014), and little is known about how current practices compare to prevailing guidelines on disclosure or how current practices are experienced by HIV-infected adolescents. Moreover, while the existing literature provides insight into parents/caregivers' perceptions of their children's and adolescents' responses to disclosure, parents/caregivers are not always attuned to their children's feelings of distress (Cremeens, Eiser, & Blades, 2006).

Guidelines on HIV Disclosure to Children and Adolescents

A range of guidelines on HIV disclosure to children and adolescents are currently available from professional societies (Committee on Pediatrics AIDS, 1999; Miah, 2004), the World Health Organization (WHO, 2011), and the African Network

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