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Disclosure of HIV Diagnosis to HIV-Infected Children in South Africa: Focus Groups for Intervention Development

G. Anita Heeren,

University of Pennsylvania

John B. Jemmott III,

University of Pennsylvania

Lulama Sidloyi, and

University of Fort Hare, East London, South Africa

Zolani Ngwane

Haverford College

Abstract

Worldwide about 2.5 million children younger than 15 years of age are living with HIV, and more than 2.3 million of them live in sub-Saharan Africa. Antiretroviral therapy has reduced mortality among HIV-infected children, and as they survive into adolescence, disclosing to them their diagnosis has emerged as a difficult issue, with many adolescents unaware of their diagnosis. There is a need to build an empirical foundation for strategies to appropriately inform infected children of their diagnosis, particularly in South Africa, which has the largest number of HIV-positive people in the world. As a step toward developing such strategies, we conducted a study in Eastern Cape Province, South Africa to identify beliefs about disclosing HIV diagnosis to HIV-infected children among caregivers, health-care providers, and HIV-positive children who knew their diagnosis. We implemented 7 focus groups with 80 participants: 51 caregivers in 4 groups, 24 health-care providers in 2 groups, and 5 HIV-positive children in 1 group. We found that although the participants believed that children from age 5 years should begin to learn about their illness, with full disclosure by age 12, they suggested that many caregivers fail to fully inform their children. The participants said that the primary caregiver was the best person to disclose. The main reasons cited for failing to disclose were (a) lack of knowledge about HIV and its treatment, (b) the concern that the children might react negatively, and (c) the fear that the children might inappropriately disclose to others, which would occasion gossip, stigmatization, and discrimination towards them and the family. We discuss the implications for developing interventions to help caregivers appropriately disclose HIV status to HIV-infected children and, more generally, communicate effectively with the children to improve their health outcomes.

Keywords

HIV; disclosure; children; caregivers; stigma

Introduction

Worldwide about 2.5 million children younger than 15 years of age were living with HIV in 2009, and about 2.3 million of them were in sub-Saharan Africa (UNAIDS, 2010). South Africa is experiencing one of the most devastating HIV epidemics. In 2009, 29.4% of pregnant women ages 15 to 49 years attending antenatal clinics in South Africa were HIV-positive (Department of Health, 2010b). Recent years have ushered in a remarkable success in prevention of vertical transmission (Goga et al., 2011; UNAIDS, 2010). Nevertheless, in 2009, 330,000 children under age 15 were living with HIV in South Africa, second highest in the world (UNAIDS, 2010). Antiretroviral therapy (ART) has occasioned a durable suppression of HIV replication, prevented AIDS-defining infections and malignancies, and reduced mortality among HIV-infected children (Martinson et al., 2009; UNAIDS, 2010; Violari et al., 2008). As more of these children survive into adolescence, there has been increased attention to the issue of informing them of their HIV diagnosis (Blasini et al., 2004; Kallem, Renner, Ghebremichael, & Paintsil, 2011; Lesch et al., 2007; Wiener, Mellins, Marhefka, & Battles, 2007).

The South Africa Department of Health (Department of Health, 2010a) and the World Health Organization (World Health Organization, 2011) recommend informing children of their HIV diagnosis. Studies suggest benefits of disclosing to children their HIV diagnosis, including improved ART adherence and psychological well-being (Bikaako-Kajura et al., 2006; Blasini, et al., 2004; Menon, Glazebrook, Campain, & Ngoma, 2007; Santamaria et al., 2011). Moreover, many people who know their status avoid behaviors that can transmit the virus to others (Crepaz & Marks, 2002). However, growing evidence suggests that many HIV-infected children under medical care are uninformed (Brown et al., 2011; Kallem, et al., 2011; Menon, et al., 2007; Moodley, Myer, Michaels, & Cotton, 2006; Vaz et al., 2011).

Although most research on pediatric HIV disclosure has been conducted in developed countries (Kallem, et al., 2011; Vaz, et al., 2011), studies in South Africa report that caregivers of HIV-positive children commonly do not discuss HIV with them (Kouyoumdjian, Meyers, & Mtshizana, 2005; Moodley, et al., 2006). Fear that the children will reveal their diagnosis to other children or neighbors is the main barrier to disclosing, and the reasons for disclosing include the children's right to know, their mental health, and ART (Moodley, et al., 2006). Studies conducted in the Democratic Republic of Congo (Vaz, et al., 2011) and Nigeria (Brown, et al., 2011) reveal similar findings.

The development of effective strategies to assist caregivers to disclose HIV diagnosis to HIV-infected children requires an understanding of caregivers' beliefs about disclosure as well as those of health-care providers and children living with HIV. Focus groups are a useful tool to elicit people's beliefs. By integrating population-specific beliefs about disclosing with behavior-change theory, it is possible to develop a theoretically grounded intervention that is tailored to the population (Jemmott, In press). This article reports the results of focus groups conducted in South Africa to identify beliefs about disclosing HIV diagnosis to HIV-infected children among caregivers, health-care providers, and HIV-positive children who know their diagnosis.

Methods

We recruited the participants—caregivers, health-care providers, and HIV-positive children who know their HIV diagnosis—from clinics, hospitals, and churches and through community contacts in rural and urban areas in Eastern Cape Province, South Africa, between October 2010 and March 2011. A nurse, other health-care provider, or community contact informed potential participants about the study. They told them the purpose was to

collect information on their experiences, opinions, and ideas to develop an intervention to help caregivers disclose HIV diagnosis to HIV-infected children. To participate, adults provided written consent and children provided written parent/guardian consent and child assent.

Facilitators followed a standard protocol and script to conduct the focus groups. They asked participants questions about whether caregivers would want to participate in a program to help them disclose HIV diagnosis to HIV-infected children, why disclosure should occur, the age at which children should know their diagnosis, and who should disclose to them. Social cognitive theory (SCT) (Bandura, 1986) has been employed to develop many behavioral interventions in many settings, including South Africa (Jemmott et al., 2011; Jemmott et al., 2010; Kalichman et al., 2009; Kalichman et al., 2007). In one caregiver focus group, we included questions to elicit beliefs relevant to the SCT, including outcome expectancies regarding consequences of disclosing to children. Questions about barriers to disclosing were included to identify needs for intervention to increase skill and self-efficacy to surmount those barriers that were amenable to change. Each session lasted approximately 90 minutes.

Qualitative analysis, performed on data from facilitator notes and transcripts of audiotaped sessions, focused on questions posed within types of respondents, identified and categorized themes or patterns of responses.

The IRB of the University of Pennsylvania and the Ethical Committee of the University of Fort Hare, South Africa, approved the study.

Results

Table 1 shows the venue and location of the focus groups and the participants' sex and age range. There were 80 participants: 51 caregivers in 4 groups, 24 health-care providers in 2 groups, and 5 HIV-positive children who knew their serostatus in 1 group.

Health-care providers

A theme that emerged in the health-care provider focus groups was that caregivers lack knowledge of HIV, its symptoms, transmission, and treatment, which prevents them from disclosing the HIV diagnosis to the children. They said caregivers "should start talking to the child from the age of 5 to 7, but definitely before the child starts schooling." They felt that "the disclosure process should be completed by the age of 12 years, but definitely before the child becomes sexually active." When asked, "Who should talk to the child," they said "the parent or caregiver who stays with the child" and "the person who talks with the child and is responsible for the child." However, they also said, "Most parents do not know enough about the disease and try to hide the facts from the child." Other barriers to disclosure mentioned were "stigma," "fear of isolation," "fear of blame," "fear of guilt," and "gossip." When asked why there was stigma, they explained that in people's minds HIV is associated with "sleeping around."

The providers expressed strongly that "the child has a right to know" and "it has by the constitution the right to learn everything about the disease." This was specifically mentioned within the discussion that some parents try to prevent the child from learning about the disease. One provider said, "Some mothers would rather move from clinic to clinic before they would agree that the child learns about the disease."

The providers suggested that caregivers should disclose "to get the cooperation and understanding of the child." They also said, "the child will be empowered to make the right

decisions” and “they need to learn how they can protect themselves and others from the disease.” The providers suggested that parents would want to participate in a program to help them disclose. They said that “parents/caregivers can be educated about the disease,” and “if they are educated, they are empowered to talk to the child.”

Providers said the intervention should “be in the level of the child’s age and understanding,” but cautioned that children who are sick are much more mature than are other children. They said “adults need to stop treating children like they would not understand,” “children do understand more than adults think,” and “children who are sick often mature earlier than healthy children.” The intervention should address, they said, “details about the disease, treatment, infection,” “symptoms,” “stigmatization,” “how to accept HIV and being able to live with it,” “abstinence,” “condom use,” and “precaution measures.”

Caregivers

A theme that emerged in the caregiver focus groups was that caregivers lacked the knowledge and skills to disclose to the children and to handle the children’s reactions. The participants agreed that children age 5 or 6 years should learn about the disease. They suggested that “his mother” or “a very close person to the child,” “a person he trusts even if it’s not the mother,” or “the person who is taking care of the child” would be the best to inform the children.

There was a consensus among the participants that caregivers need help. They said, “We are desperate for help on how to help our children and would love to be able to be part of a support group.” They suggested that a program for caregivers should include “information about the disease,” “transmission,” “treatment,” “combating stigma,” as well as “healthy diet,” “nutrition,” and “growing vegetables.” An example of a gap in their knowledge was “not being sure of how the child gets infected from the mother.” One mother said, “I don’t know how I got it. I do not know what the disease is myself. How can I explain any of this to my child?” Another mother said, “I do not know how I got it. I only had my husband all my life. So, how can I explain to my daughter that she is sick?” They also said “We need counseling skills so that we know what to say” and that they needed “some counseling skills so that we will be able to convince the children that HIV is not the end of the world.” In a similar vein, some reported difficulties when they had tried to disclose to their child. One mother said, “I tried to tell my child but it insisted that it would have TB.”

Other barriers to talking to the children were “knowing the right time and age to talk to them” and “fear of the children going out to tell other people about what they have been told.” There was concern that the child might react negatively. They said, “We fear how the child might react” and “what if they do not accept and end up committing suicide?” “Fear of isolation,” fear of blame,” and particularly “stigma,” the caregivers also said prevented them from disclosing. They said, “the area is full of gossip” and assured the facilitator that “if she were to walk from the orphanage, people on the streets would ask why she visited the house as she will get infected as the people who live there are all sick.”

However, some caregivers expressed concern about not disclosing because if the children did not learn from the caregivers, the children might learn from others, at school or in the street, which might be disastrous. One caregiver said, “they end up hearing it from the streets that they have been infected by their mothers. The way it is said in the streets is not a right one because there is stigma attached to it. They will, for example, tell the children their mothers were sleeping around and use all the rude words to try and make it her fault as well as to show how she invited the disease.”

In general, the participants suggested that parents more than other caregivers were reluctant to inform their children. They said, “it is harder for parents than those that are guardians to talk to the children.” Nonetheless, caregivers all agreed that parents would want to attend a program to help them talk to their HIV-infected children.

The caregivers in the focus group that was asked specific questions to elicit beliefs relevant to SCT expressed several positive outcome expectancies regarding disclosing. They said, “the child will no longer protest to take medication but understand that if it takes the medication it will stay healthy,” “the child himself or herself will follow-up and take the medication itself and ask for healthy diet,” and “increase their CD4.” The perceived negative consequences of disclosing were: “they will live in fear since they think they will die” and “they can take poison or all ARVs at once to try to kill themselves.” Questions also addressed barriers that building skill and self-efficacy could address. One thing that makes it hard to disclose is, “the child might ask the mother how she got it.” One thing that would make it easy is, “to meet with other parents who have HIV-positive children.”

HIV-positive children

Age 5 years was the youngest any child in the HIV-positive children focus group learned their diagnosis. The others learned at the age of 7, 10, 13, or 15. Only 1 said she learned her diagnosis from a doctor; the others learned from family members. They said they were told because they were “nagging their guardians as to why they are taking this treatment and when they will ever stop taking it.” The children expressed that they thought it would be better if they had been told earlier in their lives, specifically that it would be best to be told around age 5. They indicated that the reasons why the parents or other caregivers do not talk to children about HIV include not knowing enough about the disease, symptoms, diagnosis, and treatment and fear of stigma. Another reason they cited was that caregivers were “afraid that the children might not accept it and start doing the worst things.” They explained that by worst things they meant “suicide, becoming street kids or even stopping school to defy the parents or seeing no need in continuing to take medication as they will die anyway.” They concurred that “a parent should talk to them” rather than a stranger. They indicated that if the children “understand the reason why they need to take treatment, they would have fewer difficulties to take the medication.”

Discussion

The results suggest that the focus-group participants felt that HIV-infected children should be informed about their diagnosis. There was also a consensus that parents, particularly mothers, or another caregiver who is the closest person to the children should be the person to disclose. The present results are consistent with the view of disclosure as a process rather than a single event (Lesch, et al., 2007). Thus, caregivers should begin to inform children about HIV around age 5, and they should fully disclose by age 12. For a large majority of South African children, this would be before their sexual debut (Jemmott, et al., 2010; Richter, 2006).

The participants viewed disclosing as a way to increase children’s adherence to the medication regimen and to reduce their risk of transmitting HIV to others, and some research supports this view (Bikaako-Kajura, et al., 2006; Crepaz & Marks, 2002). Caregivers and health-care providers saw disclosure as children’s basic right, which would enable them to participate actively in decisions about their care. However, the participants also highlighted important barriers that prevent disclosing. A lack of necessary knowledge and skills to communicate effectively about HIV with their children, concern about the reactions of the children, and concern about the entrenched stigma that revolves around HIV are factors that result in the consequence that caregivers do not disclose.

Of these, stigma may be the most formidable barrier. HIV is stigmatizing because it is commonly believed that people who engage in promiscuous behavior, “sleeping around,” bring it upon themselves. HIV-infected people can be stigmatized, if their diagnosis becomes known, and accordingly it is not surprising that people fear discovery and seek to conceal the infection from those who might ostracize them. For the caregivers, stigma leads to considerable concern that the informed child might disclose inappropriately and that gossipers would spread the information through the community, with consequences so adverse that caregivers avoid informing the children and even change clinics when health-care providers press too much for disclosure.

To our knowledge, only one study (Blasini, et al., 2004) tested interventions to help caregivers disclose HIV status to infected children. However, a small sample and lack of a control group limited it. Our study has implications for developing such interventions. An intervention informed by the SCT could buttress outcome expectancies supportive of disclosure, including the belief that disclosing will encourage children to adhere to the medication regimen and, more generally, a healthful lifestyle. Moreover, it could weaken outcome expectancies supportive of nondisclosure, including the belief that the children will inappropriately disclose to others and the belief that children will commit suicide. It could enhance skill and self-efficacy to communicate effectively despite barriers to communication using skill-building activities, including role playing, and using vicarious reward from testimonials of caregivers who have experienced positive consequences of disclosing. Interactive activities, including games and brainstorming, can address gaps in knowledge about HIV and its treatment.

This research has limitations. The sample is small and not randomly selected. Accordingly, the generalizability of the results is unclear. The data are from self-reports in the context of group discussions and may not be entirely accurate. The study also has strengths. It is one of the few to examine issues surrounding disclosing to HIV-infected children in South Africa their own diagnosis and to draw upon behavior-change theory to suggest implications for intervention. Conclusions are generally more persuasive when they come from a triangulation of different sources of evidence (Webb, Campbell, Schwartz, Sechrest, & Grove, 1981). Our findings are consistent across a diversity of populations, including caregivers, health-care providers, and HIV-positive children, and a variety of settings, including health-care and community venues in both urban and rural areas.

In conclusion, with the scale-up of ART in sub-Saharan Africa, more children are surviving into adolescence. Several researchers have called for a shift in emphasis from whether or not to disclose to HIV-infected children to providing culturally appropriate support to caregivers and developmentally appropriate information to the children (Domek, 2010; Kallem, et al., 2011; Lesch, et al., 2007). Consistent with this, in our focus groups we observed an urgent call for help, for interventions to assist caregivers communicate with their HIV-infected children to disclose the diagnosis and, more generally, to empower the children to adhere to ART, avoid transmitting HIV to others, and live a healthful lifestyle. By integrating qualitative information about the population with a behaviour-change theory, it may be possible to develop such interventions, which can be deployed in health-care settings in sub-Saharan Africa, where they are urgently needed.

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Table 1

Characteristics of Focus Group Participants, Eastern Cape Province, South Africa, October 2010 to March 2011.

Venue	Setting	Participants	Female, No./Total (%)	Age range, years
Clinic	Rural	Nurses	12/12 (100)	28 – 57
Hospital	Urban	Doctors/nurses	10/12 (83.3)	27 – 75
Caregiver's home	Rural	Parents/caregivers	16/18 (88.9)	23 – 67
Orphanage	Urban informal	Parents/caregivers	5/5 (100)	28 – 87
Church support group	Urban township	Parents/caregivers	12/14 (85.7)	28 – 68
Hospital ARV clinic	Rural	Parents/caregivers	14/14 (100)	27 – 74
Church support group	Urban township	Informed HIV+ children	4/5 (80.0)	10 – 17