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Caregivers' Intentions to Disclose HIV Diagnosis to Children Living with HIV in South Africa: A Theory-Based Approach

John B. Jemmott III^{1,2}, G. Anita Heeren¹, Lulama Sidloyi³, C. Show Marange³, Joanne C. Tyler³, and Zolani Ngwane⁴

¹Department of Psychiatry, Perelman School of Medicine, University of Pennsylvania, Philadelphia, PA, USA

²Annenberg School for Communication, University of Pennsylvania, Philadelphia, PA, USA

³Department of Statistics and Biostatistics, University of Fort Hare, Alice, South Africa

⁴Department of Anthropology, Haverford College, Haverford, PA, USA

Abstract

When people know their HIV serostatus, they can take steps to manage their health and the risk of transmitting HIV to others. Mounting evidence indicates that caregivers often do not disclose to HIV-positive children that the children are living with HIV, but little is known about the modifiable determinants of pediatric HIV disclosure. The present study examined theory-of-planned-behavior predictors of the intention to disclose to children their HIV diagnosis. The participants were 100 caregivers of HIV-positive children in Eastern Cape Province, South Africa. Proportional-odds logistic regression analysis revealed that normative support for disclosure and caregiver-child communication predicted the intention to disclose, whereas behavioral beliefs regarding the consequences of disclosing and self-efficacy to disclose did not. The results suggest that interventions to increase pediatric HIV disclosure in South Africa should help caregivers enlist support for disclosure among important referents and improve communication with their HIV-infected children.

Keywords

Disclosure of HIV serostatus; Intention; Caregivers; Parent-child communication; South Africa

Introduction

South Africa has one of the highest HIV infection rates in the world [1]. The main mode of exposure to HIV in South Africa is heterosexual transmission, and over one-half of the people living with HIV are females, most of whom are in reproductive ages [2]. In 2011, 29.5% of pregnant women aged 15–49 years attending antenatal clinics in South Africa were HIV positive [3]. Because HIV can be transmitted from mother to child there are many

Corresponding regarding this article should be addressed to Dr. John B Jemmott III, University of Pennsylvania, Annenberg School for Communication, 3535 Market Street, Suite 520, Philadelphia, PA 19104. Telephone 215-573-9366. Fax: 215-573-9303. jjemmott@asc.upenn.edu.

children living with HIV. In 2011, about 460,000 children aged 0 to 14 years were living with HIV in South Africa, the highest number in the world [1]. Antiretroviral (ARV) therapy, increasingly available in South Africa, is preventing AIDS-defining infections and malignancies and reducing mortality among HIV-infected children [4,5], and as more children living with HIV in South Africa and other parts of the world receive ARV therapy and survive into adolescence, there is growing concern about the issue of informing the children of their HIV diagnosis [6-8].

When people are told their HIV serostatus they can take steps to manage their health by adhering to their ARV therapy regimen and making other behavioral changes to protect their health and reduce the likelihood that they will transmit the virus to others [6,9-11]. Even children may benefit from knowing their HIV status. To be sure, medical views regarding disclosing serious illnesses to children have changed over the past 30 years [12,13]. Previously it was thought that sick children should not be told their diagnosis with life-threatening illnesses such as cancer. Today it is thought that children should be told their diagnosis [12]. Nevertheless, many children, including those in medical care, are unaware they are living with HIV [7,8,12,14-20]. Moreover, several studies indicate that sometimes caregivers inaccurately tell HIV-positive children that they have an illness other than HIV and that their ARV treatment is vitamins or medication for an illness other than HIV [17,21,22].

Parents and other caregivers are commonly the persons who control whether children are informed of their HIV diagnosis, and the great majority of caregivers want to be the person who informs the child [14,16-18,21,23], though they might want help to do so [17,18,21,23]. Accordingly, a growing number of studies is investigating why caregivers do not disclose the HIV diagnosis to children living with HIV. Most published studies on pediatric HIV disclosure have been primarily qualitative, querying health-care providers or parents and other caregivers about the reasons that caregivers do not disclose or have focused on sociodemographic variables associated with disclosing [8,12,13], variables that cannot be modified by behavior-change interventions.

Common reasons cited for not informing children of their HIV diagnosis include fear of psychological disturbance, sadness, worrying, or loss of the will to live in the children [14,17,18,21,23], inability of the children to understand [14,24], fear the children might inappropriately tell others, which would occasion gossip, stigmatization, and discrimination towards them and the family [14,16,20,23,24], fear of blaming the parents [14,24], and lack of knowledge about HIV and its treatment [23]. Reasons cited for disclosure include to increase the children's adherence to their ARV regimen [16,17,20,21,23,25], to increase the children's ability to protect themselves or stay healthy [17,25] or protect others [17], the children were becoming older [25], and to give the children the knowledge of why they are suffering [25]. Although studies have identified reasons caregivers proffer for disclosing, they have stopped short of establishing an empirical link between those reasons and self-reported disclosure; hence, whether the identified reasons actually play a role in the pediatric HIV disclosure process is unknown.

Although not focusing on variables that can be targeted by interventions, some studies have linked disclosure to sociodemographic characteristics of the child or the caregiver. For instance, similar to the finding that mothers' disclosure of their own HIV serostatus to their children is associated with children's developmental level [26], several studies have found that the child's age is positively related to pediatric HIV disclosure [7,11,14,15,18,27]. Studies have also found that caregivers were more likely to disclose to children who were receiving ARV treatment [15] and that biological mothers were more likely to disclose to children than were other caregivers [21].

Despite the low rates of pediatric disclosure, to our knowledge, only one intervention quasi-experimental study [6], but no randomized controlled trial, has tested the efficacy of a pediatric HIV disclosure intervention. Hence, there is a need for culturally appropriate pediatric HIV disclosure interventions specifically targeting caregivers. Such interventions are likely to be most effective if they influence the modifiable antecedents of pediatric HIV disclosure: that is, the mediating variables that interventions should target. In addition, interventions are likely to be most effective if they are based on a theoretical framework adapted to the target population[28,29], but research on pediatric HIV disclosure has generally not drawn upon behavior-change theories. The theory of planned behavior [30,31] can be employed to identify modifiable antecedents pertinent in diverse cultural and social contexts and has been successfully applied to a broad range of behaviors in many settings [32,33], including South Africa [29,34,35].

The theory-of-planned-behavior constructs of behavioral beliefs, normative beliefs, self-efficacy, and intention have been identified as important determinants of behavior [31]. Behavioral beliefs, a construct similar to the social cognitive theory construct of outcome expectancy [36,37], are the consequences people expect if they perform of a certain behavior and have predicted intention or behavior in a variety of populations. Normative beliefs are people's beliefs about whether important referents would approve of their engaging in a specific behavior. Self-efficacy, the confidence people have that they can perform a behavior, is a key construct in both the theory of planned behavior and the social cognitive theory [36-38]. Considerable research has tied the intention to engage in specific behaviors to subsequent engagement in those behaviors [32,33,39].

To our knowledge, no previous studies have empirically examined the relations of Caregivers' beliefs about pediatric HIV disclosure to their intention to disclose or to self-reported disclosure. Here we report the results of a survey conducted to identify theory-of-planned-behavior predictors of the intention of parents and other caregivers to disclose HIV serostatus to children living with HIV in Eastern Cape Province, South Africa. We developed the survey based on previous qualitative research on reasons caregivers give for disclosure and nondisclosure. We hypothesized that behavioral beliefs, normative beliefs, and self-efficacy regarding pediatric HIV disclosure would be associated with a stronger intention to disclose HIV diagnosis to children living with HIV. Consistent with reasons highlighted in previous research, the behavioral beliefs regarding the children's reactions to disclosure included negative emotional responses [14,17,18,21,23], denial [14,24], telling others [14,23,24,40], and positive reactions [16,17,21,23,25]. In addition, we explored whether variables external to the theory of planned behavior, including other modifiable

variables, HIV risk-reduction knowledge and caregiver-child communication, and sociodemographic characteristics were related to intention.

Methods

Participants

Adults were eligible to participate in the study if they were at least 18 years of age, provided care to a HIV-positive child 9 to 13 years of age who was infected through mother-to-child transmission but did not know his or her serostatus, and could read and speak isiXhosa, the first language of over 95% of people living in Eastern Cape Province, South Africa, the area of the study [41]. We focused on caregivers to a HIV-positive child who did not know his or her serostatus because our primary outcome of interest was the intention to disclose to the child the child's HIV serostatus. Potential participants were told that they would complete a survey about their attitudes, beliefs, knowledge, experiences, and feelings regarding talking to the HIV-infected child for whom they were a parent or other caregiver about HIV and its treatment. Research assistants screened and recruited the participants from pediatric HIV clinics, churches, and nongovernmental organizations (NGOs) in a town, a township, and a village during October and November 2011.

Procedure

The Institutional Review Board of the University of Pennsylvania and the Ethics Committee of the University of Fort Hare, Alice, South Africa, approved this research. Eligible caregivers signed a consent form before completing an anonymous paper-and-pencil survey. Meeting rooms in clinics, churches, and NGOs were the venues where data collection was implemented. The survey was administered in isiXhosa following translation and back translation from English. Methods were employed that have been associated with more truthful self-reports on sensitive topics [42-44], including emphasizing (a) that honest responses would help the researchers develop a pediatric HIV disclosure program that is most appropriate for caregivers like them and (b) that their responses would be anonymous. Present to answer questions about the items was an experienced data collector who had received 5 days of training in the collection of paper-and-pencil, computer-based, and biological-specimen data in connection with other HIV-related studies, training that included modeling of data-collection procedures by trainers and role-playing by the data-collector trainees and that emphasized adherence to data-collection protocols and maintenance of the participants' confidentiality. The participants received refreshments and 30 Rand (value of \$ 6.00 US) as compensation for their time.

Measures

Theory-of-planned-behavior variables were assessed with items rated on a 5-point Likert scale from 1 (Disagree strongly) to 5 (Agree strongly). Intention to disclose was measured with a single item: "I plan to tell my child he or she has HIV in the next 3 months."

Negative emotions disclosure behavioral belief was measured with 5 items ($\alpha = 0.89$) that covered a range of negative emotional responses HIV-seropositive children might have to being told their serostatus identified in previous research, including anger, sadness, fear,

worry, and worry about dying. Higher scores on this measure indicate the belief that children would have more negative emotional responses to disclosure.

Denial disclosure behavioral belief was measured with 2 items ($\alpha = 0.69$) that concerned whether the children would reject and not believe the information that they are HIV seropositive. Higher scores on this measure indicate the belief that children deny that they had HIV.

Tell to others disclosure behavioral belief was measured with 3 items ($\alpha = 0.78$) indicating the belief that were the HIV-seropositive children told their serostatus they might tell other family members, friends, and people in the community. Higher scores on this measure indicate the belief that children would disclose their HIV serostatus to others.

Positive reaction disclosure behavioral belief was measured with 5 items ($\alpha = 0.83$) that covered a range of positive reactions HIV-seropositive children might have to being told their serostatus, including understanding and accepting the information, feeling closer to the caregiver, being more willing to take their HIV medication, and being relieved to know the name of their illness. Higher scores on this measure indicate the belief that children would have more positive reaction to disclosure.

Normative belief about disclosure was measured with 4 items ($\alpha = 0.72$) concerning whether the Caregivers' referents, including relatives, close friends, steady partner, and people the caregiver considered important, would want them to "tell my child he or she has HIV."

Self-efficacy to disclose was measured with a single item: "I am sure I can tell my child that he or she has HIV."

Caregiver-child communication about HIV and sexual risks was measured with 9 items ($\alpha = 0.92$) concerning how much information the caregiver had given to the child about sex and HIV. It was an adaptation of the 7-item scale developed by Hutchinson [45] to which we added an item regarding the child's HIV infection and an item regarding why the child was taking HIV medicine. Thus the topics included "his or her HIV infection," "HIV in general," "why he or she is taking HIV medicine," "protect others from getting HIV from your child," "preventing pregnancy," "sexually transmitted infections," "abstaining from sex until he or she is older," "resist pressure to have sex," and "using condoms if he or she has sex." The items were rated on 5-point Likert scales from 1 (None) to 5 (Everything). Previous research indicates that parents and other caregivers have difficulty talking to their children about sex and HIV [23,28].

HIV/STD risk-reduction knowledge was measured with a 24-item scale with a true-false format. The number of items answered correctly became the participant's HIV/STD risk-reduction knowledge score and higher scores indicated greater knowledge. A subscale was created: a 5-item measure of cultural myths about HIV identified in previous research [28].

The survey also included questions about sociodemographic variables, including Caregivers' gender, age, marital status, education, employment status, proficiency in English compared

with isiXhosa, relationship to the child, number of years caring for the child, and caregiver's reports of the child's gender, age, sexual experience, and prescription for ARV medication.

Data Analysis

Two research assistants independently entered all of the data with 100% verification resolving any data-entry discrepancies. We used descriptive statistics to describe the sample and Pearson product-moment correlation coefficients (r) to identify correlates of intention to disclose. We used proportional-odds logistic regression analysis to identify predictors of intention to disclose. Model 1 included the theory of planned behavior variables selected a priori as predictors: behavioral beliefs regarding the children's reactions to disclosure, including negative emotional responses, denial, telling others, and positive reactions, normative beliefs, and self-efficacy. Model 2 included the Model 1 variables plus other variables that had a significant univariate relation to intention. The $\alpha = .05$, two-tailed significance criterion was used. SAS 9.3 was used to perform the analyses.

Results

We screened 114 people, and 100 (95 women and 5 men) met the inclusion criteria and were enrolled. The age of the caregivers ranged from 19 to 79 years, and their mean age was 44.5 years ($SD = 13.9$). About 56.4% of the caregivers had a steady partner, 43.8% lived with their steady partner, and 39.8% were married. They reported providing care for the child a mean of 6.98 years ($SD = 4.2$). About 33.7% of the caregivers had completed high school and 46.0% were employed. About 46.2% said they were HIV positive. About 52.0% spoke only isiXhosa, 34.7% spoke isiXhosa better than English, and 13.3% spoke isiXhosa and English equally well. The caregivers were parents (35.4%), including biological parents (24.4%), grandparents (24.2%), aunts (22.2%), uncles (2.0%), or unrelated persons such as paid caregivers of children who lived in orphanages (16.2%).

The mean number of correct answers on the HIV knowledge test was 18.5 ($SD = 3.9$) or 80.4% of the 23 questions. For the most part, the caregivers knew that HIV is present in blood, semen, and vaginal fluid (90.9%), that people with HIV who take HIV medicine can live a long life (91.9%), and that contracting HIV by sharing a sink, shower, or toilet seat with someone who has HIV is unlikely (86.0%). In addition, they did not believe the following common cultural myths about HIV: that a person could contract HIV as a result of a curse (91.0%) or witchcraft (87.9%) or bad muti (90.7%), medicine given by sangomas or traditional healers. However, 23.5% did not know that a HIV-positive person can transmit the virus to other people even if he or she does not look sick, 23.2% did not know that most people do not get sick with AIDS until several years after being infected with HIV, 92.0% did not know that sexually transmitted infections (STIs) can be asymptomatic, 42.4% thought that HIV could be spread by mosquitoes, and 40.4% did not know that storing condoms in a warm or hot place can destroy their effectiveness.

The caregivers reported that the children for whom they provided care were 9 to 13 years of age, with a mean age of 10.9 years ($SD = 1.1$), and 56.4% reported that the child was a girl. All of the caregivers said the child did not know his or her HIV serostatus. As shown in Table I, large percentages of the caregivers said the child believed he or she had an illness

other than HIV, a virus or “bug,” or a problem with his or her blood. About 87.0% of the caregivers said the child had a prescription for HIV medication. As shown in Table I, a majority of the caregivers said that the child believed that the medications were vitamins, for an illness other than HIV, or simply medicine to help stay healthy.

As shown in Table II, which presents the percentage of caregivers who agreed (ratings of 4 or 5) with each of the items regarding beliefs about the consequences of disclosing to the child the child's HIV diagnosis, caregivers expressed both positive and negative consequences. For instance, a majority said that if they disclosed, the child would feel closer to them, would be more willing to take his or her HIV medicine, and would be relieved to know the name of his or her illness. On the other hand, large majorities also said the child would be sad, afraid, and worried, and about one-third said the child would tell his or her friends and people in the community.

Table III shows that a large majority of participants saw strong normative support for disclosing. People important to them (80.4%), relatives (73.9%), and close friends (71.4%) were seen as most supportive, but a majority also said their steady partner (61.9%) would support disclosing to the child. Those who reported currently having a steady partner were especially likely to agree that their partner would be supportive as compared with those who did not currently have a steady partner (75% versus 45%, $P = .003$).

Table IV presents Pearson product-moment correlation coefficients summarizing the relations of theory-of-planned-behavior variables and external variables to the intention to disclose. Although normative belief and self-efficacy were positively associated with disclosure intention, none of the disclosure behavioral beliefs was associated with intention. Indeed, the correlations for behavioral beliefs were very small, ranging from $r = -0.00$ to 0.05 . Table IV also shows that two external variables were correlated with disclosure intention: caregiver-child communication was positively correlated with disclosure intention and completing high school was negatively correlated with intention. Not significantly correlated with intention were the other external variables, including, for instance, Caregivers' HIV risk-reduction knowledge, HIV serostatus, age, and marital status and their reports of the child's age and whether the child was prescribed ARV medication. As shown in Table V, proportional-odds logistic regression analysis revealed that only normative belief was associated with intention in Model 1, which included the six theoretical variables as predictors of intention. Model 2, a proportional-odds logistic regression analysis that included the six theoretical variables and the two external variables that had significant univariate relations with intention, revealed that normative belief, caregiver-communication about HIV, and whether the caregiver completed high school were associated with intention. Thus, caregivers who perceived greater normative support for disclosure, who reported giving the child more information about sex and HIV, and who had not completed high school expressed a stronger intention to disclose to the child.

Discussion

The results suggest that the theory-of-planned-behavior constructs of normative belief and self-efficacy are related to a stronger intention to disclose HIV serostatus to South African

children living with HIV, whereas the disclosure behavioral beliefs that the children would have a negative emotional response, deny the diagnosis, tell others, or have a positive reaction were not. The regression analysis that included all six theory-based predictors indicated that only normative belief had an independent relation to intention, controlling for the behavioral beliefs and self-efficacy. That none of the behavioral beliefs about disclosing predicted intention to disclose is puzzling. Numerous studies have identified beliefs about pediatric HIV disclosure, reporting the reasons caregivers give for not disclosing, the reasons caregivers give for disclosing, reasons that were similar to many of the beliefs that comprised the behavioral beliefs measured in this study. For instance, consonant with other studies [16,17,20,23,25], a large majority of caregivers agreed that disclosing would make the child more willing to take his or her HIV medication. Similarly, consistent with studies identifying negative emotional reactions in the child as a reason for nondisclosure [14,17,18,21,23], large percentages of caregivers said disclosing would make the child sad, afraid, or worried. Thus, we had reasonable measures of behavioral beliefs, yet they were unrelated to intention.

Nevertheless, the lack of a relation between behavioral beliefs and intention does not contradict the empirical literature on pediatric HIV disclosure because other studies have not examined this relation. Although previous studies have enumerated the reasons caregivers give for disclosing and not disclosing, they did not examine whether the reasons that were given were empirically related to disclosing or the intention to disclose. Moreover, in non-Western cultures people are seen as less individualistic and more collectivist [46]. This study, conducted in a non-Western culture, measured both behavioral beliefs, an individualistic factor, concerning Caregivers' beliefs about the consequences of disclosure, and normative beliefs, a collectivist factor, concerning Caregivers' beliefs about whether important referents would approve of disclosure. The results revealed that it was the expectation of approval by important family members, close friends, and steady partners that was the key factor for these caregivers in determining the intention to disclose, and perhaps, given the non-Western society, this should not be surprising. By the same token, the current results do not preclude the possibility that behavioral beliefs might be related to disclosure intention in other more Western settings.

On the other hand, it might be argued that it is not the nature of the setting, but the nature of behavior that is important. According to theory of planned behavior, whether behavioral beliefs, normative beliefs, or self-efficacy beliefs are most important varies depending upon not only the population, but also the behavior [29-31], which suggests another possible interpretation of the present results: that normative beliefs may be key to the decision to disclose HIV diagnosis to children irrespective of whether the behavior, disclosure, occurs in a Western or non-Western society. Future research will have to clarify which explanation, whether the findings reflect the setting or the behavior, is correct.

Both the univariate analysis and the regression analysis indicated that caregiver-child communication was related to intention to disclose. Caregivers who reported giving their HIV-positive children more information about sex and HIV expressed a stronger intention to disclose to their children. Several studies have tied caregiver or parent communication with their children about sex and HIV to increased knowledge [47] and reduced sexual-risk

behavior in children [48]. In addition, several studies have reported that interventions have increased parent-child communication about sex and HIV in sub-Saharan Africa [49-51]. However, to our knowledge, this is the first study to empirically examine the relation of caregiver-child communication to pediatric HIV disclosure or intention to disclose. Our finding suggests that caregivers who are able to talk to their children about sex and HIV may feel more equipped to inform their children about their HIV serostatus.

We also found that caregivers who graduated from high school expressed a lower intention to disclose to their children than did those who did not graduate. Though not examining disclosure intention, a study in Ethiopia reported that caregivers who had less education were more likely to have disclosed to their HIV-positive children than were those who had more education [52]. One possible explanation for the negative relation between education and the intention to disclose in the present study is that being associated with HIV is more stigmatizing to caregivers who have more education than to those who have less education, which leads the more educated caregivers to want to conceal their children's HIV-positive serostatus. In a similar vein, the authors of the study in Ethiopia suggested that in Ethiopia higher educated caregivers might have wanted to maintain their family's "status quo" by avoiding disclosure [52].

Similar to other studies [17,21,22] we found that most caregivers said that the children believed that their illness was something other than HIV and the medication they were taking were vitamins or medicine for another illness. The fact that the Caregivers' children were 9 to 13 years of age and still did not know their HIV serostatus raises concerns because the children are approaching the age of sexual debut [53]. A recent study in Eastern Cape Province, South Africa found that whereas only 3% of adolescents reported being sexually experienced at age 12, over 60% reported being sexually experienced three and one-half years later, about 15% of whom tested positive for a STI [54,55]. Adolescence is a time of exploration and of increasing independence from adult authority, which may include experimentation with sexual behavior that poses risk of STI, a risk that is likely heightened for children who do not know they have HIV. Likewise, adolescents' assertion of independence may include refusal to adhere to HIV medication regimens for which they have increasing responsibility without knowing why the medication is necessary. Moreover, the possibility of children learning their HIV serostatus from sources other than the caregiver, or inadvertently from the caregiver, increases with age.

Clearly, then, there is a need for HIV pediatric disclosure interventions for caregivers, many of whom are struggling to cope with their children's HIV and their own lack of knowledge or lack of skills to disclose. Caregivers say they would like help to disclose; health-care providers concur that caregivers need help; indeed, even adolescents who have been told their serostatus say caregivers need help to disclose [23,56]. Moreover, although consistent with other studies [14,17,18,21,23] we found that caregivers were concerned about their children having negative psychological reactions on learning their serostatus, fearing that their children might be angry, sad, or worried if they learned the disease is HIV, there is scant evidence that disclosure has enduring negative consequences[11,15,27,57]. Most studies indicate that disclosure does not result in psychological harm or mental health problems, that fears of negative effects of disclosure on children's mental health may be

unwarranted, and there is even evidence linking knowledge of HIV serostatus with greater adherence to medication regimens [10] and slower HIV disease progression in children [58].

The present findings suggest that those who would develop interventions to increase the likelihood of disclosure should seek to help caregivers enlist social support among their important referents for disclosing to their children. Even though self-efficacy was significant only in the univariate analysis we would still recommend that interventions try to increase self-efficacy to disclose as a strategy to prepare caregivers to disclose. Previous research has documented that parents and other caregivers have difficulty talking to their children about sex and HIV [23,28]. Accordingly, pediatric HIV disclosure interventions should also seek to provide caregivers skills to communicate effectively with their children not only as a means to equip them to disclose, but also more broadly to help them equip the children to deal with all of the issues surrounding being a child who is living with HIV in South Africa today. Such interventions should integrate the culture and environment in which caregivers and children live and consider the communication style within the community.

The limitations of this study should be considered. The participants' self-reports may have been affected by social desirability response bias. We tried to mitigate this bias by using an anonymous survey and by emphasizing to participants that their honest responses would contribute to the development of valid interventions for other caregivers like themselves. The primary outcome was the intention to disclose rather than self-reported disclosure. However, strong evidence from meta-analyses of not only prospective studies[32,33] but also true experiments[39] indicates that intention is related to subsequent self-reported behavior. The relatively small sample size ($N = 100$) limited statistical power to detect relations. Still, the correlation coefficients for the nonsignificant relations between the theoretical constructs and intentions in Table IV were all extremely small (i.e., r ranged from -0.00 to 0.05). We would not have achieved the conventional 80% statistical power to detect such tiny correlations even with a sample as large as 500. The cross-sectional design of the study limits our ability to draw conclusions regarding causal priority among the study variables; hence, prospective studies with larger samples are needed to confirm the relations we observed. Finally, the sample may not be representative of all caregivers of children who do not know they are living with HIV in South Africa.

Despite these limitations, this study provides the first empirical evidence on modifiable variables that are related to plans to disclose HIV serostatus to children living with HIV in South Africa. Another strength of the study is that caregivers were recruited from several venues, clinics, churches, and NGOs in a town, a township, and a village, which increases generalizability. Moreover, this is the first study to apply a behavior-change theory, the theory of planned behavior, to pediatric HIV disclosure. The results suggest that interventions to increase pediatric HIV disclosure should especially focus on training caregivers to enlist support for disclosure among their important referents and increasing self-efficacy to disclose and skills for caregiver-child communication about sex and HIV. Future research, preferably employing a prospective design, must seek to confirm the relations of normative beliefs, self-efficacy, and caregiver-child communication to intention to disclose that we observed and extend them to self-reported disclosure. Such research might inform efforts to increase disclosure of HIV serostatus to children living with HIV,

help the children to live a longer healthy life, and reduce the likelihood that they will transmit the virus to others.

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Table I

Caregivers' reports of children's awareness of their HIV diagnosis and medication.

The child believes:	N (%) Agreed
<u>Regarding HIV diagnosis</u>	
He or she has some other illness	66/96 (68.8%)
He or she has a virus or "bug"	42/97 (43.3%)
He or she has a blood problem	42/99 (42.4%)
<u>Regarding HIV medication</u>	
The medicine is vitamins	78/87 (89.7%)
The medicine is for another illness	74/86 (86.0%)
The medicine is to help stay healthy	85/86 (98.8%)

The N varies due to missing data. The questions about HIV medication include only children who were taking HIV medication according to caregiver self-reports.

Table II
Caregivers' beliefs about consequences of informing the child of the child's HIV diagnosis

Belief	Mean (SD)	N (%) Agree
Child would be angry	3.05 (1.14)	45/99 (45.4%)
Child would be sad	3.64 (1.18)	71/99 (71.7%)
Child would be afraid	3.52 (1.15)	67/98 (68.4%)
Child would worry	3.60 (1.13)	69/100 (69.0%)
Child would worry a lot about dying	3.32 (1.32)	57/99 (57.6%)
Child would reject the information	2.79 (1.15)	28/99 (28.3%)
Child would not believe me	2.99 (1.30)	43/98 (43.9%)
Child would tell other people in the family	3.11 (1.24)	46/99 (46.5%)
Child would tell his or her friends	2.81 (1.20)	37/99 (37.4%)
Child would tell people in the community	2.64 (1.24)	31/100 (31.0%)
Child would understand me	2.84 (1.23)	29/99 (29.3%)
Child would accept the information	2.65 (1.20)	28/99 (28.3%)
Child would feel closer to me	3.42 (1.35)	60/99 (60.6%)
Child would be more willing to take his or her HIV medicine	3.45 (1.33)	63/98 (64.3%)
Child would feel relieved to know the name of his or her illness	3.13 (1.35)	52/100 (52.0%)

The N varies due to missing data. Statements were rated on a 5-point scale from 1 (disagree strongly) to 5 (agree strongly). N Agree is the number of caregivers who gave a rating of 4 (agree) or 5 (strongly agree).

Table III
Caregivers' normative beliefs about referents who would want them to inform the child of his or her HIV diagnosis

Belief	Mean (SD)	N (%) Agree
People important to me	3.94 (0.80)	80/100 (80.0%)
My relatives	3.81 (0.81)	76/100 (76.0%)
My close friends	3.65 (0.98)	69/99 (69.7%)
My steady partner	3.51 (1.07)	60/97 (61.9%)

The N varies due to missing data. Statements were rated on a 5-point scale from 1 (disagree strongly) to 5 (agree strongly). N Agree is the number of caregivers who gave a rating of 4 (agree) or 5 (strongly agree).

Table IV
Pearson product-moment correlations (r) and significance probabilities (p) for relations
of pediatric HIV disclosure intention to theoretical constructs and external variables

Variable	r	p
<u>Theoretical constructs</u>		
Negative emotions disclosure behavioral belief	-.00	.9938
Denial disclosure behavioral belief	-.00	.9891
Tell others disclosure behavioral belief	.05	.6409
Positive reaction disclosure behavioral belief	-.00	.9912
Disclosure normative belief	.29	.0038
Self-efficacy to disclose	.23	.0235
<u>External variables</u>		
HIV risk-reduction knowledge	.16	.1119
Cultural myths	.10	.3252
Caregiver-child communication about sex and HIV	.27	.0083
Age	-.09	.3666
Biological parent	.04	.6966
Years caring for child	.02	.8183
Has steady partner	.05	.6042
Lives with steady partner	.03	.7718
Married	.03	.7943
Speaks English	-.16	.1134
Completed high school	-.25	.0134
Employed	.00	.9816
HIV positive	-.00	.9753
Child's age	-.06	.5286
Child's gender	-.11	.3011
Child sexually experienced	-.03	.8048
Child receives ARV	-.03	.7607

Note. External variables are variables that are not part of the theoretical framework. Gender is coded 1=male and 2=female. Child variables are based on Caregivers' self-report.

Table V
Odds ratios (OR), 95 % confidence intervals (95 % CI), and significance probabilities (p)
from multiple logistic regression analyses of pediatric HIV disclosure intention with
theoretical constructs (Model 1) and with theoretical constructs and potentially
confounding external variables (Model 2)

Variable	Model 1		Model 2	
	OR (95% CI)	p	OR (95% CI)	p
<u>Theoretical constructs</u>				
Negative emotions disclosure behavioral belief	0.81 (0.50, 1.31)	.3848	0.73 (0.64, 1.93)	.2130
Denial disclosure behavioral belief	1.08 (0.72, 1.61)	.7107	1.27 (0.82, 1.98)	.2906
Tell others disclosure behavioral belief	1.13 (0.72, 1.77)	.5863	1.30 (0.79, 2.14)	.2970
Positive reaction disclosure behavioral belief	0.90 (0.57, 1.40)	.6306	1.00 (0.62, 1.64)	.9843
Disclosure normative belief	2.17 (1.15, 4.10)	.0171	2.34 (1.20, 4.56)	.0127
Self-efficacy to disclose	1.32 (0.92, 1.91)	.1340	1.27 (0.86, 1.89)	.2336
<u>External variables</u>				
Caregiver-child communication about sex and HIV			1.79 (1.21, 2.67)	.0039
Completed high school			0.15 (0.06, 0.39)	.0001

Note. External variables are variables that are not part of the theoretical framework. Model 1 includes six theoretical constructs as predictors. Model 2 adds to Model 1 caregiver-child communication and completed high school, the two external variables with significant univariate relations to intention.