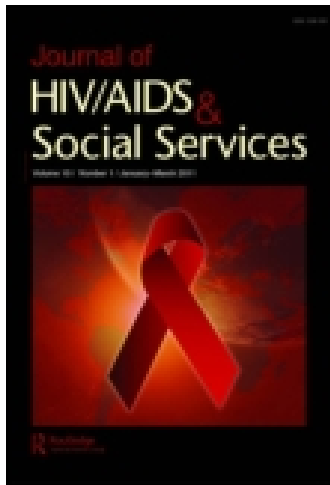


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### Foundation for the Future: Meeting the Psychosocial Needs of Children Living With HIV in South Africa and Uganda

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## **Foundation for the Future: Meeting the Psychosocial Needs of Children Living With HIV in South Africa and Uganda**

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*Successes in diagnosing and treating pediatric HIV have necessitated care that extends beyond basic medical needs. However, capacity for providing childhood psychosocial support (PSS) remains limited. Programmatic research with young PLHIV, care providers and parents in Uganda and South Africa explored challenges in meeting the psychosocial needs of HIV-positive children. Three areas for childhood PSS were examined: disclosure, stigma, and grief/bereavement. This research identified programming gaps, strategies and good practices in five focal areas: providing*

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*immediate postdiagnosis support, stigma reduction, capacity building, addressing grief, and promoting peer support. Recommendations are presented for enhancing PSS for HIV-positive children in resource-limited settings.*

*KEYWORDS* adolescents, AIDS, care, children, counseling, HIV, psychosocial, testing

## INTRODUCTION

Increased efforts to diagnose HIV in infants and provide antiretroviral therapy (ART) have contributed to reductions in HIV-related deaths among children under age 15. While many infections in children still go undiagnosed, these recent advances enable a new generation of children to live longer, healthier lives (Ferrand et al., 2010; Sopena, Evangeli, Dodge, & Melvin, 2010). As HIV management shifts toward a chronic disease model, addressing the psychosocial concerns of people living with HIV (PLHIV)—especially children—becomes a pressing priority for ensuring their long-term well-being (Gutmann & Fullem, 2009; Rochat, Mitchell, & Richter, 2008).

Children with HIV are likely to experience more psychological problems than are their uninfected peers (Gaughan et al., 2004; Gosling, Burns, & Hirst, 2004). Therefore, good psychosocial support (PSS) is especially critical, creating the foundation from which children can establish their identity and place in society, manage their care and live positively, cope with challenges, and plan for their future (Regional Psychosocial Support Initiative [REPSSI], 2003; Rochat, Mitchell, & Richter 2008). PSS for children entails meeting their emotional, mental, and social needs, often through counseling, cognitive behavior therapy, and play groups (Clay, Bond, & Nyblade, 2003; Richter, Foster, & Sherr, 2006). For most children with HIV, the first line of support is family caregivers who also face HIV-related stressors, including their own HIV status, challenges with disclosure, and social isolation due to stigma (Brown & Lourie, 2000; King, De Silva, Stein, & Patel, 2009). Such stresses can render these adults less capable of providing much-needed support to the children in their care (Abasiubong, Bassey, Ogunsemi, & Udobang, 2011; Murphy, Marelich, Armistead, Herbeck, & Payne, 2010). Despite these findings, few studies have explored how programs equip parents, caregivers, and service providers to meet the psychosocial needs of children with HIV.

This article presents findings about PSS for children based on a literature review and data collection including expert informants, parents, children, and caregivers. Interviews with experts in pediatric HIV identified three key threats to the psychosocial well-being of children with HIV: mishandling of disclosure, stigma, and grief and bereavement (Instone, 2000; Lin et al., 2010). Qualitative field research then explored how these challenges

are currently addressed by parents, caregivers, and professionals providing PSS to 0- to 12-year-old children with HIV in Uganda and South Africa. The research also identified promising practices in bridging the gap between children's psychosocial needs and the capacity of those who care for them.

## METHODS

### Data Collection

Investigators conducted interviews with global HIV program experts in government and civil society to explore strengths and gaps in providing care for children with HIV. These background interviews informed a desk survey of peer-reviewed and gray literature on the psychosocial needs of children with HIV and current programming responses. Through this review and in consultation with a Technical Advisory Group (TAG), the research team narrowed the study focus to three core themes of disclosure, stigma, and grief and bereavement, and developed the research protocol. Semistructured in-depth interview (IDI) and focus group discussion (FGD) guides were designed for three groups of research participants: pediatric care providers, parents/family caregivers of children with HIV from birth to 12, and perinatally infected young people aged 15 to 18 years. The guide for the third group was designed to help young people reflect on how their psychosocial needs were met or could have been better addressed.

Through these conversations, the study team sought to understand current approaches and persistent gaps in providing support to children with HIV and their caregivers as they navigate the disclosure process, encounter stigma, and experience grief and bereavement. With the project's TAG and U.S. government stakeholders in Washington, DC, Johannesburg, and Kampala, eight programs (four each in South Africa and Uganda) were selected to participate. Field visits occurred between May and November 2010. Parents/caregivers and young people living with HIV were invited by program staff to participate in FGDs if support groups already existed on-site; otherwise, they were invited to take part in IDIs. Providers were identified by the program leadership and invited to participate in FGDs or IDIs, based on their availability and scheduling preferences.

The research protocol was reviewed by the Institutional Review Board of the International Center for Research on Women and received ethical approval from three in-country ethics committees: Uganda National Council for Science and Technology, University of Witwatersrand (South Africa), and Hospice Palliative Care Association (South Africa). Written informed consent was obtained from all participants before each interview or focus group using the language preferred by the participant: Luganda or Runyankole in Uganda, Xhosa or Sotho in South Africa, and English in both countries.

Participants unable to read the documents were asked to provide verbal consent before beginning the interview or focus group. The voluntary nature of participation was emphasized at the recruitment phase, when reviewing the consent forms, and during the interview process to ensure that participants understood their participation would in no way affect their receipt of benefits from the service provider. Members of the research team facilitated discussions in English (J.M.S., A.K., J.B., M.V.) and in local languages (K.D., E.N., R.N.), and information was recorded through handwritten notes.

## Analysis

Qualitative data were collected through selective transcription of quotes and topics within each of the three key themes. Notes from FGDs and IDIs were recorded by multiple team members using a standardized data collection matrix to ensure consistency and data quality. The research team compared matrices at the end of each day to assess the extent to which key themes had been addressed, and the degree of agreement within and across participant groups. If gaps in responses relevant to a particular theme were identified, this domain was prioritized for the remaining sessions at that site. When the team agreed that saturation had been reached on a topic, this line of inquiry was de-prioritized in subsequent interviews. This triangulation helped identify consistency across the three perspectives: young people with HIV, caregivers of children with HIV, and service providers. This process allowed for iterative validation of data within and across discussions as well as program sites. Once all data had been collected for each country, the research team conducted cross-program analyses to identify common themes, promising practices, and emerging recommendations. After data collection ended, additional thematic comparisons were conducted to identify divergences and consistencies across the two country contexts.

## RESULTS

### Sample Description

A total of 216 parents/caregivers, service providers, and young people with HIV participated in this study. These included 128 individuals in Uganda: FGDs with 49 young PLHIV (30 female participants), 39 parents/caregivers (33 female participants), and 22 service providers (16 female participants). Some of this latter group also participated in IDIs, in addition to 18 other providers. In South Africa, a total of 88 people participated: FGDs with 15 young adult PLHIV (all female participants), 22 parents/caregivers of children

living with HIV (21 female participants), and IDIs with 51 service providers (43 female participants). Three-quarters ( $n = 165$ ; 76%) of all participants were female. One South African ethics committee restricted recruitment to participants over 18; thus, Ugandan youth participants were perinatally infected 15- to 18-year-olds, while in South Africa they were behaviorally infected 18- to 25-year-olds.

## Findings

This research revealed some important commonalities in the experiences of parents, caregivers, and providers in supporting children who are living with HIV, as well as in the experiences of the young people themselves. Findings related to three key areas (disclosure, stigma and discrimination, grief and bereavement) are presented next, with illustrative quotes about the challenges in meeting children's psychosocial needs at key points in the diagnosis and treatment processes.

## Disclosure

The necessity of catering to children's psychosocial needs and disclosure-related concerns begins at the time of initial HIV testing and counselling. Many young people interviewed revealed that they had been lied to during the testing and counselling about the reason for giving a blood sample. They recalled being upset by the adults' decision not to tell them the true reason for their test.

I was hurt. They did not tell me they were taking off the blood sample for HIV testing. (Youth, Uganda)

Participants highlighted the period immediately following a child's initial diagnosis as a time during which children's needs are often inadequately addressed. Young people again expressed frustration and anger over being lied to about their diagnosis.

Doctors lied to me. They gave it a funny name, told me it was malaria. They gave my father the results, not me. (Youth, Uganda)

While this was a commonly cited practice, young people overwhelmingly did not support the decision to lie to children. Many instead suggested gradual, partial disclosure based on children's readiness to comprehend the information.

You need to tell the character of the kid. Do you tell him fast or slow? Do you hit him in the face with it and teach him later or teach first, then hit him with the truth? (Youth, Uganda)

Many providers also promoted partial disclosure, citing age and developmental readiness as important criteria for determining whether and how to inform a child that he has HIV.

I tell a little child that he's sick and needs to take his medicine so he can be strong and play like other kids, but I don't tell him that he is HIV-positive unless he's old enough to understand and handle the news. (Provider, Uganda)

Providers in both countries expressed concern about the impact that a family's decision to not tell a child has on overall well-being and adherence to life-saving medication.

Every time a child takes a drug without knowing its purpose, adherence becomes a challenge. (Provider, Uganda)

Participants noted that lack of willingness to disclose is often dictated by factors not related to the child's own readiness. Rather, the willingness of parents and family caregivers and their level of comfort are very influential in determining when a child learns of his HIV-positive status.

Mums are not happy to disclose. They are scared. (Provider, South Africa)

He is asking, why must I take my pills? I don't know how to answer him and I am hoping this will be done by our nurses at hospice. (Caregiver, South Africa)

Programs use a number of approaches to address the PSS needs of children during the pre- and post-test periods, such as by assigning individual counselors to accompany children through the testing process.

We try to create a friendship with the children from the first moment we meet them in pre-test counseling. We escort them to the lab and stay with them during the test if they want us to be there. (Provider, Uganda)

Other programs also work with and provide support to parents who are navigating decisions around partial, full, and third-party disclosure about their children's status.

We train childcare workers to help mum disclose the child's status to him or her as early as possible so that the child can take responsibility for himself or herself. (Provider, South Africa)

### Stigma and Discrimination

In addition to parents' feeling unprepared to answer their children's questions, they also fear their children will experience stigma and discrimination if others find out they are living with HIV.

Parents don't tell because they're protecting their children. Children can be cruel, and parents don't want people to be mean to their children. (Provider, South Africa)

Concerns about stigma infused all the conversations and were consistently linked to participants' decisions about informing a child of his status and disclosing to third parties. Parents, providers, and young people all underscored the pervasiveness of HIV-related stigma in their communities, and expressed concerns about how experiences with externalized and internalized stigma can harm children's well-being.

Children need a constant loving presence because they can often be isolated from others because of stigma. (Youth, Uganda)

Many adult participants emphasized the importance of helping children with HIV feel special and giving them extra attention, saying that such efforts were important to ensuring the self-esteem and well-being of children who struggle to accept the need for medication and special diets.

I don't want her to feel bad about having to take medicine and eat different foods than the other children. I tell her that she gets to have those things because she's special. (Caregiver, Uganda)

Young people, however, felt that special treatment could make others view them as different, and therefore lead to discrimination. Many expressed a desire to have the same household chores and responsibilities as their siblings.

We don't want to feel like we are special. We want to feel like every other child. (Youth, Uganda)

Youth respondents were proponents of support groups as sources of a peer network and role models, and felt that such support should be available to children immediately after they learn of their seropositive status.

You should go into peer support. Maybe it's hard for you to talk about, but so many people are talking so freely about it, you can talk. (Youth, Uganda)

Both support groups and individual counseling were mentioned as useful in helping young people fend off internalized stigma.

My counselor helped me see that whatever they said, I had the power to take it in or not, let it affect my life or not. (Youth, Uganda)

Programs also attempted to address stigma experienced within children's social environments, especially in their communities and at school.

We have had problems with teachers ostracizing our children in school, so now we go to the schools and engage with the teachers. (Provider, South Africa)

## Grief and Bereavement

In both countries, the need for addressing children's grief, particularly helping them cope with the loss of a parent or caregiver, was strongly expressed. Providers and parents felt that cultural prohibitions keep children from receiving bereavement support.

We have many kids who don't want to talk about loss. The cultural situation is that children are not part of death. Children don't even go to the graveside. They don't have closure. (Provider, South Africa)

Even a child of three years old can know that someone has died, but we don't talk to them about it. (Caregiver, Uganda)

While most programs struggled to actively address children's grief, several had introduced activities to stimulate dialogue about illness and dying.

We really need to be talking about death, dying, and health. For this reason, our social workers come into class and read stories about kids who get sick. (Provider, South Africa)

A few of the programs used books, recreational therapy, and tailored activities to encourage children and their caregivers to talk about a loved one who has died.

That Memory Box ... helps us a lot. When we think about the mother, we open the box, look at the photographs and feel comforted and accept that she has passed away. (Caregiver, South Africa)

## DISCUSSION

Across the focus group discussions and in-depth interviews, participants consistently revealed that children with HIV and those who care for them experience multiple challenges related to disclosure, stigma, and grief and bereavement. Improving the management of these processes is critical to supporting children's psychosocial well-being (Gosling et al., 2004; Rochat et al., 2008). As programs expand their services to incorporate PSS within their continuum of HIV care, concentrated efforts are necessary to build the capacity of caregivers to meet the psychosocial needs of children (Brouwer, Lok, Wolffers, & Sebagalls, 2000). Many studies have found that enhancing

the coping strategies and minimizing the stress of caregivers are necessary elements of PSS for children (Palattiyil & Chakrabarti, 2008; Van Wingham et al., 2008). Several studies also suggest that the psychosocial well-being of children and their caregivers can improve adherence to ART and other clinical outcomes (Bikaako-Kajura et al., 2006; Brouwer et al., 2000; Mellins, Brackis-Cott, Dolezal, & Abrams, 2004; Williams et al., 2006).

Participants recognized that disclosure is not a single event but rather a process that occurs over the course of a child's life (Nabilek, 2009; Wiener, Mellins, Marhefka, & Battles, 2007). While they understood that many factors influence why, how, and when disclosures occur, there was consensus that such decisions should be based on a child's developmental and emotional maturity. Although this concept was accepted across the projects and participant groups, there was little evidence of tools to guide such assessments of children's readiness, which instead was often dependent on an individual provider's perception of a child's understanding and maturity level. Similarly, while stigma was viewed as a substantial obstacle to disclosure and the receipt of appropriate PSS, programs lacked clear strategies to proactively prevent and address stigma at the institutional or community level. The impact of grief and bereavement on children's psychosocial development was also recognized by all programs, though few had ongoing or systematic activities or services to help children through their bereavement. The two most significant obstacles faced by all programs were limited resources and lack of targeted training on providing PSS to children. These challenges held true for programs centered on both biomedical models and social service models.

While this study included a large number of participants, some methodological limitations inhibit cross-programmatic and cross-context comparisons. First, the South African youth interviewed were not able to discuss the PSS needs of children with HIV from first-hand experience. However, many of these participants were raising children living with HIV and were able to share their opinions on how to meet the needs of children with HIV. Second, while every effort was made to include male and female participants, most caregivers and providers interviewed were female. Finally, the study incorporates findings from only a small number of the many programs working throughout Sub-Saharan Africa addressing these issues. Despite these limitations, this review illustrates some promising practices that enhance the psychosocial well-being of children living with HIV.

Recognizing that parents, caregivers, providers, and program staff are often overburdened and under-resourced, the following five recommendations are offered for improving capacity to meet the psychosocial needs of children aged 0 to 12 years living with HIV. Many of these recommendations should not require significant resources to implement, especially those that emphasize the role of caregivers, parents, community members, and/or children and adolescents in programming. Where staffing, technical capacity,

time, and financial resources are limited, programs can select those pieces that best address current priorities or complement existing programs.

1. Focus on the period immediately following a child's HIV diagnosis.

Parents and caregivers identified the time after HIV testing as being critical to their own psychosocial well-being and to effective planning for care of the child. This is also an important stage to build support and prevent/address stigma within the household. Programs should prioritize resources that maximize this opportunity to provide the information and support that families need. This should include three key elements: (a) strengthening providers' capacity in child and family counseling and communication, and allowing adequate time for these initial conversations; (b) helping the family develop care plans that consider the disclosure process, medical treatment and adherence, on-going psychosocial well-being (including access to education and other social interactions) and planning for bereavement, grief, and family transitions (such as succession planning); and (c) providing systematic post-test follow-up through clinic- or home-based visits to meet the needs of children and their parents/caregivers (e.g., for couples testing and counseling) and support family adjustments to providing on-going care (e.g., skill-building of family members, facilitation of discussions and disclosure among family members).

2. Reduce stigma within children's "circles of care."

The intersecting spheres in which children are socialized include households, clinics, schools, and communities. Stigma can be experienced in any of these circles, and often several at once. Programs should proactively aim to reduce stigma by (a) building awareness and understanding of stigma within all program staff and partners through trainings and values-analysis, (b) reducing fear and value-driven stigma in households and communities through on-going screening (e.g., during routine clinic or home visits) and targeted outreach (e.g., intervening at schools where stigma has emerged as a problem), and (c) promoting peer or community-led stigma reduction activities through outreach activities, mentoring, and role modeling. Such efforts should be integrated into PSS programs from the start to optimize outcomes for children and limit the potential harm of program activities such as unintended disclosure.

3. Build the capacity of caregivers and children to meet their own PSS needs.

By building the capacity of caregivers and children to provide PSS to themselves and each other, programs can encourage more responsive, sustainable models extending beyond the clinic or program activities. While trainings or

workshops can be one approach, emphasis should be placed on developing simple forms of support within the home, such as one-on-one skill building, mentoring, and facilitated communications. Such skills-transfer can be integrated into all interactions between trained providers and caregivers and/or children at little additional cost. Three specific areas emerge: (a) building capacity of parents and primary caregivers in listening and communication skills, as well as in creating opportunities for play and/or other interactions with their children; (b) developing skills of children with HIV to manage their own care, including issues of managing disclosure and stigma; and (c) cultivating the ability of older children or youth living with HIV to provide peer support or mentoring for younger children through structured activities (e.g., during clinic visits, support groups, camps) or more informal interactions in the home, school or community.

#### 4. Address grief as a process.

Addressing grief is critical to building the PSS capacity of caregivers and children. Programs should acknowledge grief and bereavement as long-term influences on psychosocial health rather than a discrete event. Programs should help children and their parents discuss and plan for death before it happens and process grief after. Many programs use culturally appropriate strategies for encouraging family and/or parent-child preparation for a death, including planning for succession and continuous child care, will writing, and creating memory boxes, books, and family trees. Several approaches can be used throughout the grief process, including play therapy, reading stories about illness and loss, and peer support groups for children and caregivers.

#### 5. Create forums for interaction and peer support.

Programs with limited resources can create structured and unstructured opportunities for children and caregivers to interact with peers, providing important ways to share experiences and learning. Activities that are decentralized from a program/clinic setting and led by young people or caregivers can cultivate a sense of leadership, shared experience, and support. These can include peer support and counseling groups, performance troupes, sports teams or events, livelihoods-based groups, and interactive educational sessions about important themes such as the nutritional needs of children with HIV and living positively. It is also important for programs and providers to consider fostering opportunities for children living with HIV to interact with peers who are not known to be HIV-positive. While it is important to ensure that these exchanges be carefully facilitated to avoid unintentional disclosure of HIV status and exposure to stigma and discrimination, such opportunities can promote a greater sense of common ground and mutual

understanding in the long term. More deliberate efforts to offer and integrate these forms of interaction into the core services and support provided for children living with HIV during initial stages of their HIV care may help build a set of resources to provide ongoing social capital and build resilience and capacity for children to manage their psychosocial well-being into the future.

## CONCLUSION

This study of eight programs in South Africa and Uganda offers opportunities for other programs to learn about promising approaches for providing psychosocial support to children with HIV. As the pendulum of HIV programming and funding swings back toward a more biomedical focus, program resources will be even more constrained and less able to address the critical PSS needs of these children and their families. Thus, it is recommended that program staff, planners, and funders dedicate their limited resources for non-medical care to the five strategies outlined here to best meet the PSS needs of the children they serve and to improve their chances for long, healthy lives.

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### Programs Participating in Technical Reviews

#### South Africa

- St. Nicholas Bana Pele Network, Free State
- Butterfly House, Drakenstein Palliative Hospice, Western Cape
- Cotlands, Western Cape
- National Association of Child Care Workers, Eastern Cape

#### Uganda

- Baylor Uganda, Kampala
- Joint Clinical Research Center (JCRC), Mbarara

- Mildmay Uganda supported-site, Naggalama Hospital, Mukono
- The AIDS Support Organization (TASO), Masaka

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