

Study explores how to tell children they have HIV

January 20 2017, by Anne Wolf



Research assistant Betty Nyangoma talks with a study participant. Credit: University of California, San Francisco

For the past two years, Rachel King, PhD, MPH, an academic coordinator at UCSF Global Health Sciences, has been helping Ugandan parents and caregivers find developmentally appropriate ways to tell their children that the child has HIV.

There are an estimated 150,000 HIV-infected children in Uganda, and studies indicate less than a third of children under the age of 15 know they are infected.

King, and the collaborating team, designed and implemented a study to determine the effectiveness of an [intervention](#) to improve caregiver disclosure to their HIV-positive children the child's HIV-positive status (pediatric disclosure). King is the UCSF principal investigator. UCSF is a sub-partner to University of Connecticut, where the principal investigator is Lisa Butler, PhD.

The intervention, called Dialogue Interventions to Support Communication & Openness-Kids (DISCO), included a series of three group meetings for [caregivers](#) and one-on-one counseling sessions for the caregiver, the child, and the caregiver-child pair. The meetings were held at the healthcare facility, ideally at the same time caregivers and children came to get their anti-retroviral medication.

In the [group meetings](#), caregivers learn developmentally appropriate ways to talk with their child about difficult subjects, from the death of a grandmother to the fact that the child has HIV. "It's very difficult to tell a child he or she has HIV because it has to do with sex and death and the fact that the parent passed HIV to the child," King said.



Sylvia Malemo Elyanu (left) and Rachel King discuss study metrics. Credit: University of California, San Francisco

Many caregivers were afraid to tell their children and had made up elaborate stories to explain to the child why he or she needed to take medication, King said. But by the end of the intervention, most caregivers had told their children that they were infected.

"Many caregivers were grateful for the group sessions, and were able to disclose to their child much more quickly," King said.

In addition, the adults liked being able to talk with others like themselves. HIV remains highly stigmatized in Uganda, and so many people feel as if they are the only one infected.

Three hundred pairs of caregivers and children participated in the study, which is funded by the National Institutes of Health, USAID and Project SOAR; 150 of the pairs were in the intervention group. The DISCO team collected data to study the effectiveness of this intervention in improving pediatric disclosure (the primary outcome), as well as improving children's adherence to treatment; in improving the children's understanding of their HIV status; and in relieving the caregiver's anxiety and depression.



Study participant Sara Nabasirye talks with a counselor. Credit: University of California, San Francisco

The team also will be analyzing the data to see whether the intervention is cost-effective and scalable. Earlier studies by King's team and others

have indicated that both caregivers and children have a high demand for [health](#) provider-facilitated communication about HIV and disclosure to HIV-infected children.

Despite the rapid expansion of HIV services for children in Uganda, very few health providers receive formal training in how to support disclosure of an HIV diagnosis to an infected child. And even though the World Health Organization recommends children learn their HIV status by the age of 12, there are no tested models for supporting caregivers and HIV-infected [children](#) in Sub-Saharan Africa through the process of disclosure.

"We'd like to discuss with the Ministry of Health what parts of our intervention it can scale up to other clinics," King said. "The Ministry and health care providers have been struggling with this issue for as long as I've been working on HIV in Uganda, more than 20 years."

Provided by University of California, San Francisco

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