

A Cross-Sectional Study of Pediatric HIV Disclosure in Rural Zimbabwe

by

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Thesis submitted in partial fulfillment of
the requirements for the degree of
Master of Science in the Duke Global Health Institute
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ABSTRACT

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Abstract

Background: An estimated 2.6 million children under 15 years are living with HIV. Children often begin antiretroviral therapy (ART) without learning why they are sick or the purpose of their medication. The objective of this study was to estimate the prevalence of pediatric HIV disclosure in two districts in rural Zimbabwe, characterize the process of disclosure, and begin investigating the predictors and consequences of disclosure.

Methods: This was a cross-sectional survey of 372 primary caregivers of HIV-positive children between the ages of 9 and 15 years living in Bikita and Zaka districts and receiving ART or pre-ART from a network of 21 eligible clinics. Surveys were administered individually in Shona by trained Zimbabwean enumerators. Disclosure was referred to if a child knows he or she has a health condition called HIV. Full disclosure was defined as a caregiver's report that the child knows he or she has an illness called HIV, how he or she acquired the illness, and can pass the infection to someone else. The prevalence of disclosure was estimated for the overall sample, by district, and by clinic. Characteristics of the process of disclosure as well as predictors and consequences of disclosure were identified for the overall sample.

Results: The overall prevalence of disclosure in the sample is 66.9 percent (95% CI 62.0 to 71.5%). Disclosure rates are similar across districts: 64.1 percent in Bikita (56.5 to 71.7%) and 69.0 percent in Zaka (62.8 to 75.2%). Across the 21 study clinics, disclosure

rates ranged from 47.8 to 85.7 percent. Among the children who know that they are HIV-positive, 69.9 percent know how they were infected (63.9 to 75.2%) and 48.6 percent know that they could pass the infection to someone else (42.5 to 54.8%). The average child learned about his or her illness at age 10.0 ($SD=1.9$). In the majority of cases, the caregiver informed the child directly (58.6%) and 28.5 percent of children learned of their status from a health worker. Most caregivers who have disclosed to their child reported that their overall disclosure experience was positive (81.5%), with 76.7 percent having improved their adherence to medication following disclosure. Predictors of disclosure were identified as follows: caregivers' high level of self-efficacy to disclose ($p<0.05$); HIV-positive caregivers' high level of HIV-related shame ($p<0.001$); HIV-positive caregivers' high level of awareness of their own HIV symptoms and implications of HIV on their health and future ($p<0.05$); caregivers' assessment that their child has cognitive skills and is emotionally mature ($p<0.10$); higher levels of child's formal education ($p<0.05$); and caregivers who are not currently married or living with someone else ($p<0.01$). The following were not predictors of disclosure: caregivers' assessment of benefits of disclosure outweighing the risks of disclosure, perception of HIV-related stigma and/or discrimination, access to health care, quality of health care, child or caregiver gender, or socioeconomic status did not appear to influence the caregivers' decision to disclose to their child.

Conclusions: Caregivers who are taking care of children between the ages of 9 and 15 need proper support and assistance from health workers for pediatric HIV disclosure. More efforts are needed to encourage and assist caregivers to inform their child about his or her HIV status. In the future, helpful disclosure support interventions would address caregivers' HIV-related shame, improve the psychosocial wellbeing of the caregivers, educate caregivers about HIV and HIV treatment, and help them improve parent-child communication, all of which may allow caregivers to increase their overall self-efficacy and therefore facilitate a successful, age-appropriate disclosure process for both the caregivers and their children.

Dedication

This thesis is dedicated to my family for their endless support and encouragement. I would like to especially thank my mom, Misun Park, who instilled in me the values of kindness, integrity, and perseverance.

I also would like to dedicate this work to children living with HIV and their caregivers whom I have met in Zimbabwe. Despite the adversity they face every day, their courage, resilience, and motivation have inspired me to work harder and be just as strong as they are.

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Lastly, I extend special thanks to the study participants who are caring for children living with HIV and/or affected by HIV/AIDS. I sincerely appreciate their courage in allowing their story to influence research for pediatric HIV disclosure. I am

hopeful that our collaboration will contribute to better support services for children with HIV and those who care for them.

1. Introduction

1.1 Background

Globally, an estimated 1.8 million children under the age of 15 years live with HIV (“UNAIDS 2016”). Before antiretroviral therapy (ART) became available, HIV-infected infants in sub-Saharan Africa had a 50% probability of dying prior to reaching the age of 2 (Newell et al., 2004). The advent of ART has allowed more children to survive into adulthood (Qiao, Li, & Stanton, 2013; Vreeman, Gramelspacher, Gisore, Scanlon, & Nyandiko, 2013a), and HIV is now considered a chronic illness among adolescents. Children who are surviving to adolescence and beyond now face a novel challenge to HIV care as they cope with the chronic illness, are confronted with psychosocial distress, and must maintain adherence to medications. Disclosure of HIV status to children also remains a complex psychosocial process in the care of HIV-positive children. Caregivers may be reluctant to inform their child about his or her HIV status for fear of subsequent stigma, parental sense of guilt, fear of child’s emotional distress following disclosure, perception that their child is too young, and fear that the child would not keep the diagnosis to themselves (Gerson et al., 2001; Kouyoumdjian, Meyers, & Mtshizana, 2005; Oberdorfer et al., 2006; Punpanich et al., 2014; Vaz et al., 2011; Vreeman et al., 2013a). However, several studies have documented the benefits of disclosing children’s HIV status to the children including child’s improved

psychological wellbeing and higher levels of adherence to medications (Bhatia et al., 2012; Bikaako-Kajura et al., 2006; Butler et al., 2009; Madiba & Mokgatle, 2015; Vreeman et al., 2013a).

Zimbabwe is no exception to the challenge of pediatric HIV prevalence and disclosure. Zimbabwe has the fifth highest HIV prevalence in sub-Saharan Africa with 14.7% of its population is living with HIV. As of 2015, there are 1.4 million people who are HIV-positive in Zimbabwe, including 77,000 children (“HIV and AIDS in Zimbabwe | AVERT,” “Zimbabwe | UNAIDS 2015”). Although the proportion of eligible children under the age of 15 years receiving ART increased from 9.7% to 55% in 2007 and 2014, respectively (“UNAIDS 2015”), the number of HIV-positive children surviving to older ages is projected to continue to increase. Yet most children who are receiving ART are not fully informed of their HIV status (Pribram, 2011). Pediatric HIV disclosure is critical as it allows children to make appropriate decisions about their sexual relationships and plan for the future.

The meaning of "full disclosure" varies in research and practice, but the term generally refers to when a child is explicitly told the name of the illness as HIV/AIDS, learns the source of the infection, and knows that he or she can transmit the virus to others (Madiba & Mokgatle, 2015; L. Wiener, Mellins, Marhefka, & Battles, 2007). In contrast, partial disclosure occurs when nonspecific or incorrect health information regarding child's illness is shared with the child, sometimes using explanations of other

coinfections such as tuberculosis to account for clinic visits and the need for medication. Studies have reported that partial disclosure is often viewed as appropriate for children in their early adolescent years (John-Stewart et al., 2013; Kallem, Renner, Ghebremichael, & Paintsil, 2011; Vaz et al., 2011), and some also consider it to be an important part of the disclosure process before adopting full disclosure. For instance, if children are too young to understand the implication of living with HIV, their caregivers labeling the illness as HIV does not help the young children to cope with their fears about symptoms and willingness to adhere to medications (Mellins et al., 2002).

Current global guidelines from the World Health Organization recommend disclosure to children of school age (defined as those with the cognitive skills and emotional maturity of a normally developing child of 6-12 years) whereas younger children are encouraged to be told of their own and their caregivers' HIV status incrementally in accordance with their cognitive skills and emotional maturity ("WHO | Guideline on HIV disclosure counselling for children up to 12 years of age 2011"). In practice, however, disclosure to children living with HIV in sub-Saharan Africa varies widely and is often inconsistent with these recommendations. Studies have shown that estimates of number of children knowing that they have a health condition called HIV in low-resource settings—predominantly in sub-Saharan Africa—range from 3 to 44% (Bikaako-Kajura et al., 2006; John-Stewart et al., 2013; Kallem et al., 2011; Menon, Glazebrook, Campain, & Ngoma, 2007; Palin et al., 2009; Tadesse, Foster, & Berhan,

2015; Turissini et al., 2013; Vaz et al., 2011) despite the reported benefits of disclosure such as improved adherence to ART and child's psychosocial wellbeing (Brown et al., 2011; Lowenthal et al., 2014; Madiba, 2012), and preventing further spread of infections (Kallem et al., 2011). These low disclosure rates, in addition to the limited availability of ART regimes and high levels of stigma in low resource settings, may mean that disclosure to children in these settings is even lower than what has been documented previously (Vaz et al., 2011).

1.2 Models of Pediatric HIV Disclosure

Disclosure of HIV status to children is typically conceptualized as a process, not an event, but this process remains understudied in resource-limited settings (Qiao et al., 2013). There are largely two types of models—theoretical and clinical—that are applicable to HIV disclosure. Theoretical models include those that incorporate decision-making (e.g. Consequence Theory (Serovich, 2001)), the disclosure process (e.g. Disclosure Process Model (Chaudoir & Fisher, 2010)), the concept of how individuals think about and respond to their social environment (e.g. Social Cognitive Theory (Britto, Mehta, Thomas, & Shet, 2016; Jemmott et al., 2014)), and the role of children's development stages in understanding HIV (e.g. Piaget's Stage of Cognitive Development (Li et al., 2010)).

Several empirical studies have been conducted within a theoretical framework of disclosure. Blasini et al. developed a five-phase model, which include the following components: disclosure training for health workers; caregiver preparation through peer support and education provided by health workers; individual, interactive assessment sessions; the disclosure event; and support groups following disclosure (Blasini et al., 2004). Their disclosure model was based on the four-phase Tasker model involving secrecy, exploratory, readiness, and full disclosure (Tasker, 1992). Additionally, Boon-yashidhi et al. proposed the four-step disclosure model of screening, readiness assessment, provider-assisted disclosure session, and post-disclosure follow-up (Boon-Yasidhi et al., 2013). Another clinical framework for pediatric HIV disclosure by Gerson et al. included five steps: information gathering and trust building; ongoing assessment of the knowledge and attitudes of the caregiver and child; determining the right time for disclosure; the actual disclosure event; and monitoring post-disclosure through direct and indirect observations (Gerson et al., 2001).

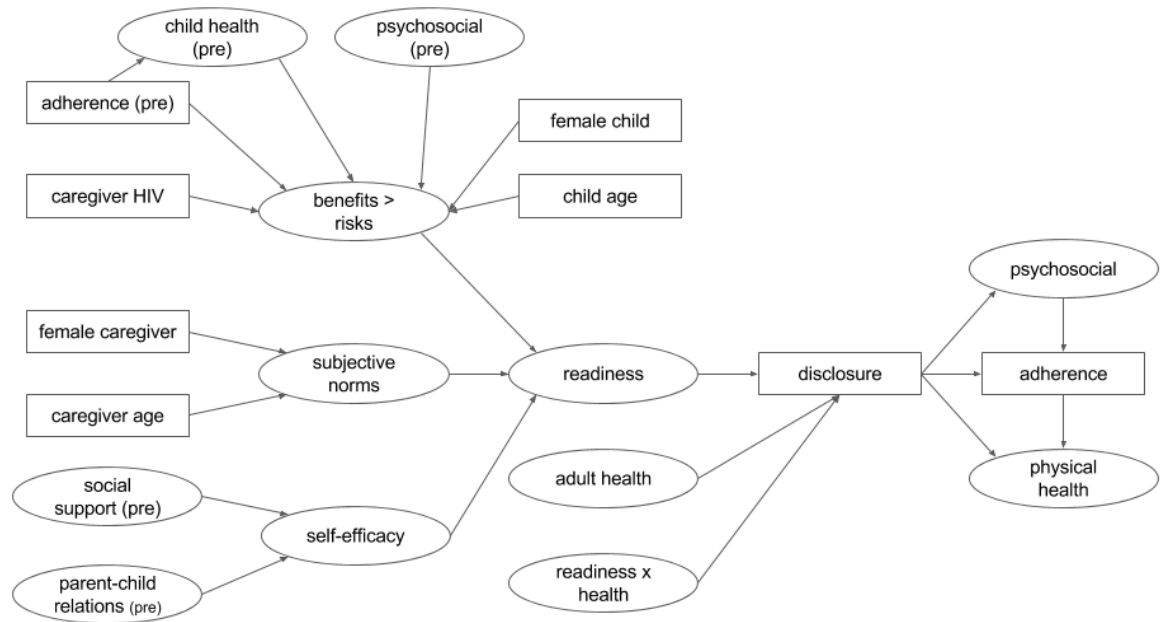


Figure 1: Proposed conceptual model of pediatric HIV disclosure

The existing models and the model proposed in Figure 1 are largely based on clinical observation and theory, not empirical evidence. Therefore, the primary objective of this study was to generate empirical evidence about the disclosure process and correlates of disclosure. This paper reports on the first wave of a panel survey in rural Zimbabwe with a prospective cohort of parents and guardians of HIV-infected children. Based on prior literature, we hypothesized that the prevalence of full disclosure would be below 50 percent (Biadgilign, Deribew, Amberbir, Escudero, & Deribe, 2011; Bikaako-Kajura et al., 2006; John-Stewart et al., 2013; Kallem et al., 2011; Menon et al., 2007; Nam et al., 2009; Nzota, Matovu, Draper, Kisa, & Kiwanuka, 2015; Palin et al., 2009; Vreeman et al., 2014), disclosure would be correlated with child and caregiver factors as specified

in these models, and that disclosure would be associated with improved medication adherence and health.

2. Methods

2.1 Study Design

We conducted a cross-sectional survey on issues related to HIV disclosure with a cohort of primary caregivers (parents and guardians) of HIV-positive children. This was the first wave of a 3-wave panel survey. Future waves will follow the subsample of caregivers of children who do not know that they have a condition called HIV.

2.2 Setting

The study was conducted from May to August 2016 in Bikita and Zaka districts, Masvingo Province. Masvingo is home to more than 1.5 million people, and 2 out of every 3 people in this rural province are estimated to live in poverty (“UNICEF Zimbabwe”). In 2014, the prevalence of HIV among adults (15 to 49 years) was estimated to be 12.0% and 16.4% in Bikita and Zaka district, respectively (“Zimbabwe | UNAIDS”). Nearly 14,000 children younger than 15 years are thought to be living with HIV/AIDS today, and more than 300 new children are infected each year (“AIDS & TB Programme Ministry of health and Child Care 2014”).

The government of Zimbabwe has adopted the UNAIDS Fast-Track strategy called, the 90-90-90 target that involves the following goals by 2020: 90% of all people

living with HIV will know their HIV status; 90% of all people with diagnosed HIV infection will receive sustained antiretroviral therapy; 90% of all people receiving antiretroviral therapy will have viral suppression (“Zimbabwe Country Report 2014”). The country’s ART services have increased from 2004 to 2013 by up to five times. Many ways to enter Zimbabwe’s ART program may contribute to the successful ART services as patients can initiate the ART program through various ways: outpatient departments and clinical wards; client or provider-initiated testing and counselling; prevention of mother-to-child transmission; early infant diagnosis, Expanded Programme on Immunization, family planning, and community- and home-based care (“Guidelines for ART for the Prevention and Treatment of HIV in Zimbabwe 2013”).

The number of treatment sites has also increased from 530 in 2010 to 1459 in 2014, with most districts having over 85% of their population living within 3 km of an ART site. Coverage of ART has also increased from 5% to 83% in 2004 and 2011, respectively, although it decreased to 77% in 2014 due to changes in eligibility and indicator definition (“Zimbabwe Country Report 2014”). Since 2013, ART initiation has been prioritized for those who have a CD4 count of ≤ 500 cells/mm³, HIV positive pregnant and lactating women, HIV positive partners in sero-discordant couples, and HIV positive children under 5. For children who are 5 years old and above are recommended to initiate ART when they reach the WHO stage 3 or 4, or have a CD4

count of ≤ 500 cells/mm³ (“Guidelines for ART for the Prevention and Treatment of HIV in Zimbabwe 2013”).

In May we assessed the eligibility of 42 of the 48 health clinics that provide HIV care in Bikita and Zaka districts. We excluded 6 clinics that were not affiliated with our implementing partner BHASO, the Batanai HIV & AIDS Service Organization, because we relied on BHASO's network of HIV-positive patient advocates called CHASAs (Community HIV & AIDS Support Agents) to recruit study participants.

2.3 Participants

CHASAs worked with clinic staff to create a sampling frame of eligible caregivers by reviewing the clinic pre-ART/ART registers and patient medical records. To be eligible for inclusion in the sampling frame, adults had to be caring for a child between the ages of 9 to and 15 years (inclusive) living with HIV. This exercise identified 757 caregivers (sibling duplicates possible). At the time of recruitment, the median clinic served 13 HIV-positive children between the ages of 9 and 15, and 75% of clinics had fewer than 20 pediatric patients in this age range. Our assumption was that clinics serving 1 to 12 eligible patients would not be systematically different than clinics serving 13 to 20 eligible patients as all clinics are relatively small (see Appendix A for the test of this assumption). Therefore we restricted clinic eligibility to the 21 clinics serving a minimum of 13 HIV-positive children in the eligible age range. This allowed us to use

simple random sampling (stratified by district) to select 450 caregivers of pediatric patients and thus create a self-weighting sample that was feasible to survey within study constraints.

2.3 Procedures

Data collection took place from June to August, 2016. CHASAs invited selected caregivers to visit clinics on assigned days to enroll and participate in the study. A team of Zimbabwean enumerators met the caregivers at the clinic, explained the study, and obtained informed consent. Enumerators administered the survey in Shona and used Android tablets running ODK collect to record participant responses.

2.4 Measurement

Because there were no existing comprehensive survey questionnaire specifically measuring caregiver's readiness and self-efficacy for pediatric HIV disclosure, some of the survey items for this cross-sectional study had been developed through formative qualitative research. From August 2015 to January 2016, we recruited 73 health workers, 8 adult caregivers of HIV positive children, and 17 HIV positive adolescents from 21 health clinics in Bikita district to participate in 32 focus group discussions (FGDs) about HIV disclosure. Concepts about pediatric HIV disclosure were extracted from literature, including facilitators, barriers, predictors, and consequences of disclosure. During the

FGDs, participants were asked to free list their own concepts of the disclosure process. Matching and non-matching concepts of disclosure from the participants and literature findings were recorded. Memos written after each FGD were reviewed and analyzed by the research team to develop the survey instrument used for this study.

A total of 21 measures were used in the survey, with 10 existing measures and 11 new measures that were categorized into the following constructs: Disclosure status; Perceived risks and benefits of disclosure; Caregiver's attitudes towards disclosure; Caregiver's self-efficacy to disclose; Caregiver's health; HIV-related stigma; Child's health and psychosocial wellbeing; Caregiver relationship and social support; and Consequences of disclosure. More details of these measures are listed below.

Exploratory factor analysis was conducted to assess the construct validity of the latent variables for 14 scales, which are explained in detail below. Varimax rotation was conducted, and all items were retained on a given factor only if they had a loading ≥ 0.3 . One factor was extracted from the following measures: Attitudes About Benefits of Disclosure (ATTDB); Attitudes About Risks of Disclosure (ATTDR); Brief Illness Perception Questionnaire (BIPQ); Self-Efficacy to Disclose (DSE); General Health Questionnaire (GHQ); HIV and Abuse Related Shame Inventory (HARSI); HIV/AIDS Stigma Instrument (HASI); Health System (HS); Survey of Parental Attitudes Towards Children's Sexual Education (PATCSE-Revised); Parent-Child Communication (PCC); Patient Health Questionnaire-9 (PHQ9); Family functioning; and Strengths and

Difficulties Questionnaire (SDQP). Two factors were extracted from the Beliefs and Attitudes About the Decision to Disclose (BADD); factor 1 contained 3 items and was labeled “social support.” Factor 2 contained 9 items, all of which referred to caregiver’s assessment of their child’s cognitive and emotional capacity. Cronbach's alpha coefficient was calculated for each measure to confirm internal consistency among items in a measure.

2.4.1 Demographic Characteristics

Demographic data included each caregiver’s age, gender, relationship to the child, marital status, education level, and household income.

2.4.2 Disclosure Status

Full disclosure was defined as a caregiver's report that the child knows (i) he or she has a chronic medical condition, (ii) that this condition is called HIV, (iii) how he or she acquired HIV, (iv) that he or she can pass the infection to others. Partial disclosure was defined as any subset of these four criteria. The prevalence of full disclosure was estimated for the overall sample, by district, and by clinic. Additionally, we asked caregivers of children who did not know that the name of their condition was HIV about any steps they are taking to prepare for disclosure. Caregivers of disclosed children

were asked to recall what, if anything, they did to prepare their children to learn about their status.

2.4.3 Perceived Risks and Benefits of Disclosure

Two measures were developed to assess caregivers' perceived risks and benefits of disclosure. The attitudes about risks of disclosure (attDR) is a 15-item measure that aims to assess the perceived risks of disclosure among caregivers. The attitudes about benefits of disclosure (attDB) is a 16-item measure that aims to assess the perceived benefits of disclosure among caregivers. Participants who had disclosed their child's HIV serostatus to the child were asked to rate the attDR items by using a 4-point Likert scale, ranging from 0, "not at all worried," to 3, "very worried." The attDB items were also assessed by using a 4-point Likert scale, with responses ranging from 0, "strongly disagree," to 3, "strongly agree." Participants who had already disclosed their child's status completed different versions of the two measures, written in past tense, that asked them to recall their experiences prior to disclosure. Cronbach's alpha coefficients of the attDR and attDB scales were found to be 0.96 and 0.98, respectively.

2.4.4 Caregiver's Attitudes Towards Disclosure

We used a revised 4-item version of the Survey of Parental Attitudes Towards Children's Sexual Education (PATCSE) to measure caregivers' attitudes towards child's sexual education and abilities to provide sexual education children through four items

(Sieswerda & Blekkenhorst, 2006). Participants used a 4-point Likert scale from 0, “strongly agree” to 3, “strongly disagree” to respond to questions like, “It is mainly my responsibility for teaching my child about sex when I think [he/she] is ready.” A Cronbach’s alpha coefficient of 0.93 was recorded. We also created 26 items to assess caregivers' beliefs and attitudes about the decision to disclose (BADD). These items were asked to caregivers who had not disclosed as well as those who had disclosed *and* had time to prepare for disclosure. Caregivers who had disclosed, but had not had time to prepare for the disclosure were excluded from responding to these questions. For example, these caregivers consisted of those who learned of their child’s HIV status after or on the same day as the child did. Participants used a 4-point scale to indicate the likelihood of events, their degree of worry about events, or their agreement with statements about disclosure such as “How likely is it that your child would understand if you decided today to tell [him/her] [his/her] status?”, “How much do you worry that your child will become sexually active before [he/she] learns about [his/her] status?”, “Sometimes it's best to give [him/her] false information about [his/her] status to protect [him/her] from the truth”, “My child could keep [his/her] status a secret if asked.”, and “My child is strong enough emotionally to handle learning about [his/her] status.” Caregivers of disclosed children were asked to recall the period prior to disclosure and answer these questions in the past tense. In a factor analysis, two factors, namely caregiver’s perception of social support (9 items including 1 reverse-scored item) and

caregiver's assessment of their child's cognitive and emotional abilities (3 items), were identified. Cronbach's alpha coefficients of the BADD-Social support and BADD-Child assessment were determined to be 0.65 and 0.86, respectively. Additionally, we created 8 items to assess nondisclosed caregivers' beliefs about what children should know about their status.

2.4.5 Caregiver's Self-efficacy to Disclose

Seven items were created for the Self-efficacy to Disclose (DSE) to assess caregivers' knowledge about HIV, perceived abilities to counsel their child, and abilities to offer emotional support to their child. Participants were asked to rate on a 4-point Likert scale, ranging from 1, "strongly disagree," to 4, "strongly agree." Participants who have disclosed to their child completed a past tense version of the same measure, DSE-R. A Cronbach's alpha coefficient of 0.89 was reported.

2.4.6 Caregiver's Health

A modified version of the Brief Illness Perception Questionnaire was used for this study (Broadbent et al., 2006). Our final version after an exploratory factor analysis includes five items assessing caregivers' cognitive and emotional representations of HIV. One item was reverse scored. Participants used a 10-step ladder response, where 1 indicates "no effect at all" and 10 as "severely affects my life." A Cronbach's alpha coefficient of 0.64 was recorded. The Patient Health Questionnaire-9 (PHQ-9) is a 9-item

screening instrument for depression (Kroenke, Spitzer, & Williams, 2001). Participants used a 4-point scale to indicate the frequency of each symptom over the past two weeks. A modified version of the General Health Questionnaire (GHQ) consisting of seven items was used to assess caregivers' physical health (Goldberg & Hillier, 1979). Participants used a 4-point scale to indicate if they experienced each symptom more or less than usual. One item was reverse scored. Cronbach's alpha coefficients of the PHQ-9 and GHQ were found to be 0.83 and 0.85, respectively. We also invited caregivers to indicate if they have been tested for HIV, know their status, and are willing to share this information with us.

2.4.7 HIV-related Stigma

A modified version of the HIV/AIDS Stigma Instrument was used for this study (Holzemer et al., 2007). Thirty-one questions assessed stigma and/or discrimination experienced by HIV-positive caregivers during the past 3 months before the survey. Participants reported on a 4-point scale of "never," "once or twice," "several times," and "most of the time." A Cronbach's alpha coefficient of 0.93 was recorded for this scale. The HIV and Abuse Related Shame Inventory is a 13-item measure (Neufeld, Sikkema, Lee, Kochman, & Hansen, 2012) that assesses caregivers' perception of HIV-related shame in the past month before the survey was administered. Participants reported in a

4-point Likert scale to indicate their level of agreement with each statement. A Cronbach's alpha of 0.87 was recorded.

2.4.8 Child's Health and Psychosocial Wellbeing

The Strengths and Difficulties Questionnaire (SDQ)—Parent version is a brief behavioral screening questionnaire about children ages 4 to 10 years, and for ages 11 and 17 years (GOODMAN, 2001). The 25 items in the SDQ comprise 5 subscales of 5 items each. The subscales include: emotional symptoms; conduct problems; hyperactivity/inattention; peer relationship problems; and prosocial behavior. The prosocial subscale is presumed to exist as a conceptually distinct construct representing behavioral strengths, whereas the remaining 4 subscales were grouped together to represent emotional and behavioral difficulties. A Cronbach's alpha of 0.76 was recorded for the combination of emotional symptoms, conduct problems, hyperactivity/inattention, and peer relationship problems subscales. In addition, we asked caregivers four questions about their child's physical health and adherence to medication: (i) "Who collects medication for your child?"; (ii) "In the past two weeks, how many days was your child unable to play, learn, or do household chores because [he or she] was sick?"; (iii) "How often does your child forget or refuse to take [his/her] medication?"; and (iv) "How often does your child ask you questions about [his/her] status or medication?"

2.4.9 Caregiver Relationship and Social Support

We assessed parent-child communication using a 22-item measure that one of the study investigators (EP) developed in Kenya. Participants used a 4-point Likert scale to indicate their level of agreement with each statement, with higher values indicating greater agreement with the item. Nine items were reverse scored, and 1 item was excluded from the scale after a factor analysis was conducted. A Cronbach's alpha coefficient of 0.89 was observed. We also used 10 items from a family functioning measure developed by the same investigator. Participants were asked to rate how often they encountered the experiences within their family described in the items on a 4-point Likert scale, ranging from 1, "often," to 4, "never." Our final version after an exploratory factor analysis comprises 6 items including 4 reverse coded items. A Cronbach's alpha coefficient of 0.76 was reported. Additionally, we created 6 items that assess caregivers' perceptions of the health system quality and support on a 4-point scale. All items from the scale were used in the analysis. A Cronbach's alpha coefficient of 0.90 was recorded.

2.4.10 Consequences of Disclosure

We created a 26-item post-disclosure questionnaire (PDQ) to assess the consequences of disclosure. This measure included questions like "Overall, how would you rate YOUR overall disclosure experience?"; "Overall, how would you rate YOUR CHILD'S disclosure experience?"; "Looking back, do you think disclosure was a good

thing for your child?" These questions were only asked to caregivers who had disclosed to their child and had time to prepare for the disclosure before disclosing to their child.

2.5 Study Size

With a population of 757 caregivers assumed to be eligible at the time of recruitment, a target sample size of 450, and 95% confidence level, the margin of error to detect a prevalence of 50% was $\pm 2.9\%$. During the invitation process, we learned that 50 caregivers were not eligible, so the target sample size reduced to 400 from a population of 707 caregivers. This is a margin of error of $\pm 3.2\%$.

2.6 Statistical Methods

All analyses were conducted using STATA version 14.0. Descriptive statistics were performed to describe the participant demographics. Student's t tests with a 0.10 two-sided significance were used to compare variables between children who knew their HIV status and those who did not. Multivariate analyses using linear regression models were employed to examine the predictors of HIV disclosure.

2.7 Ethical considerations

The study protocol was reviewed and approved by Duke University, the Medical Research Council of Zimbabwe, and the Joint Research Ethics Committee for the

University of Zimbabwe College of Health Sciences and the Parirenyatwa Group of Hospitals. Written informed consent was obtained from all caregivers.

3. Results

3.1 Characteristics of study participants

We randomly selected 450 caregivers from the sampling frame and conducted a secondary screening for eligibility. Fifty caregivers (11.1%) did not meet the criteria for inclusion into the study and were excluded. Twenty-eight eligible caregivers (7.0%) refused to participate, did not show up, or could not be reached. A total of 372 caregivers completed the survey (see Figure 1). As shown in Table 1, the majority of caregivers were female (87.6%), were married or living with someone (53.2%), were in the lowest wealth index quintile (59.4%), and completed primary school education (61.8%). The mean age of the caregivers was 47.8 years (SD=12.9) (age range, 18-86 years). The biological parent was the primary caregiver for 43.3% of the target children, followed by grandparent (26.9%) and aunt or uncle (17.2%). A total of 208 caregivers reported being HIV positive (55.9%). The target children had a mean age of 12.1 (SD=1.8), and 51.1% were female (Table 2).

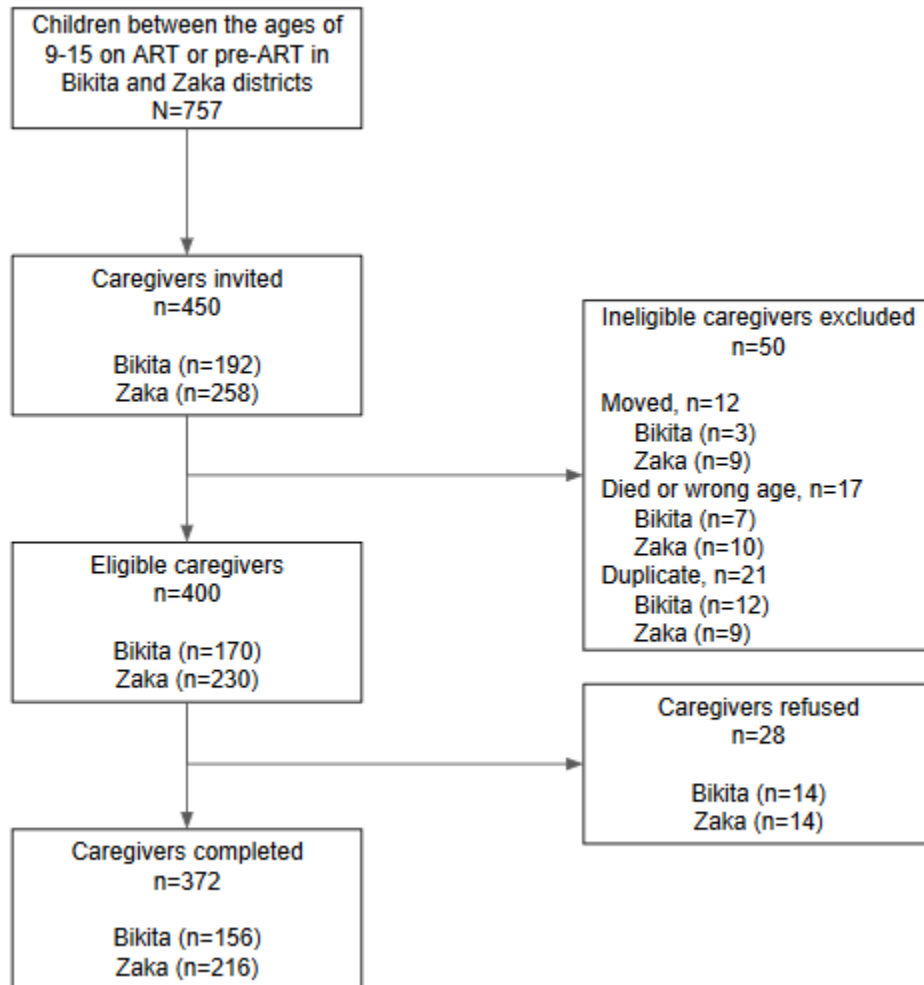


Figure 2: Flowchart of study participant selection

Table 1: Demographic characteristics of caregivers by disclosure status

Caregiver characteristics (%)	Total (N=372)	Disclosed‡ (N=249)	Not disclosed (N=123)	p-value
Mean age (SD)	47.8 (12.9)	47.1 (12.1)	49.1 (14.5)	0.150
Female	87.6	86.8	89.4	0.461
Relationship to child				
Biological parent	43.3	46.2	37.4	0.072
Step parent	1.3	1.2	1.6	
Foster parent	0.3	0.4	0.0	
Adopted parent	8.6	8.4	8.9	
Grandparent	26.9	23.3	34.2	
Sibling	1.6	1.6	1.6	
Aunt/uncle	17.2	18.9	13.8	
Other	0.8	0.0	2.4	
HIV Status				
Unknown or refused	6.2	6.0	6.5	0.213
Negative	37.9	34.9	43.9	
Positive	55.9	59.0	49.6	
Marital status				
Currently married	51.9	47.8	60.2	0.067
Living with someone	1.3	1.2	1.6	
Not in union	46.8	51.0	38.2	
Post primary education	38.2	36.6	41.5	
Socioeconomic status				
1 (lowest wealth)	59.4	59.4	59.4	0.325
2	34.7	35.3	33.3	
3	4.8	4.0	6.5	
4	0.8	1.2	0.0	
5 (highest wealth)	0.3	0.0	0.8	

Note. In this table, "disclosed" refers to the children who know that they have a health condition called HIV.

Table 2: Demographic characteristics of children by disclosure status

Child characteristics (%)	Total (N=372)	Disclosed‡ (N=249)	Not disclosed (N=123)	p-value
Mean age (SD)	12.1 (1.8)	12.3 (1.7)	11.7 (1.8)	0.001
Female	51.1	50.6	52.0	0.796
Highest level of education completed				
Primary	90.1	88.0	94.3	0.004
Post primary	8.3	11.2	2.4	
None	1.6	0.8	3.3	

Note. ‡ "disclosed" refers to the children who know that they have a health condition called HIV.

3.2 Prevalence of disclosure

The overall prevalence of disclosure in the sample was 66.9% (95% CI 62.1 to 71.7%; see Table 3). Disclosure, in this context, is defined as caregivers disclosing to the child that the illness they have is called HIV. Disclosure rates were similar between the two districts, with 64.1% in Bikita (56.5 to 71.7%) and 69.0% in Zaka (62.8 to 75.2%).

Across the 21 study clinics, disclosure rates ranged from 47.8 to 85.7%. The overall prevalence of full disclosure was 26.9% (22.4 to 31.4%).

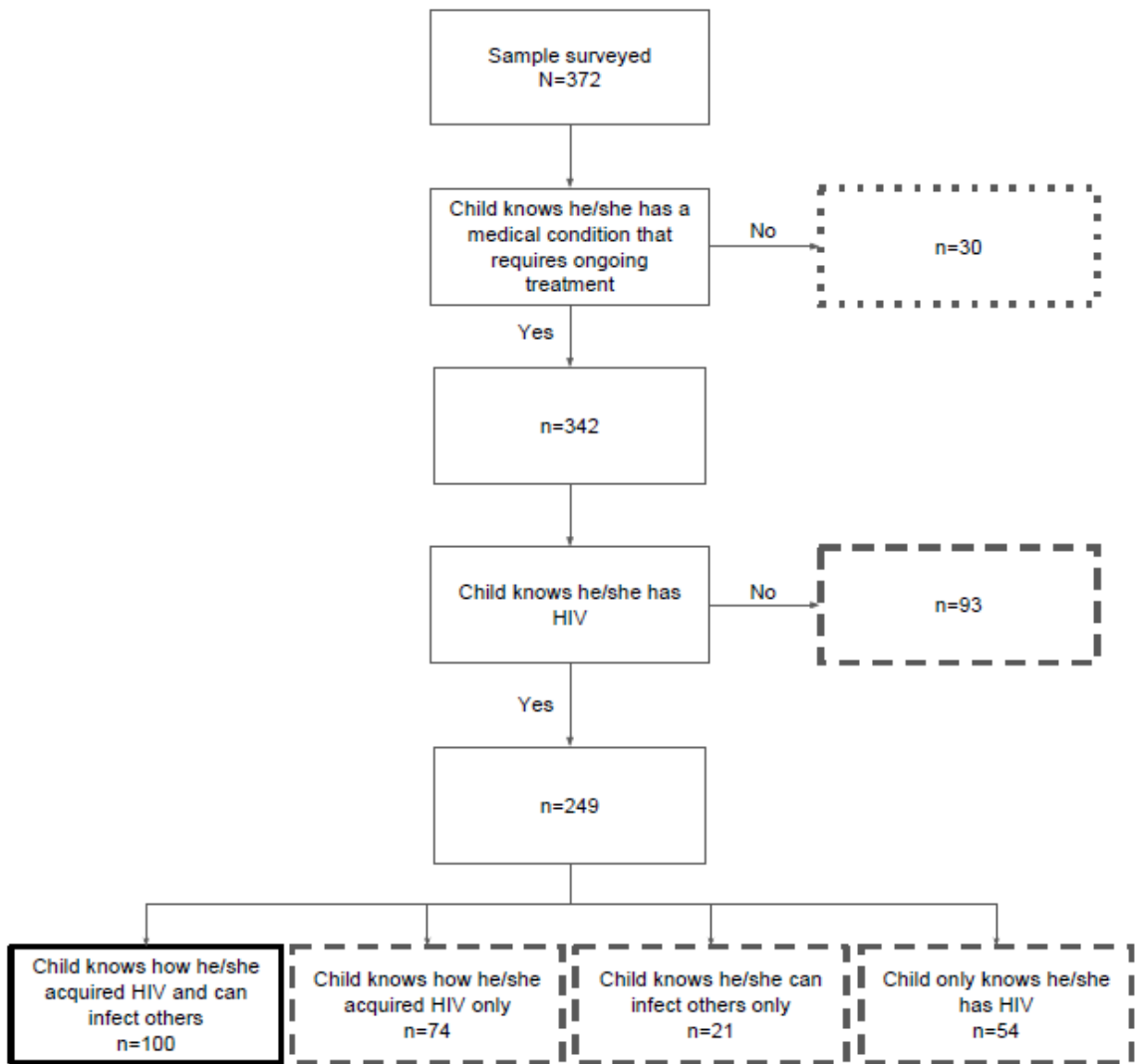
Table 3: Prevalence of disclosure

Child knows (%)	Total (N=372)	Bikita (N=156)	Zaka (N=216)
a. He/she has medical condition requiring ongoing treatment	91.9	92.9	91.2
b. Medical condition is called HIV	66.9	64.1	69.0
c. How he/she contracted HIV	46.8	44.2	48.6
d. He/she can transmit the disease to others	32.5	27.6	36.1
No disclosure (none of a-d)	8.1	7.1	8.8
Partial disclosure (at least one of a-d)	65.1	72.4	59.7
Full disclosure (all four of a-d)	26.9	20.5	31.5

3.3 Disclosure process

Of the 372 caregivers who completed the survey, 30 caregivers (8.1%) reported not having provided their child with any information about the child's health including the fact that he or she has a medical condition that requires ongoing treatment (Figure 2). Others reported partial disclosure; 93 caregivers (25.0%) had only told their child about the chronic nature of his or her illness; 54 caregivers (14.5%) had only labeled the illness as HIV; 74 caregivers (19.9%) had told their child that he or she has HIV and disclosed how the child acquired the infection; 21 caregivers (5.6%) had told the child that he or she has HIV and how he or she could pass the infection to someone else. Among the 100 caregivers (26.9%) who had fully disclosed to their child (i.e., revealing the name of the illness as HIV, sharing information on how their child was infected, and how they could spread the infection to others), at the time of the survey, 52 caregivers

had disclosed that the child's infection can be transmitted to others and the origin of the child's infection within the same year as when they had revealed the exact name of the illness, whereas 48 had informed their child over a broader length of time.



*Dotted lines = non-disclosure; dashed lines= partial disclosure; solid lines= full disclosure

Figure 3: Flowchart of disclosure process

Table 4: Characteristics of disclosure process by time at which caregivers learned of child's status

	<i>When caregivers learned of their child's status with respect to when their child learned:</i>			
	Total (N=244)	Before child (N=150)	Same day (N=75)	After child (N=19*)
How child learned				
Health worker	29.1	14.7	56.0	36.8
Teacher	0.4	0.7	0	0
Another family member	11.9	8.0	8.0	57.9
Caregiver	57.8	76.0	36.0	0
Someone else	0.8	0.7	0	5.3
Caregiver wanted child to know status at disclosure (%)	84.4	88.7	85.3	63.2

Note: Data collected from caregivers who have disclosed to their child that the name of the illness is called HIV. Caregivers were asked if they learned their child's HIV status before (had time to prepare for disclosure), after (did not have time to prepare), or on the same day (may or may not have had time to prepare) as the child learned about his or her HIV status.

*5 participants who answered "caregiver" to how their child learned of his or her HIV status were excluded from the analysis as they could not have been the ones to tell their child about his or her HIV status since they learned of their child's status after the child did.

3.4 Rationale for disclosure

3.4.1 Consequences of disclosure

For those who have told their child that he or she is HIV positive, the majority of the caregivers reported that their overall disclosure experience was positive (81.5%) and that their child's experience was positive (76.7%). Upon disclosure, most caregivers reported that their child did not get angry (71.1%) or sad at all (65.1%), but almost half of the children (45.7%) asked questions afterwards. The majority of the caregivers (89.6%) also reported that their child has accepted his or her status, with 30.9% of children

taking less than a day, 16.1% taking 1-2 days, and 13.5% taking more than a month to accept their status. When looking back, 77.9% of the caregivers reported that “disclosure was a good thing for my child.” While 70.3% reported that their child learned about his or her status at a good age, 3.6% indicated that they should have disclosed sooner and 17.3% said that they should have waited until the child was older. Most caregivers (83.5%) were satisfied with how their disclosure took place and reported that they would not change anything about it. Since disclosure, no one reported worse adherence to medication compared to the time before the child learned of his or her status, 76.7% of the children improved their adherence to ART, 17.3% stayed the same, and 6% of the caregivers were either unsure or declined to answer this question. Additionally, children’s psychosocial wellbeing, parent-child communication, and family relations and support did not vary significantly between the fully disclosed and partially disclosed children who know that they have HIV (Appendices B-D).

3.4.2 Opinions of caregivers who have not disclosed their child’s HIV status on disclosure

Among the 123 caregivers who have not told their child that he or she is HIV positive, 65 caregivers (52.9%) reported that their child should know some details about his or her status. Generally, the majority of caregivers who have fully disclosed to their child (91.5%), as well as a majority of those who have not disclosed at all (96.7%), agree that disclosure is a process that unfolds over time. Although 103 caregivers (83.7%) of

non-disclosed children felt that their children should be told that they are taking medications for an illness, only 44 caregivers (36.1%) felt that their child should know that the illness is called HIV. Caregivers felt that their child should know that they have HIV when they are 12.3 years old (SD=1.6); for comparison, the mean child age of caregivers who felt that their child should not know the status was 11.4 years (SD=1.8). Fifty caregivers (41.0%) felt that their child should know the consequences and implications of living with HIV, and their children's mean age was 12.5 years (SD=1.5), whereas the mean age of their counterpart was 11.2 years (SD=1.8). The majority of caregivers noted that their child should not know about how he or she was infected with HIV (72.7%) and the fact that he or she could pass the infection to someone else (59.7%). The mean age of the children whose caregivers felt that their children should know that they can transmit the infection to others was 12.1 years (SD=1.6) compared to 11.3 years (SD=1.9) for children whose caregivers said their children should not know they can transmit the infection. Most caregivers, however, reported that their child's school should teach students about HIV (83.1%). Additionally, 67 caregivers (54.5%) collect their child's medication for the child, whereas 27 caregivers (22.0%) go to the clinic with their child to pick up the medication. However, 21 children (17.1%) who had not been told that they have a condition called HIV were reported to collect medication by themselves.

Over half of the caregivers (55.7%) have begun to assess their child's readiness to learn about his or her status. Sixty-eight percent of the caregivers wanted their child to learn more than a year from when the survey took place, 15.1% reported in the next few weeks, 8.4% said in the next few months, and another 8.4% noted between 6 months and 12 months from the time of the survey. The majority of caregivers (56.9%) reported that they want to inform the child directly, followed by 31.7% of caregivers who reported that they want the child to learn from a doctor or a nurse. Although 52.0% of the caregivers did not have a plan for telling their child about his or her status, 96.5% of the caregivers who did have a plan reported that they will likely follow through. At the time of the survey, 15 caregivers reported having taken steps to prepare for disclosure (12.2%), and 20 caregivers (16.3%) had discussed the possibility of disclosing to the child with a doctor, nurse, or counselor. On a scale of 1 to 10 with 1 being the least ready and 10 being the most ready, the caregivers reported a mean score of 4.4 (SD=3.4) on their readiness to disclose to the child.

3.4.3 Association between disclosure and caregiver and child characteristics

Child age ($p=0.001$), child education level ($p=0.004$) (Table 2), caregiver perception of their ability to talk about sex with their child ($p=0.002$), child lack of adherence to medication ($p=0.001$), and parent-child communication ($p=0.012$) were positively associated with disclosing to children that they have an illness called HIV

(Table 5). Among the caregivers who are HIV positive, ability to cope with their HIV-related shame (HARSI) ($p=0.067$) was also associated with disclosure.

Caregivers' attitudes towards risks of disclosure including anticipating child's negative psychological reaction, worrying about questions from the child, potential social rejection of the child, and anger or blame from the child were not associated with disclosure. Their attitudes towards benefits of disclosure such as better adherence to medication after disclosure, anticipated improvement in child's health, better coping mechanisms against stigma in the community, etc. were not associated with disclosure. Caregivers' perception of their child's mental health, assessment of their self-efficacy to disclose to the child, assessment of their HIV status and its impact on their own health, perception of their child's and their own social support were also not associated with disclosure.

Table 5: Correlates of disclosure (unadjusted analyses)

	Total		Non-disclosed		Disclosed‡		p-value
	Mean	SD	Mean	SD	Mean	SD	
Attitudes towards risks of disclosure [Not at all worried=0; Very worried=3]	1.3	0.9	1.3	0.9	1.4	0.9	0.292
Attitudes towards benefits of disclosure [Not at all likely=0; Very likely=3]	2.0	0.9	2.1	0.9	2.0	0.9	0.364
Beliefs and attitudes about decision to disclose (perceived social support) [Strongly disagree=0; Strongly agree=3]	1.2	0.8	1.3	0.8	1.2	0.8	0.355
Beliefs and attitudes about decision to disclose (assessing child's characteristics) [Not at all worried or likely=0; Very worried or likely=3]	1.1	0.7	1.1	0.7	1.1	0.6	0.883
General Health Questionnaire (physical health) [Not at all=0; Much more than usual=3]	0.8	0.7	0.8	0.7	0.8	0.7	0.530
Patient Health Questionnaire (mental health) [Not at all=0; Nearly every day=3]	0.4	0.4	0.4	0.5	0.4	0.4	0.168
HIV/AIDS Stigma Instrument [Never=0; Most of the time=3]	0.1	0.2	0.1	0.2	0.1	0.2	0.702
HIV-related shame (HIV and Abuse Related Shame Inventory) [Not at all=0; Very much=4]	0.3	0.6	0.3	0.6	0.2	0.5	0.067
Brief Illness Perception Questionnaire [No effect at all=1; Severely affects my life=10]	1.4	1.7	1.3	1.7	1.5	1.7	0.239
Perception of accessibility and quality of health care system [Strongly disagree=0; Strongly agree=3]	2.6	0.5	2.6	0.5	2.6	0.5	0.720
Self-efficacy to disclose [Strongly disagree=0; Strongly agree=3]	1.7	0.8	1.7	0.8	1.8	0.8	0.285
Child's adherence to medication (refusing or forgetting to take medications)* [Never=0; Often=3]	0.2	0.6	0.4	0.7	0.1	0.4	0.001
Strengths and Difficulties Questionnaire* [Not true=0; Certainly true=2]	0.3	0.3	0.3	0.3	0.3	0.3	0.116
Parent-Child Communication* [Strongly disagree=0; Strongly agree=3]	2.5	0.4	2.4	0.4	2.6	0.4	0.012
Family functioning* [Often=1; Never=4]	3.5	0.4	3.5	0.4	3.5	0.4	0.561
Parental Attitudes Towards Children's Sexual Education* [Strongly disagree=0; Strongly agree=3]	1.9	0.9	1.7	1.0	2.1	0.9	0.002

Note: *The following scales were not used for multivariate analysis to identify the predictors of disclosure as they did not ask participants to think back to the time prior to when their child was informed about his or her HIV status.

‡ "disclosed" refers to the children who know that they have a health condition called HIV.

3.5 Predictors of disclosure

Model 1 includes all caregivers in the sample population regardless of the caregivers' disclosure status (Table 6). Models 2 and 3 only include two subsets of the population—those who had disclosed after having had time to prepare for the disclosure and those who had not yet disclosed, therefore excluding those who had disclosed but had not had time to prepare for the disclosure (caregivers learned of their child's HIV status after or on the same day as the child did).

Across all three models, the caregivers who are more likely to disclose to their child that he or she has HIV are HIV-positive caregivers who experience less shame about their own HIV status and HIV-positive caregivers who are aware of their HIV symptoms and effects of HIV/AIDS on their health and future. Although barely statistically significant, child's higher education level is also a predictor of disclosure in all three models. Across all caregivers, caregivers who are not married were more likely to disclose to their child. However, when only comparing the caregivers who have disclosed and have had time to prepare for the disclosure to those who have not disclosed, the caregivers who have higher perception of their abilities (self-efficacy) to disclose to their child were more likely to disclose than those who have low self-efficacy. Model 3 controlled for caregivers' assessment of benefits and risks of disclosure (ATTDB and ATTDR), self-efficacy to disclose (DSE), beliefs and attitudes about their decision to

disclose to the child (BADD-social support; BADD-child assessment); in this model, caregivers who perceive that their child is responsible and mature enough to understand the consequences of HIV (higher scores on BADD-child assessment), were more likely to disclose.

Other variables worth mentioning—such as child age, caregiver weighing of benefits and risks of disclosure, and perception of support system—did not predict disclosure.

Table 6: Predictors of disclosure‡

	Model 1 ^a		Model 2 ^b		Model 3 ^c	
	Coef	SE	Coef	SE	Coef	SE
Child age	0.02	0.01	0.02	0.02	0.03	0.02
Child gender	-0.01	0.04	-0.05	0.05	-0.02	0.05
Child's highest level of education completed	0.04*	0.01	0.05*	0.02	0.05*	0.02
Caregiver age	-0.00	0.00	-0.00	0.00	-0.00	0.00
Caregiver gender	-0.07	0.05	0.08	0.09	0.08	0.09
Caregiver's highest level of education completed	-0.00	0.05	0.03	0.07	0.03	0.07
Marital status	-0.13**	0.04	-0.10	0.06	-0.10	0.06
Caregiver's HIV status	0.02	0.08	0.01	0.13	0.00	0.13
Biological vs. foster parent	0.06	0.07	0.08	0.10	0.08	0.10
SES	0.01	0.05	0.00	0.05	-0.01	0.06
General Health Questionnaire (Physical health)	0.04	0.04	0.02	0.06	0.02	0.06
Patient Health Questionnaire (Mental health)	-0.07	0.06	-0.06	0.07	-0.06	0.08
Accessibility and quality of health care system	-0.05	0.05	-0.01	0.06	0.00	0.06
HIV stigma	-0.04	0.09	-0.12	0.10	-0.14	0.10
HIV-related shame	-0.20***	0.05	-0.23**	0.07	-0.24**	0.07
Brief Illness Perception Questionnaire	0.03 ⁺	0.02	0.05 ⁺	0.02	0.05*	0.02
Assessment of benefits vs. risks of disclosure					-0.00	0.00
Caregiver's self-efficacy					0.08*	0.03
Beliefs and attitudes in deciding when to disclose; assessment of child's characteristics					-0.09 ⁺	0.05
Perception of caregiver's and child's social support					-0.04	0.04
_cons	0.54*	0.23	0.23	0.27	0.07	0.25
N			370		265	
R-sq			0.12		0.13	

⁺ p<0.10 * p<0.05 ** p<0.01 *** p<0.001

Note: There were 23 caregivers who declined to share their HIV status. 208 caregivers reported positive HIV status. 141 caregivers reported negative HIV status. Adding 23 caregivers with unknown status to negative HIV status group did not show any difference in the results of the linear regression. Therefore 23 caregivers with unknown status were combined with the HIV-negative caregivers for this analysis.

^a This model includes caregivers of all categories—nondisclosed caregivers and disclosed caregivers regardless of whether or not they had time to prepare for the disclosure. ^b This model includes nondisclosed caregivers and disclosed caregivers who had time to prepare for the disclosure. This model did not control for the following variables: assessment of benefits vs. risks of disclosure; self-efficacy; beliefs and attitudes in deciding when to disclose; assessment of child's characteristics; perception of caregiver's and child's social support. ^c This model includes nondisclosed caregivers and disclosed caregivers who had time to prepare for the disclosure. ‡ "disclosed" refers to the children who know that they have a health condition called HIV.

4. Discussion

This study is part of a larger body of research aimed at developing an instrument that assesses a caregiver's readiness and self-efficacy to disclose their child's HIV status to the child. Our goal was to empirically describe the disclosure process and predictors and consequences of disclosure through conducting a survey with caregivers who are taking care of HIV-positive children between the ages of 9 and 15 receiving ART or pre-ART in Bikita and Zaka districts in Zimbabwe. Through a multivariate analysis, we identified various caregiver and child characteristics that predict pediatric HIV disclosure. In summary, caregivers' perception of their own knowledge and social skills to disclose to their child (self-efficacy), their ability to cope with HIV-related shame regarding their own positive HIV status, their awareness of HIV symptoms and implications of HIV on their health, their assessment of their child's readiness for disclosure, marital status, and child's level of education predicted caregivers' disclosure to their child. Factors such as caregivers' assessment of risks and benefits of disclosure, perception of HIV-related stigma and/or discrimination, access to health care, quality of health workers, child or caregiver gender, or socioeconomic status did not appear to influence the caregivers' decision to disclose to their child.

Our findings suggest that approximately 66.9% of HIV-positive children in Zimbabwe's Bikita and Zaka districts know that they have a medical condition called

HIV, with a full disclosure rate of 26.9%. This estimate is substantially higher than previously reported prevalence of disclosure in sub-Saharan Africa (Biadgilign et al., 2011; Fetzer et al., 2011; John-Stewart et al., 2013; Oberdorfer et al., 2006; Vreeman et al., 2014, 2013a). One possible explanation is that the mean age of children is different across the studies. However, comparing the predicted probabilities of children knowing their HIV status by age between our study and a study in Western Kenya indicated that a higher mean age of children in our sample compared to those of other studies may not contribute to the higher prevalence of disclosure in our study. For example, in our study, the predicted probabilities of children knowing that they are HIV positive increased from 0.42 at age 9 to 0.78 at age 14 while Vreeman et al. reported predicted probabilities of disclosure of 0.14 at age 9 and 0.62 at age 14 (Vreeman et al., 2014). One factor that may have contributed to the higher prevalence of disclosure in our study is that every child in our study population was on ART. Previous findings have suggested that children who receive ART are more likely to know their HIV status (Menon et al., 2007; Vreeman et al., 2014). Previous investigations reported proportions of children receiving ART in their studies of 63%, 86%, and 84.3% with disclosure rates at 19%, 26%, and under 40%, respectively (Biadgilign et al., 2011; John-Stewart et al., 2013; Vreeman et al., 2014). Another explanation of the discrepancy of the prevalence of disclosure between our study and other studies is that many of other studies are based on small convenience

samples that make it difficult to detect meaningful differences between the children who know their status and those who do not.

Caregivers who disclosed and had time to prepare for the disclosure tended to have better quality of parent-child communication and better perception of their abilities to talk about sex with their child, compared to non-disclosing caregivers. Although open discussions with children regarding sexuality are not culturally sanctioned in sub-Saharan Africa (Kyaddondo, Wanyenze, Kinsman, & Hardon, 2013), Jemmott III et al. reported that caregivers who were better equipped to talk to their children about sex and HIV expressed a stronger intention to disclose to their children (Jemmott et al., 2014; Kyaddondo et al., 2013). The correlation we report between disclosure and better quality of parent-child interactions is consistent with previous studies (De Baets, Sifovo, Parsons, & Pazvakavambwa, 2008; Gachanja & Burkholder, 2016; Kallem et al., 2011; Lester et al., 2002; Mellins et al., 2002; L. Wiener et al., 2007). Interestingly, however, some studies examining parental HIV disclosure to children who may or may not be HIV-positive have reported that *higher* family cohesion was associated with *lower* levels of self-valuing and *higher* levels of depression for children. Therefore a closer relationship between caregivers and children after disclosure may suggest psychological problems of children who experience anxiety and hypervigilance from knowing their caregivers' HIV status (Ledlie, 1999; Murphy, 2008; Qiao, Li, & Stanton, 2013a). Therefore, factors that facilitate disclosure may also be related to specific psychological

constructs that influence general family relationships, though this link requires further research.

Replicating previous findings (Bhattacharya, Dubey, & Sharma, 2011; Demmer, 2011; Kidia et al., 2014; Rujumba, Mbasaalaki-Mwaka, & Ndeezi, 2010; Vaz, Eng, Maman, Tshikandu, & Behets, 2010; Vreeman et al., 2010), our study found higher prevalence of disclosure among older children ($p < 0.01$) and children who completed more years of school ($p = 0.004$). Existing literature has identified child's age as one of the predictors of disclosure with children learning of their HIV status at older ages (Abadía-Barrero & LaRusso, 2006; Bikaako-Kajura et al., 2006; John-Stewart et al., 2013; Kallem et al., 2011; Lesch et al., 2007; Menon et al., 2007; Vreeman et al., 2010; Vreeman, Gramelspacher, Gisore, Scanlon, & Nyandiko, 2013b). Caregivers delay disclosure until their children are older because they believe that the children lack emotional and intellectual capacity to understand the disease and implications, and a sense of responsibility to care for themselves at a young age. Their enrollment in school is also associated with disclosure (Bhattacharya et al., 2011; Kallem et al., 2011; Vreeman et al., 2010, 2014), likely in tandem with the relationship between higher levels of education at older age. However, although our study shows that child age is correlated with disclosure, it is not a predictor of disclosure. Thus, child age may not be the underlying mechanism for disclosure, with their correlation reflecting other variables that influence disclosure more directly. One likely candidate is child education, given that it was found

to predict disclosure, and given that age predicted disclosure only when controlling for all variables except child's education. Caregivers may be more inclined to disclose to their child if he or she has received formal education about sex and HIV at school. Similarly, caregivers' assessment of their child's cognitive ability and emotional maturity ($p < 0.10$) also predicted disclosure. Disentangling the respective influences of age, education, and child cognitive development and emotional maturity on disclosure will require further investigation outside the scope of the present study.

We found that decision to disclose is influenced by caregivers' current level of shame and subsequent stigma post-disclosure, which replicates previous literature (Biadgilign et al., 2011; Kallem et al., 2011; Paintsil et al., 2015). For example, Paintsil et al. noted that non-disclosing caregivers had higher scores on the 18-item HIV Stigma Scale (Paintsil et al., 2015), which includes internalized stigma, attributed stigma (concern with public attitudes about people with HIV), and perception of actual stigma/discrimination from others. Instead, all three multivariate models showed that HIV-positive caregivers who experience a high level of HIV-related shame about their own HIV status were less likely to disclose. The difference between the concept of shame and self-stigma was explored in multiple studies; internalized stigma was defined as a socially-constructed concept related to a defect or disgrace, rooted at the cultural level that is more resistant to change, whereas shame was perceived as an internally constructed emotional response that is more amenable to change (Fortenberry et al.,

2002; Neufeld et al., 2012). This indicates that if psychosocial interventions tailor their guidance at helping HIV-positive caregivers to overcome their shame related to living with HIV, these caregivers may be able to disclose to their child more readily.

Previous studies have found that caregivers concerned about stigma associated with HIV chose to conduct partial rather than full disclosure (Instone, 2000; Lorenz et al., 2016; L. S. Wiener, Battles, & Heilman, 1998). In our study, however, variables such as child's mental health, parent-child communication, and family cohesion and support did not vary significantly between fully- and partially-disclosing caregivers. In other words, partially-disclosing caregivers who were concerned about potential negative consequences of disclosure including child's worsened health, poor parent-child communication, and a lower level of family cohesion and support, may not actually experience these consequences any less than those who have fully disclosed to their child. As our findings on caregivers' HIV-related shame mentioned above indicates, it could also mean that caregivers' concern for these consequences is not necessarily the main driver in their decision to disclose to their child. Gaining this knowledge and considering that partial disclosure, rather than full disclosure, has been studied to strain the relationship between the caregiver and the child (Bikaako-Kajura et al., 2006), caregivers may be recommended to conduct full disclosure sooner rather than later.

In Model 3, HIV-positive caregiver scores on the Brief Illness Perception Questionnaire predicted disclosure, such that higher scores predicted higher chance of

disclosure. The caregivers who were more likely to disclose to their child tended to score higher on this scale and felt that their HIV status affected them every day, experienced HIV symptoms more frequently, and were more concerned about their status. One plausible explanation for this finding is that they are more familiar with their own HIV status and are more aware of its implications on their and their child's health.

Our study also found that among nondisclosed caregivers and disclosed caregivers who had time to prepare for the disclosure, caregivers were more likely to disclose to their child when they had higher perception of their social/counseling skills, emotional strength, knowledge about HIV, and ability to find resources or social support for the child following disclosure. It is understandable that caregiver's self-efficacy does not predict disclosure in Model 1, which includes disclosed caregivers who either learned about their child's HIV status after or on the same day as the child did, and therefore did not have time to prepare for the disclosure. We found that higher self-efficacy in caregivers leads to an increase in likelihood of disclosing, which is supported by Kiwanuka et al. They reported that non-disclosing caregivers use deception to avoid disclosure or delay disclosure until they perceive their self-efficacy to be sufficient (Kiwanuka, Mulogo, & Haberer, 2014). These findings imply that caregivers' perception of knowledge and skills is the critical factor associated with caregivers' readiness for disclosure.

Our findings on caregivers' attitudes of the benefits of disclosure weighed against risks of disclosure, which had been proposed in our conceptual model of the disclosure process, did not predict disclosure. These are contrary to a qualitative study in Western Kenya that reported caregivers weighing potential risks and benefits as they made decisions when to disclose to their child (Vreeman et al., 2010). Several existing theories of HIV disclosure are also based on the idea that individuals living with HIV are likely to disclose if the benefits of disclosure outweigh the risks (Chaudoir & Fisher, 2010; Qiao et al., 2013; Serovich, 2001). Our findings show that caregivers who disclosed to their child had perceived a lower benefits-to-risks of disclosure ratio prior to the disclosure. They retrospectively reported their attitudes towards benefits and risks of disclosure to the time before disclosure was conducted; caregivers who have already disclosed may render their later recollection of their attitudes towards disclosure unreliable. However, one study found that caregivers' self-efficacy is related to a stronger intention to disclose their child's HIV status to the child, whereas their behavioral beliefs that their child would have a negative emotional response, deny the diagnosis, tell others, or have a positive reaction was not (Kyaddondo et al., 2013). Our findings on self-efficacy as a predictor of disclosure, but no association between the likelihood of disclosure and caregivers' assessment of the benefits and risks of disclosure, shared the same conclusion as this study.

Only in Model 1, caregivers who are not married were more likely to disclose to their child than those who are HIV-positive and are married. This predictor variable may not have reached statistical significance in Models 2 and 3 due to the small sample size in those two models. Previous studies have reported that child having a deceased biological father or not having a biological father was a predictor of disclosure (Kallem et al., 2011; Oberdorfer et al., 2006; Vreeman et al., 2013b). One explanation could be that disclosure would now encourage the children to adopt more responsibility for their health or around their homes without constant supervision by their single parent. In order to fully understand the association between caregivers' marital status and disclosure, further research must account for local, cultural constraints and beliefs in Zimbabwe surrounding the role of children within families, and how this role may influence disclosure.

Most caregivers who have disclosed to their child noted that their child's adherence to medication has improved since the disclosure (76.7%). No caregiver reported worsened adherence following disclosure. These findings support the hypothesis that disclosure has a positive effect on adherence, consistent with other studies that reported caregivers sharing responsibilities of adherence with the child after disclosure (Havens & Mellins, 1996; Marhefka, Tepper, Brown, & Farley, 2006), and caregivers experiencing less frustration with their child's adherence (Nichols, Steinmetz, & Elijah, 2016; L. Wiener et al., 2007). However, a recent systematic review found the

association between HIV disclosure and adherence to ART to be inconclusive, with some studies showing no statistically significant relationship between the disclosure and adherence, some showing increased adherence after disclosure, and some showing decreased adherence after disclosure (Nichols et al., 2016). A review by Nichols et al., however, noted the limitations of generalizability of the studies' results, which stem from their research design, varying definitions of adherence across the studies, social desirability bias, etc.

In our study, although disclosed children's adherence to medication improved after disclosure, caregivers reported that these children refused or forgot to take medications more often than those who have not been told about their HIV status ($p < 0.001$). This may suggest that caregivers disclose in order to improve adherence in children who initially show low adherence, resulting in better subsequent adherence. It may also mean that caregivers may not be motivated to disclose if their child currently adheres well to the medication.

One of the strengths of our study is that this is one of the first quantitative studies that aimed to examine the prevalence, predictors, and consequences of pediatric HIV disclosure in rural Zimbabwe. One other study conducted in Eastern Zimbabwe was a qualitative study that compared perspectives of health workers and community members on the process of pediatric HIV disclosure. Compared to other relevant studies based in low-resource settings, this study included a large number of participants from

21 clinics, which allowed us to provide a comprehensive, nuanced understanding of the decision-making process of the caregivers to disclose to their child. Prior to generating survey items, we were also able to gain an in-depth understanding of the process of disclosure through an iterative, qualitative process that incorporated insights from health workers, caregivers, and HIV-positive adolescents who were aware of their HIV status. We were able to more accurately reflect diverse perspectives of the disclosure process in the questionnaire. In our study, we also collected data on the characteristics of partial and full disclosure.

Due to the cross-sectional study design, conclusions cannot be drawn regarding a causal relationship between the characteristics of caregivers and disclosure.

Additionally, the population from which our sample was drawn is unique, and therefore our findings are only generalizable to children between the ages of 9 and 15 receiving ART or pre-ART from clinics in Bikita and Zaka districts in Zimbabwe. The study also required self-reporting of the caregivers who may have introduced social desirability bias and recall bias for those who have already disclosed to their child. Caregivers' reports on their children not being upset or sad seem questionable and would require more investigation. Our study also did not collect data on CD4 count or WHO disease stages, which would have allowed us to examine the association of disclosure and children's disease progression. However, with ART becoming increasingly available in low-resource settings and HIV-positive children experiencing

less symptoms, the association between disclosure and disease progression may have decreased. In the interest of time, we could not analyze data regarding the duration of ART for children, which has been reported as a predictor of disclosure. We also only looked at the survey questions collectively as a scale. In the future, we may want to examine individual items to further investigate the disclosure process.

In our multivariate analysis, the following scales, SDQP (assessing psychosocial wellbeing of the child), PCC (assessing parent-child communication), and PATCSE (perception of caregiver's ability to talk to their child about sex), were excluded as we had not specified if the questions were asked to the disclosed caregivers in response to children already knowing HIV status or prior to the disclosure. These are important factors of disclosure and may require further investigation. For example, examining caregivers' response in the SDQP scale would allow us to explore how caregivers' assessment of their child's readiness for disclosure influences their decision to disclose. In addition, some qualitative factors may have influenced unique disclosure patterns at the clinic level, but were not accounted for in the current design. For instance, an anecdote about a health worker that is unique to a clinic would have been important to capture as it may explain a particular pattern of disclosure at the clinic. It is also true that our study may have inevitably encouraged caregivers who otherwise had no intention to disclose to their child to do so after the survey. This may have resulted in negative consequences for the caregivers and their child and possibly introduced a bias in our

study for the rest of the survey. Finally, children were not surveyed in this study. The most accurate way to determine if, when, and how their caregivers disclosed would be through interviewing the children. However, due to sensitivity around potential accidental disclosure and our interest in examining caregiver's readiness and self-efficacy to disclose, the survey was only administered to the caregivers.

In the future, longitudinal analysis about the process of disclosure will be able to provide more information on not just whether or not caregivers fully disclose to their child, but also on when and how. Additionally, this study could improve with qualitative data collection especially from the perspective of the children.

5. Conclusion

Our study measured a substantially high prevalence of children who know that they have a health condition called HIV compared to other studies conducted in sub-Saharan Africa. We found the following characteristics of caregivers to be predictors of pediatric HIV disclosure: perceived ability of HIV-positive caregivers to cope with the stigma of living with HIV, perceived ability of caregivers to disclose to their child, caregiver marital status, and child education level. Successful intervention programs to assist caregivers and their children would provide guidance and support for caregivers to improve their own psychosocial wellbeing, gain the necessary counseling skills, and provide them with knowledge about HIV. Our study results indicate that targeting to improve caregivers' self-efficacy and help caregivers overcome their HIV-related shame will be the most effective method in eventually facilitating successful disclosure. A more immediate step to achieving this goal, however, would be a longitudinal study design with a large sample population to identify a causal relationship between pediatric HIV disclosure and characteristics of caregivers and their children such as caregiver's self-efficacy, adherence to medication, child's mental health, and family relations.

Appendix A

Our target population was primary caregivers of HIV-positive children between the ages of 9 and 15 years living in Bikita and Zaka districts and receiving ART or pre-ART from a BHASO-affiliated clinic with more than 12 children in this age range on ART or pre-ART. We wanted to test: (i) if there is a difference on estimated HIV prevalence between our target population and population from excluded clinics and (ii) if our estimated disclosure rates are related to estimated HIV prevalence.

Because HIV prevalence of was not measured by the survey, we drew on interpolated estimates of HIV prevalence among adults (ages 15-49) as measured in the 2010 Zimbabwe Demographic and Health Survey.

For our study clinics, GPD coordinates were collected at the time of the survey (21 clinics). For clinics excluded from the study, GPS coordinates in Bikita and Zaka districts were collected as part of compiling the sample frame and placed on a Google map (12 clinics), 3 clinics were found using Open Street Map (an open source version of Google Maps), 1 clinic was found using a map provided by Relief Web and the remaining 5 clinics were provided upon request from DHIS2 (District Health Information System 2).

We used Lamarange's ASCII grid of HIV prevalence estimates for Zimbabwe, which was produced using the 2010 ZDHS data on HIV prevalence and population at survey clusters. Interpolating HIV prevalence requires an algorithm that provides an

estimate of HIV-positive population at locations within a certain radius of the ZDHS survey cluster. In Lamarange's algorithm, a circle is drawn around each cluster such that the number of people surveyed is at least equal to a fixed minimum number of people. The size of the circle corresponds to the density of the clusters; the more widely dispersed the clusters, the larger the circle. The algorithm then draws an intensity surface, which is computed depending on that circle and a height proportional to the weighted number of observations at each point. This means the more densely populated circles will have higher peaks in the middle of the circle. The algorithm is repeated for each survey cluster until all surfaces are summed to produce the intensity surface of the observed population. This algorithm ultimately creates a density surface of HIV positive cases and calculates prevalence at each pixel in the surface. We used this ASCII grid of HIV prevalence and overlaid it on top of the GPS coordinates of each of the 21 clinics in our sampling frame. We used this method to see if HIV prevalence was related to: (i) a clinic size (number of children on ART or pre-ART) and (ii) HIV disclosure at our sample clinics.

We found that there is no relationship ($p < 0.22$) between HIV prevalence of adults (ages 15-49) and the number of children between 9 and 15 on ART or pre-ART at our sample clinics (see Figure 3). We also found that there is no relationship ($p < 0.49$) between HIV prevalence and the proportion of children who know that they have a condition called HIV.

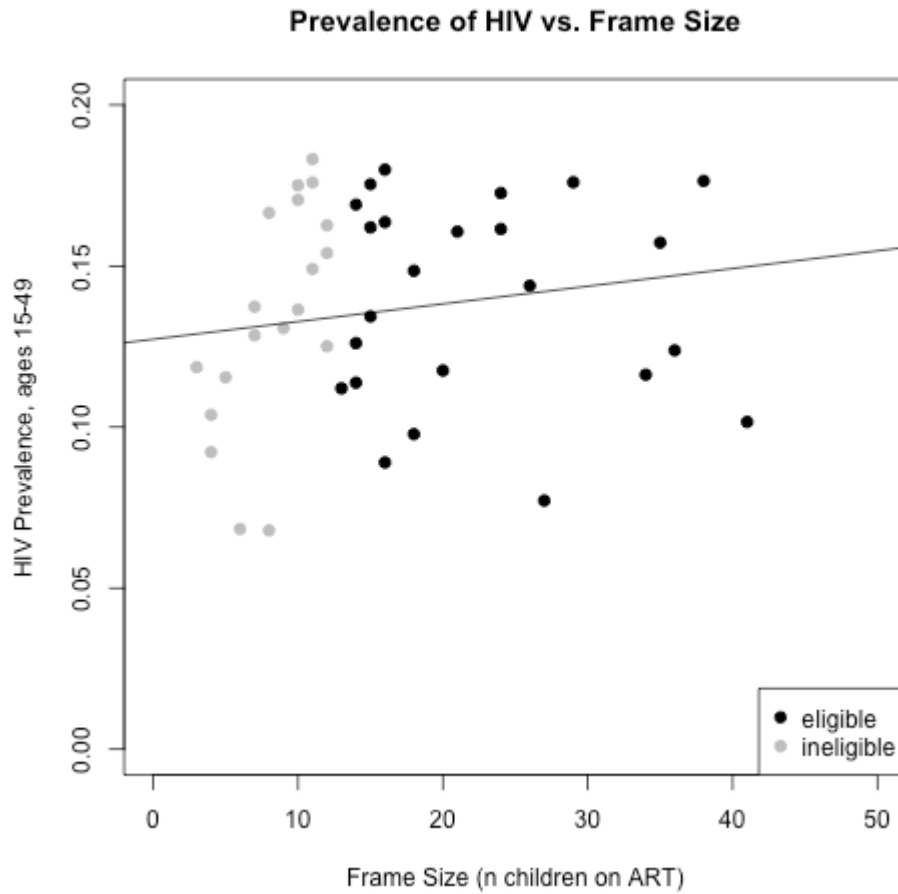


Figure 4: Relationship between prevalence of HIV at each clinic in our sampling frame and the number of children between ages 9 and 15 on ART or pre-ART

In summary, excluded clinics serving less than 13 children on ART or pre-ART in Bikita and Zaka districts were not systematically different than clinics serving 13 to 20 children on ART or pre-ART.

Appendix B

Items	Questions	scale	Total, mean (sd)	N	Full, mean (sd)	N	Partial, mean (sd)	N
pdq12	Caregiver's overall disclosure experience	0-3	2.52 (0.63)	203	2.49 (0.68)	85	2.54 (0.59)	118
pdq13	Child's overall disclosure experience	0-3	2.44 (0.69)	193	2.37 (0.74)	84	2.50 (0.64)	109
pdq14	Child became angry	0-3	0.25 (0.67)	197	0.26 (0.71)	84	0.24 (0.64)	113
pdq15	How long did this last?							
pdq16	Child got sad	0-3	0.41 (0.84)	199	0.42 (0.89)	85	0.39 (0.81)	114
pdq17	How long did this last?							
pdq18	Child asked questions	0-3	0.81 (0.97)	210	0.78 (0.99)	88	0.83 (0.96)	122
pdq19	How long did this last?							
pdq20	Child has accepted his/her status	1,0	0.99 (0.12)	207	0.99 (0.11)	85	0.98 (0.13)	122
pdq21	How long did it take for your child to accept [his/her] status?							
pdq22	Disclosure was good for my child	1,0	0.87 (0.33)	204	0.87 (0.34)	84	0.88 (0.33)	120
pdq23	Child learned about his/her status at a good age							
pdq24	I would change something about how I disclosed to child	1,0	0.09 (0.29)	213	0.08 (0.27)	88	0.10 (0.31)	125
pdq26	After disclosure, child's adherence to medication is better, worse, or stayed the same as before disclosure. 0=same; 1=better	1,0	0.79 (0.41)	149	0.72 (0.45)	53	0.82 (0.38)	96

Appendix C

Items	Questions	scale	Total,	N	Full,	N	Partial,	N
			mean (sd)		mean (sd)		mean (sd)	
all		0-2	0.29 (0.25)	225	0.28 (0.29)	90	0.29 (0.23)	135
sdqp04103	Often complains of headaches, stomach-aches or sickness		0.92 (0.87)	225	0.80 (0.86)	90	1.00 (0.86)	135
sdqp04108	Has many worries or often seems worried		0.28 (0.62)	225	0.28 (0.62)	90	0.27 (0.62)	135
sdqp041013	Often unhappy, depressed or tearful		0.16 (0.47)	225	0.14 (0.44)	90	0.16 (0.49)	135
sdqp041016	Nervous or clingy in new situations, easily loses confidence		0.17 (0.50)	225	0.23 (0.58)	90	0.13 (0.44)	135
sdqp041024	Has many fears, easily scared		0.32 (0.68)	225	0.31 (0.68)	90	0.32 (0.69)	135
sdqp_emotional			0.37 (0.38)	225	0.35 (0.43)	90	0.38 (0.35)	135
sdqp04105	Often loses temper		0.41 (0.68)	225	0.43 (0.70)	90	0.40 (0.67)	135
sdqp04107r	Generally well behaved, usually does what adults request		0.12 (0.37)	225	0.12 (0.39)	90	0.11 (0.36)	135
sdqp041012	Often fights with other children or bullies them		0.12 (0.42)	225	0.11 (0.41)	90	0.12 (0.42)	135
sdqp041018	Often lies or cheats		0.34 (0.68)	225	0.33 (0.65)	90	0.34 (0.69)	135
sdqp041022	Steals from home, school or elsewhere		0.05 (0.29)	225	0.06 (0.31)	90	0.04 (0.27)	135
sdqp_conduct			0.21 (0.29)	225	0.21 (0.34)	90	0.20 (0.26)	135
sdqp04102	Restless, overactive, cannot stay still for long		0.22 (0.59)	225	0.19 (0.56)	90	0.24 (0.62)	135
sdqp041010	Constantly fidgeting or squirming		0.19 (0.52)	225	0.16 (0.50)	90	0.21 (0.53)	135
sdqp041015	Easily distracted, concentration wanders		0.49 (0.80)	224	0.46 (0.80)	90	0.51 (0.81)	134
sdqp041021r	Thinks things out before acting		0.37 (0.60)	223	0.37 (0.57)	90	0.38 (0.62)	133
sdqp041025r	Good attention span, sees work through to the end		0.32 (0.59)	225	0.30 (0.55)	90	0.33 (0.62)	135
sdqp_hypact			0.32 (0.37)	225	0.29 (0.38)	90	0.34 (0.36)	135
sdqp04106	Rather solitary, prefers to play alone		0.18 (0.53)	225	0.14 (0.49)	90	0.21 (0.56)	135
sdqp041011r	Has at least one good friend		0.29 (0.55)	223	0.36 (0.59)	90	0.25 (0.53)	133
sdqp041014r	Generally liked by other children		0.27 (0.49)	224	0.36 (0.55)	89	0.21 (0.45)	135
sdqp041019r	Picked on or bullied by other children		0.33 (0.69)	224	0.26 (0.63)	90	0.38 (0.72)	134
sdqp041023	Gets along better with adults than with other children		0.20 (0.52)	225	0.22 (0.56)	90	0.18 (0.50)	135
sdqp_peerprob			0.25 (0.30)	225	0.27 (0.30)	90	0.25 (0.30)	135

Appendix D

Item	Questions	scale	Total, mean (sd)	N	Full, mean (sd)	N	Partial, mean (sd)	N
all		0-3	2.48 (0.37)	225	2.46 (0.38)	90	2.49 (0.37)	135
pcc1	You can discuss your beliefs with your child without feeling restrained or embarrassed.		2.43 (0.62)	225	2.53 (0.56)	90	2.36 (0.64)	135
pcc2r	Sometimes you have problems believing everything that your child tells you.		2.78 (0.79)	225	2.71 (0.78)	90	2.82 (0.80)	135
pcc3	Your child listens carefully every time.		2.37 (0.62)	225	2.38 (0.61)	90	2.36 (0.63)	135
pcc5r	Your child usually tells you things that would have been better left unsaid.		0.76 (0.68)	225	0.81 (0.70)	90	0.72 (0.67)	135
pcc6	Your child can tell how you are feeling without asking.		2.24 (0.68)	225	2.26 (0.70)	90	2.23 (0.68)	135
pcc7	You are satisfied with how you talk together with your child.		2.48 (0.54)	225	2.42 (0.60)	90	2.52 (0.50)	135
pcc9	You usually show love openly to your child.		2.80 (0.40)	225	2.81 (0.39)	90	2.79 (0.41)	135
pcc10r	When you have a problem, you often don't talk to your child.		2.52 (0.91)	225	2.46 (0.89)	90	2.56 (0.93)	135
pcc11r	You think carefully about what you will say to your child.		1.60 (0.50)	225	1.58 (0.52)	90	1.61 (0.49)	135
pcc12r	When you talk to your child you normally say things that would have been better left unsaid.		3.35 (0.69)	225	3.44 (0.64)	90	3.28 (0.72)	135
pcc13	When you ask a question, you get an answer you trust from your child.		2.27 (0.67)	225	2.23 (0.72)	90	2.29 (0.63)	135
pcc14	Your child tries to understand your opinion.		2.39 (0.56)	225	2.40 (0.56)	90	2.38 (0.56)	135
pcc15r	There are some things you avoid discussing with your child.		2.27 (0.84)	225	2.29 (0.78)	90	2.26 (0.87)	135
pcc16	You find it easy to discuss problems with your child.		1.77 (0.78)	225	1.78 (0.72)	90	1.76 (0.82)	135
pcc17	It is easy for you to discuss all your true feelings with your child.		1.63 (0.80)	225	1.61 (0.79)	90	1.64 (0.81)	135
pcc18r	Your child's behavior bothers you.		3.41 (0.72)	225	3.33 (0.72)	90	3.47 (0.71)	135
pcc19r	Your child verbally abuses you when they are angry with you.		3.69 (0.57)	225	3.70 (0.55)	90	3.68 (0.58)	135
pcc20r	You don't think you can tell your child how you really feel about some things.		2.41 (0.84)	225	2.36 (0.78)	90	2.44 (0.88)	135
pcc21	You can talk about almost anything with your child.		1.53 (0.80)	225	1.42 (0.76)	90	1.61 (0.81)	135
pcc22r	Your child sometimes doesn't listen to you at all.		3.35 (0.67)	225	3.23 (0.65)	90	3.42 (0.67)	135
pcc23	You can tell your child how you feel about everything.		1.55 (0.81)	225	1.52 (0.80)	90	1.57 (0.82)	135
pcc24	Your child knows how to talk to you.		2.45 (0.57)	225	2.42 (0.62)	90	2.47 (0.53)	135

Appendix E

Table 7: Predictors of full disclosure‡

	Model 4 ^a		Model 5 ^b		Model 6 ^c	
	Coef	SE	Coef	SE	Coef	SE
Child age	0.04*	0.02	0.02	0.02	0.02	0.02
Child gender	0.01	0.05	-0.02	0.05	-0.03	0.05
Child's highest level of education completed	0.01	0.02	0.02	0.02	0.02	0.02
Caregiver age	-0.00 ⁺	0.00	-0.00	0.00	-0.00	0.00
Caregiver gender	-0.04	0.06	0.08	0.05	0.09	0.06
Caregiver's highest level of education completed	0.01	0.06	0.03	0.07	0.02	0.07
Marital status	-0.08*	0.04	-0.02	0.05	-0.01	0.05
Caregiver's HIV status	0.11	0.07	0.01	0.09	-0.02	0.09
Biological vs. foster parent	-0.08	0.06	-0.06	0.08	-0.06	0.08
SES	0.01	0.04	0.01	0.04	0.00	0.04
General Health Questionnaire (Physical health)	-0.02	0.03	-0.03	0.04	-0.03	0.04
Patient Health Questionnaire (Mental health)	-0.04	0.04	-0.03	0.06	-0.04	0.06
Accessibility and quality of health care system	-0.04	0.05	-0.03	0.06	-0.04	0.06
HIV stigma	0.07	0.06	-0.01	0.14	-0.04	0.15
HIV-related shame	-0.15*	0.05	-0.14*	0.05	-0.12 ⁺	0.06
Brief Illness Perception Questionnaire	0.02	0.02	0.02	0.03	0.02	0.03
Assessment of benefits vs. risks of disclosure					0.00	0
Caregiver's self-efficacy					0.06	0.04
Beliefs and attitudes in deciding when to disclose; assessment of child's characteristics					-0.03	0.04
Perception of caregiver's and child's social support					0.04 ⁺	0.02
_cons	0.03	0.27	0.09	0.27	-0.01	0.27
N						
R-sq						

⁺ p<0.10 * p<0.05 ** p<0.01 *** p<0.001 ‡ "fully disclosed" refers to the children who know all details of their HIV status. Note: There were 23 caregivers who declined to share their HIV status. 208 caregivers reported positive HIV status. 141 caregivers reported negative HIV status. Adding 23 caregivers with unknown status to negative HIV status group did not show any difference in the results of the linear regression. Therefore 23 caregivers with unknown status were combined with the HIV-negative caregivers for this analysis.

^a This model includes caregivers of all categories—nondisclosed caregivers and disclosed caregivers regardless of whether or not they had time to prepare for the disclosure. ^b This model includes nondisclosed caregivers and disclosed caregivers who had time to prepare for the disclosure. This model did not control for the following variables: assessment of benefits vs. risks of disclosure; self-efficacy; beliefs and attitudes in deciding when to disclose assessment of child's characteristics; perception of caregiver's and child's social support. ^c This model includes nondisclosed caregivers and disclosed caregivers who had time to prepare for the disclosure.

Appendix F

	Coef.	Std. Err.	z	P>z	[95% Conf. Interval]	
1	(base outcome)					
2						
Child age	0.11	0.08	1.41	0.16	-0.04	0.26
Child gender	-0.04	0.27	-0.13	0.90	-0.57	0.50
Child's highest level of education completed	0.23	0.09	2.50	0.01	0.05	0.41
Caregiver age	-0.01	0.02	-0.48	0.63	-0.04	0.02
Caregiver gender	0.18	0.45	0.41	0.68	-0.69	1.06
Caregiver's highest level of education completed	0.08	0.35	0.24	0.81	-0.61	0.78
Marital status	-0.52	0.25	-2.08	0.04	-1.02	-0.03
Caregiver's HIV status	0.07	0.73	0.10	0.92	-1.35	1.50
Biological vs. foster parent	0.66	0.54	1.22	0.22	-0.40	1.71
SES	-0.06	0.33	-0.17	0.86	-0.70	0.59
General Health Questionnaire (Physical health)	0.24	0.31	0.76	0.45	-0.38	0.85
Patient Health Questionnaire (Mental health)	-0.20	0.44	-0.45	0.66	-1.06	0.67
Accessibility and quality of health care system	0.15	0.32	0.45	0.65	-0.49	0.78
HIV stigma	-0.77	0.61	-1.27	0.20	-1.96	0.42
HIV-related shame	-1.01	0.39	-2.59	0.01	-1.77	-0.24
Brief Illness Perception Questionnaire	0.23	0.13	1.73	0.08	-0.03	0.50
Assessment of benefits vs. risks of disclosure	0.00	0.00	-1.35	0.18	0.00	0.00
Caregiver's self-efficacy	0.31	0.19	1.65	0.10	-0.06	0.67
Beliefs and attitudes in deciding when to disclose; assessment of child's characteristics	-0.46	0.26	-1.80	0.07	-0.97	0.04
Perception of caregiver's and child's social support	-0.35	0.21	-1.66	0.10	-0.75	0.06
_cons	-2.53	1.31	-1.92	0.05	-5.10	0.05
3						
Child age	0.22	0.17	1.32	0.19	-0.11	0.54
Child gender	-0.26	0.30	-0.87	0.38	-0.85	0.33
Child's highest level of education completed	0.25	0.19	1.33	0.18	-0.12	0.63
Caregiver age	-0.03	0.02	-1.41	0.16	-0.06	0.01
Caregiver gender	0.72	0.53	1.36	0.17	-0.32	1.76
Caregiver's highest level of education completed	0.23	0.49	0.46	0.65	-0.74	1.19
Marital status	-0.30	0.40	-0.76	0.45	-1.09	0.48

Caregiver's HIV status	-0.14	0.55	-0.26	0.80	-1.22	0.93
Biological vs. foster parent	-0.06	0.53	-0.12	0.91	-1.11	0.98
SES	-0.12	0.32	-0.37	0.71	-0.74	0.50
General Health Questionnaire (Physical health)	0.00	0.27	0.02	0.99	-0.52	0.53
Patient Health Questionnaire (Mental health)	-0.67	0.51	-1.31	0.19	-1.66	0.33
Accessibility and quality of health care system	-0.24	0.41	-0.57	0.57	-1.05	0.57
HIV stigma	-0.90	1.00	-0.90	0.37	-2.86	1.06
HIV-related shame	-1.94	1.09	-1.79	0.07	-4.07	0.19
Brief Illness Perception Questionnaire	0.33	0.22	1.55	0.12	-0.09	0.76
Assessment of benefits vs. risks of disclosure	0.00	0.00	-0.41	0.68	0.00	0.00
Caregiver's self-efficacy	0.63	0.28	2.27	0.02	0.08	1.17
Beliefs and attitudes in deciding when to disclose; assessment of child's characteristics	-0.48	0.27	-1.77	0.08	-1.00	0.05
Perception of caregiver's and child's social support	0.15	0.21	0.73	0.47	-0.26	0.56
<u>_cons</u>	<u>-3.77</u>	<u>1.87</u>	<u>-2.01</u>	<u>0.04</u>	<u>-7.44</u>	<u>-0.09</u>

Note: 1= nondisclosure; 2=partial disclosure (children do not know the name of the illness, but know that they have an illness that requires ongoing treatment; children know the name of the illness, but do not know all details of their HIV status); 3=full disclosure (children know all details of their HIV status)

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