

Increasing Pediatric HIV Disclosure to Children in Uganda

Worldwide, approximately 1.8 million children under 15 years of age are living with HIV,¹ with almost 90 percent residing in sub-Saharan Africa (SSA). With increased availability of antiretroviral therapy (ART) and improved care, growing numbers of perinatally HIV-infected children are surviving into adolescence.

As HIV care and treatment programs for children expand,² a growing challenge facing health providers and caretakers is disclosure of HIV serostatus to children living with HIV. Although disclosing to a child that he or she is living with HIV is an important and integral part of providing comprehensive HIV medical care, studies conducted in SSA have indicated that only about 10 percent of these school aged children (up to 10 years of age) know their HIV status.³ Studies conducted in high-income as well as low- and middle-income countries have shown that children who know their HIV status have, in general, better mental health, behavioral, and clinical outcomes, while their caretakers have reduced rates of emotional and psychological distress.⁴⁻⁸

The World Health Organisation recommends that disclosure to children about their HIV status should happen between ages 6 and 12 years old.⁹ However, very few health providers receive formal training in how to support disclosure of an HIV diagnosis to an infected child.¹⁰

As pediatric HIV care programs expand to provide treatment services, there is an urgent need for effective, culturally appropriate, and scalable disclosure interventions that: 1) improve caretaker's ability to communicate with their child about chronic illness, HIV, and adherence to ART; and 2) promote sustained, positive mental health, behavioral, and clinical outcomes of HIV-positive children who know their HIV status.



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Key Messages

- By six months the DISCO-Kids intervention was effective in fostering disclosure by caregivers to their child.
- The intervention was very acceptable among caregivers—97 percent attended all group sessions and 96 percent of caregiver-child dyads attended all dyad sessions.
- Findings suggest that DISCO-Kids could be a potential model for scale up in Uganda and elsewhere in the region.

Study Objectives

The overall goal of this study was to assess the effectiveness of a caretaker and child-focused cognitive-behavioral intervention that is culturally appropriate and potentially feasible to scale up within the context of HIV care and treatment clinical programs in SSA. The objectives were to determine:



- The effectiveness of the intervention in increasing disclosure of children’s HIV diagnosis by a caretaker to their children living with HIV ages 7 to 12 years old.
- The effect of disclosure on immediate and longer-term caretaker and child mental health, and on child behavioral and clinical outcomes.
- Whether the intervention modifies these effects.

Intervention Description

The intervention, called DISCO-Kids (Dialogue Intervention to Support Communication and Openness), included:

- **Caregiver group sessions:** Three problem-focused, cognitive-behavioral intervention sessions with up to 10 caretakers in each group, each lasting three hours, were delivered by a lay health counselor over a three- to six-week period. Session topics included: HIV and antiretroviral medication review, developmental stages of childhood and adolescence, communicating sensitively with children, skills and strategies for disclosing the child’s HIV status to the child, and providing support to children after disclosure. Participatory group counseling methods were used, including modeling, role-playing, and other interactive activities. One of the group sessions included facilitated discussion about a film on pediatric HIV disclosure, produced by our team specifically for the study (<https://vimeo.com/lbutler/powerofknowinguganda>).
- **Individualized counseling sessions for caretakers and their children:** Three individualized sessions were delivered by a lay health counselor over a three-month period. These sessions were tailored to the circumstances of the caretaker’s case, her/his disclosure expectations, and her/his child’s age and developmental readiness.
- **Booster sessions:** Caretakers participated in a facilitated “booster” session and caretakers with their children participated in a “booster” individualized counseling session approximately nine months after the last caretaker-child session. These sessions were included to reinforce learning by revisiting concepts and making connections to experiences the caretakers and children had in the interim.

Description of Standard Care

Following the *Uganda National Policy Guidelines for HIV Counselling and Testing*,¹¹ counselors are expected to assess caregiver willingness to discuss HIV and test results with the child openly and to provide support and counseling until the child is old enough to be disclosed to. However, there is no specific guidance as to how to determine the caregiver’s or child’s readiness, or to advise or support caregivers to prepare for disclosure or how to support children after disclosure.

Methods

We used a randomized controlled trial to assess the effectiveness of the DISCO-Kids intervention. Eligible participants were caregivers 18 years of age or older and their children living with HIV aged 7 to 12 years old who, by caregiver report, did not know their status and were in care at one of six clinics in Kampala, Uganda. At each of the six study clinics, participants were randomized to either receive the DISCO-Kids intervention or standard care (i.e., no specific counseling or support for disclosure). Data were collected at baseline, 6, 12, 18, and 24 months, including:

- Structured and semi-structured interviews with both caregivers and children to assess the primary outcome—full and accurate disclosure of children’s HIV-positive status by the child’s primary caretaker or counselor with caregiver’s permission, and secondary outcomes, including child social and emotional functioning, caregiver-child relationship, child adherence to ART, and caregiver depression.
- Data abstraction from children’s medical charts to evaluate somatic growth, morbidity, and hospitalizations (secondary outcomes).
- Dried blood spot collection for assessment of viral load (secondary outcome).
- Hair sample collection for assessment of antiretroviral (ARV) drug levels (secondary outcome).

Results

This brief highlights findings from the six-month follow up.

A total of 300 caregiver-child dyads were enrolled in the study and 287 of these dyads completed the six-month visit. This represented 141 dyads in the intervention arm and 146 in the control arm. The majority of caregivers were female (90 percent) and 74 percent of these women were mothers (median age 35 years [IQR 31–40 years]). The remaining 16 percent were female non-parental caregivers (median age 38 [IQR: 31–56 years]). Ten percent of the caregivers were men—6 percent were fathers (median age 41 years [IQR 39–45 years]) and 4 percent were male non-parental caregivers (median age 25 [IQR: 21–45]). More than half of all caregivers (58 percent) had an education level less than grade eight. The median age of the children at enrollment was 9.2 years (IQR: 7.9–10.2) and 97 percent were attending school. There were no significant differences in participant baseline characteristics between the intervention and control groups.

In the intervention group, almost all caregivers (97 percent) attended all group sessions, and the vast majority (96 percent) of caregiver-child dyads attended all dyad counseling sessions.

Caregivers in the DISCO-Kids intervention were much more likely to disclose to their child by the six-month visit than those in the control arm.

As shown in Table 1, 85 percent of caregivers in the intervention group fully disclosed to their child by the 6-month study visit compared to 15 percent in the control group (OR 23.7, 95 percent CI 12.7–44.3). In univariate analyses, male caregivers

had a greater odds of disclosing to their child than female caregivers (OR 2.6, 95 percent CI 1.1–5.7). In multivariate analyses, in addition to the strong intervention effect (AOR 29.8, 95 percent CI 15.0–59.3), greater caregiver disclosure self-efficacy at baseline was independently associated with full and accurate disclosure by six months (AOR 1.8, 95 percent CI 1.1–3.2). Caregiver age, education level, HIV status, relationship to the child (e.g., mother vs. other), age of child, sex of child, and child ARV use were not associated with full and accurate HIV disclosure by six months after enrollment.

Conclusion and Recommendations

Our analysis shows the DISCO-Kids intervention to be highly acceptable and effective with respect to pediatric HIV disclosure by six months after enrollment. Greater caregiver disclosure self-efficacy was independently associated with pediatric disclosure by six months. Additional results will be available at the end of 2017.

Study findings provide the basis for further research on longer term effects of early pediatric HIV disclosure, as well as interventions to support HIV-positive children as they transition to and through adolescence. In addition, monitoring long term benefits of children knowing their status and its impact on adolescent health and behavior is critical, as this highly vulnerable group of children requires innovative interventions to improve their health outcomes.

These study results will be used to inform strategic planning for scale-up of the DISCO-Kids intervention in Uganda, and further study of its implementation in Uganda and other countries will help identify the

Table 1 Caregiver disclosure

Intervention group	Total N=287	Full disclosure N=129	Not full disclosure N=158	Unadjusted OR (95% CI)	Adjusted OR** (95% CI)
DISCO-Kids (N=141)	141 (49.1%)	110 (85.3%)	31 (19.6%)	23.7 (12.7–44.3)	29.8 (15.0–59.3)
Standard care* (N=146)	146 (50.9%)	19 (14.7%)	127 (80.4%)	Ref	Ref
Caregiver disclosure self-efficacy (baseline) (median, IQR)	2.0 (1.6–2.6)	2.2 (1.8–2.7)	1.9 (1.5–2.4)	1.7 (1.1–2.5)	1.8 (1.02–3.1)

*Standard counseling as per *Uganda National Policy Guidelines for HIV Counseling and Testing*¹¹

**Adjusted for child age at baseline and caregiver sex

resources required to grow and sustain the program. To further this process, we recommend the following:

- Dissemination of these findings to HIV and AIDS stakeholders and policymakers. This is critical to ensure that this successful intervention to foster pediatric disclosure is shared broadly, included in policy documents, and implemented effectively.
- Integration of DISCO-Kids counseling strategies into the national counseling guidelines for HIV disclosure in children.
- Development of a training module for rapid sensitization and training of health workers to implement this innovative strategy for HIV disclosure in children.

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Acknowledgments

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