OPEN

Pediatric HIV Disclosure Intervention Improves Knowledge and Clinical Outcomes in HIV-Infected Children in Namibia

Kristin M. Beima-Sofie, MPH, PhD, Laura Brandt, MD,*† Ndapewa Hamunime, MD,‡ Mark Shepard, MPH, PhD,*† James Uusiku,† Grace C. John-Stewart, MD, PhD,*§‖¶ and Gabrielle O'Malley, PhD*#*

Objectives: Using routinely collected data, we evaluated a nationally implemented intervention to assist health care workers and caregivers with HIV disclosure to children. We assessed the impact of the intervention on child's knowledge and health outcomes.

Methods: Data were abstracted from national databases and patient charts for HIV-infected children aged 7–15 years attending 4 high-volume HIV clinics in Namibia. Disclosure rates, time to disclosure, and HIV knowledge in 314 children participating in the intervention were analyzed. Logistic regression was used to identify correlates of partial vs. full disclosure. Paired *t*-tests and McNemar tests were used to compare adherence and viral load (VL) before versus after intervention enrollment.

Results: Among children who participated in the disclosure intervention, 11% knew their HIV status at enrollment and an additional 38% reached full disclosure after enrollment. The average time to full disclosure was 2.5 years (interquartile range: 1.2–3 years). Children who achieved full disclosure were more likely to be older, have lower VLs, and have been enrolled in the intervention longer. Among children who reported incorrect knowledge regarding why they take their medicine, 83% showed improved knowledge after the intervention, defined as knowledge of HIV status or adopting intervention-specific language. On comparing 0–12 months before vs. 12–24 months after enrollment in the intervention, VL decreased by 0.5 $\log_{10}$ copies per milliliter (N = 42, $P = 0.004$), whereas mean adherence scores increased by 10% (N = 88, P value < 0.001).

Conclusions: This HIV disclosure intervention demonstrated improved viral suppression, adherence, and HIV knowledge and should be considered for translation to other settings.

Key Words: pediatric HIV, HIV disclosure, adherence, HIV education, program evaluation

(*J Acquir Immune Defic Syndr* 2017;75:18–26)

INTRODUCTION

In 2014, there were an estimated 2.6 million children younger than 15 years living with HIV and 190,000 children became infected.[1] HIV-infected children and adolescents have unique social and psychological issues that could affect their adherence to antiretroviral treatment (ART) and health outcomes.[2–4] One particular issue that may influence pediatric outcomes is knowledge of their own HIV status. Evidence suggests that a healthy disclosure process can improve physical and psychological health. Timely and supportive disclosure may improve treatment adherence, retention in care, psychological adjustment, family relationships, and morbidity and mortality in HIV-infected children and adolescents.[5–12]

However, disclosing an HIV-positive status to a child remains a global challenge. In high HIV prevalence settings, most perinatally HIV-infected children and adolescents are unaware of their diagnosis, including those who attend regular clinic visits and take ART.[9,12–15] There are several barriers to pediatric HIV disclosure, including caregiver fears and lack of health care worker (HCW) knowledge and tools for disclosure. Caregivers are reluctant to disclose because of potential to experience HIV stigma, guilt regarding transmission, uncertainty in how to disclose, and fears of negative child reactions or questions the child may ask.[9,16–23] In addition, high-volume pediatric HIV clinics often lack systematized processes or standardized materials for disclosure, making disclosure a challenging task for overburdened HCWs.[4,22–24] Interventions that address caregiver fears, as well as provide more training and standardized materials to HCWs, may help to improve disclosure rates and experiences and improve child outcomes. To date, limited peer-reviewed

Received for publication August 8, 2016; accepted December 19, 2016.

From the *Department of Global Health, University of Washington, Seattle, WA; †International Training and Education Center for Health-Namibia, Windhoek, Namibia; ‡Namibian Ministry of Health and Social Services, Windhoek, Namibia; Departments of §Medicine; ‖Pediatrics; ¶Epidemiology, University of Washington, Seattle, WA; and #International Training and Education Center for Health, University of Washington, Seattle, WA.

Supported by National Institutes of Health (NIH) research grant 1R21HD074071-01.

Presented at the 21st International AIDS Conference (AIDS 2016); July 18–22, 2016; Durban, South Africa, and 8th International Workshop on HIV Pediatrics; July 15–16, 2016; Durban, South Africa.

The authors have no conflicts of interest to disclose.

L.B. and N.H. led the development of the intervention. K.M.B.-S., L.B., G. O., M.S., N.H., and G.C.J.-S. conceptualized the quantitative component of the evaluation. K.M.B.-S. conducted the analysis with help from L.B., M.S., J.U., and G.C.J.-S. K.M.B.-S. drafted the manuscript, and all authors contributed to the final manuscript. G.O. supervised the project and provided financial support for the study.

Correspondence to: Kristin M. Beima-Sofie, MPH, PhD, Harborview Medical Center, Box 359909, 325 Ninth Avenue, Seattle, WA 98104 (e-mail: beimak@uw.edu).

literature describes disclosure interventions and their associated outcomes.

After a rapid expansion in ART access for children, HCWs in Namibia noted that they were unprepared for dealing with complex issues associated with telling an HIV-infected child their diagnosis. To address these concerns, the Namibian Ministry of Health and Social Services (MOHSS) HCWs who were providing pediatric HIV services, and the International Education and Training Center for Health (I-TECH), collaboratively and iteratively developed a pediatric HIV disclosure intervention. In 2010, the MOHSS introduced the intervention into routine pediatric HIV services.

We have previously published evaluation data describing how the intervention improved HCW and caregiver's confidence and communication skills for pediatric disclosure.[25,26] In this retrospective study, we evaluated the impact of the intervention on child knowledge of their HIV status, adherence to ART, and viral suppression, using the most complete routine service delivery data available.

METHODS

Intervention Design and Evaluation Sites

The evaluation was conducted at 4 high-volume HIV clinics in Namibia: Onandjokwe, Oshakati, Engela, and Katutura. Evaluation sites were selected based on the timing of intervention roll-out and pediatric HIV patient volumes. Details of the intervention design and evaluation sites have been previously described.[25,26] Briefly, the disclosure intervention is intended to be used with children aged 6–18 years. The centerpiece of the intervention is a 5-chapter cartoon book which uses empowering language and metaphors of body soldiers being strengthened by medicine [antiretroviral medications (ARVs)] and keeping the "bad guys" (HIV virus) asleep. The further the child progresses in reading the book, the more information about his or her disease and the role of medications is revealed. It is not until Chapter 5 that the words "HIV" or "ARV" are mentioned. A portion of the book is read, or reread, at each visit by a HCW until the caregiver and child are ready to read Chapter 5 in which full disclosure occurs. The chapters are read in a highly interactive manner with each one taking approximately 5–10 minutes to complete the first time it is read.

A disclosure form is attached to the patient care booklet on which the HCW notes how far in the disclosure book the child has gone at each visit and why the child thinks they are taking medicine. These notations help HCWs check comprehension and strengthen continuity across visits. A readiness assessment form helps HCWs assess the child's and family's readiness to engage in the full disclosure process. The intervention also includes HCW training on pediatric disclosure and the intervention tools. There is variation in how the intervention is implemented at each site because of site-specific contexts. For example, in facilities where children are unaccompanied by caregivers at their clinic visit, book chapters 1–4 are frequently used in group education settings for children. Although the intervention is implemented in all sites, the completeness of routine documentation associated with the intervention varies widely.

Ethical Considerations

The Namibian MOHSS Ethics Review Committee reviewed and approved the study. Given that the disclosure intervention had been implemented nationally by the Namibian MOHSS as part of routinely offered pediatric HIV treatment services, the University of Washington Institutional Review Board determined that the evaluation of this program was not human subjects research.

Data Collection

Data for this evaluation was abstracted between September and December of 2013 from routinely collected programmatic data. Data sources included patient charts and 3 national electronic databases: (1) the National Institute of Pathology database that contains all HIV viral load (VL) test results performed in the country, (2) the electronic Patient Management System (ePMS) that stores general contact and demographic information on all children enrolled in HIV care, and (3) the Electronic Dispensing Tool (EDT) which contains prescription and medication information for all HIV-infected children receiving medications. Initial participant lists for each of the 4 target clinics were generated by searching the ePMS database and identifying all children with birth dates within the appropriate date range (age 7–15 years at the time of data abstraction) who had been on ART for at least one year. Data abstractors pulled patient charts and verified and abstracted demographic data for all children identified through the ePMS database. Children missing patient files were excluded from the evaluation.

We abstracted data for 2 components of evaluation: (1) a disclosure process evaluation to determine disclosure outcomes and changes in medication knowledge and (2) a clinical outcome evaluation to assess the impact of partial and full disclosure on CD4 count, VL, and adherence to ART. Children were included in the disclosure process evaluation if they had at least one HIV VL in the National Institute of Pathology database within the previous 6 months and documentation of initiating the disclosure intervention at least 13 months before the date of abstraction. Of the children included in the disclosure process evaluation, children included in the clinical outcomes evaluation met additional inclusion criteria. The clinical outcome analysis was limited to children enrolled in the intervention during 2011 who had preintervention and postintervention initiation VL, CD4, and/or adherence data. The 2011 enrollment cutoff was selected so that children had at least 2 years of follow-up postintervention initiation at the time of data abstraction (Fig. 1).

Adherence scores were calculated using pill pick-up and dispensing information found in EDT and the following formula provided by the MOHSS:

$$\text{Adherence Score} = [(\text{PPC} + \text{QD})\text{-PC}]/(\text{CNPPD} \times \text{D})$$

PPC = Previous pill count PC = Current pill count QD = Quantity dispensed D = Days since last visit CNPPD = Number of pills per day

Children in Namibia begin receiving tablets at ages 3–4 years or earlier. Therefore, all children in this analysis should

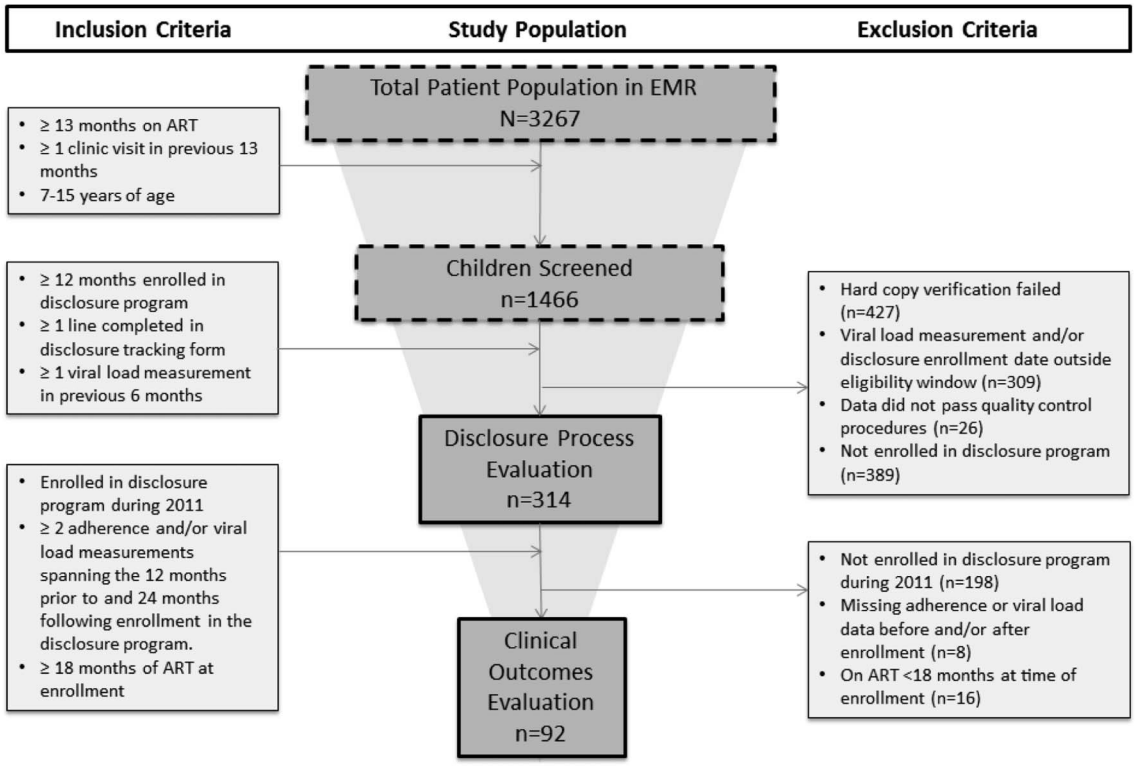


FIGURE 1. Detailed flow chart of inclusion and exclusion criteria for participants included in disclosure evaluations. Dashed line boxes include potential populations while solid-lined boxes describe actual populations included in the evaluation. EMR, Electronic Medical Record database.

have been on tablets. A select few reported visits in the EDT database included syrups for enrolled children, and those visits were removed before adherence analysis.

For children documented as initiating the disclosure intervention, disclosure status was classified as full or partial. Children who specifically mentioned that they took medication for HIV or had the full disclosure box checked and a corresponding date listed that was at or before enrollment in the intervention program were considered fully disclosed at baseline. Children participating in the program were asked if they knew why they took their medicine at each visit, and responses were recorded. Children characterized as having reached full disclosure during the intervention period had the full disclosure box checked and an appropriate date listed, had a record of reading the intervention booklet chapter where HIV is named, or a recorded response to the question "why do you take your medicine?" that included the word HIV. All other children enrolled in the intervention program were characterized as being partially disclosed.

Data Analysis

Data abstracted from patient charts and electronic medical record databases were analyzed using Intercooled STATA version 13.0 (College Station, TX). Descriptive statistics were used to summarize the data on disclosure process outcomes. Correlates of partial vs. full disclosure were determined using univariate logistic regression, and variables statistically significant ($P \leq 0.05$) in univariate analyses were included in a multivariate logistic regression model. Variables were assessed for collinearity before being included in the multivariate model, and only one variable from collinear groupings was selected to be included in the multivariate model. For the subset of children enrolled in the disclosure program during 2011, paired *t*-tests and McNemar tests were used to compare mean differences in adherence scores, CD4 counts, CD4 percent, and log VLs or the proportion of children virally suppressed or considered adherent before versus after enrollment into the intervention. We evaluated virologic success using 2 categories of clinical significance: 100 copies per milliliter and 1000 copies per milliliter. These categories reflect the WHO threshold for virologic suppression (≤1000 copies/mL) and good viral suppression (≤100 copies/mL). Children were considered adherent if they had a mean adherence percentage at or above 80% during the time period described.

RESULTS

Cohort Characteristics

Of the 1466 children screened for inclusion in the evaluation, only 314 satisfied all inclusion criteria (Fig. 1). The median age of children was 12 years, and approximately half (47%) were female (Table 1). Most children (89%) included came from 2 clinics, Katutura and Engela. More than 50% of the children had been on ART for more than 6 years. Only 64% of the study participants had a CD4 count or

TABLE 1. Population Description

	Disclosure Process Evaluation		Clinical Outcomes Evaluation	
	N	Median (IQR) or No. (%)	N	Median (IQR) or No. (%)
Demographics				
Female	314	147 (47)	92	49 (53)
Age, yr	314	12 (10–14)	92	12 (10–14)
Years in HIV care	242	7.2 (5.3–8.5)	49	7.4 (5.6–8.3)
Years on ART	314	6.2 (5.1–8.1)	92	6.0 (5.5–7.1)
Clinic	314		92	
Engela		77 (25)		45 (49)
Oshakati		16 (5)		7 (8)
Onandjokwe		19 (6)		12 (13)
Katutura		202 (64)		28 (30)
Clinical Characteristics				
CD4*				
CD4 count, cells/mm^3	203	850 (605–1052)	88	708 (528–981)
CD4 percent	197	36 (28–40)	85	34 (27–40)
Months since most recent CD4	204	6.5 (4.2–8.7)	88	9.3 (5.5–14.4)
VL†				
VL, log copies/mL	314	2.3 (1.3–3.4)	92	2.9 (1.7–3.9)
Months since most recent VL	314	3.3 (1.9–5.1)	92	3.5 (1.9–5.0)
VL ≤100 copies/mL	314	144 (46)	92	26 (28)
VL ≤1000 copies/mL	314	202 (64)	92	47 (51)
Second-line ARV regimen‡			89	6 (7)
Disclosure Characteristics				
Months enrolled in disclosure intervention	314	33 (25–43)	92	29 (25–32)
Children with more than 1 visit during intervention	314	278 (89)	92	80 (87)
No. visits during intervention§	278	5 (3–6)	80	4 (3–5)
Average months between recorded visits§	278	4.6 (3.1–6.3)	80	3.9 (2.6–5.4)
Child fully disclosed at the end of evaluation	314	154 (49)	92	34 (37)
Child knew HIV status before intervention	314	34 (11)	92	14 (15)
Full disclosure reached during intervention‖	280	120 (43)	78	20 (26)
Months to full disclosure¶	120	31 (16–36)	20	15 (7–20)
Read full disclosure chapter in intervention book	314	74 (24)	92	10 (11)
Child disclosed to during intervention	120	58 (48)	20	7 (35)

Children in Namibia have 2 clinically significant measures for VL values. VLs below 100 copies per milliliter are considered to be suppressed. VLs above 1000 copies per milliliter indicate that the child needs additional adherence and counseling interventions.
*Among children who have a CD4 measurement recorded ≤1 year before data abstraction.
†VL values were from ≤7 months before the date of data abstraction.
‡ARV regimens— first line regimens: AZT/3TC/EFV (n = 7), AZT/3TC/LPV/r (n = 2), AZT/3TC/NVP (n = 53), D4T/3TC/EFV (n = 3), and D4T/3TC/NVP (n = 18); second line regimens: ABC/AZT/3TC/LPV/r (n = 5), and ABC/DDI/LPV/r (n = 1).
§Among children who had more than 1 visit recorded during the intervention.
‖Among children who did not know their status at enrollment.
¶Among children who did not know their status at enrollment and reached full disclosure; 1 child missing disclosure date information.
ABC, abacavir; AZT, azidothymidine; DDI, didanosine; EFV, efavirenz; IQR, interquartile range; NVP, nevirapine; LPV/r, lopinavir/ritonavir; 3TC, lamivudine.

percent recorded within 1 year before data abstraction. Almost half (46%) of children had VLs at or below 100 copies per milliliter, and an additional 18% were suppressed at or below 1000 copies per milliliter. The median time since last VL ascertainment was 3.3 months.

Disclosure Process and HIV Knowledge

At the time of data abstraction, the median time of enrollment in the intervention was just below 3 years (Table 1). Most children (89%) had more than 1 visit recorded in the disclosure tracking form. For children with multiple entries, the median number of entries tracking responses to the question "Why do you take your medicine?" was 5, and the average time between entries was 4.6 months. At enrollment, only 34 children (11%) knew their HIV status. During their time enrolled in the program, there was documented full disclosure to 120 (43%) children. The average time to full disclosure was approximately 2.5 years. When stratified by age, only 20% of children aged 7–10 years were fully disclosed during the course of the intervention compared with 57% of children aged 11–15 years ($P < 0.001$). However, among those who reached full disclosure, the average time to full disclosure was not significantly different between younger and older children (29 vs. 31 months, respectively; $P = 0.40$). Just below half (48%) of the children who were disclosed after

enrollment into the intervention had a record of reading Chapter 5 of the intervention booklet, suggesting that many caregivers may have decided to disclose to their children outside the clinic setting, which is one of the options discussed with individual caregivers as part of the intervention.

Correlates of Full Disclosure

Children who reached full disclosure during the course of the intervention were similar to children who remained only partially disclosed with respect to sex and CD4 count measurements (Table 2). Children who reached full disclosure were almost 1.5 years older at enrollment and at the time of data abstraction ($P < 0.001$ for both) and had been in HIV care [odds ratio (OR): 1.33, $P < 0.001$] and on ART for longer (OR: 1.36, $P < 0.001$). More children from the clinic at Katutura were fully disclosed compared with those from the other 3 clinics. Whether evaluated continuously or as clinical cutoffs below 100 copies per milliliter or 1000 copies per milliliter, children with lower VLs were more likely to have been fully disclosed during the course of the intervention. Children enrolled in the intervention longer (OR: 1.08, $P < 0.001$) and who had more intervention visits (OR: 1.26, $P < 0.001$) were more likely to reach full disclosure.

Knowledge Changes During the Intervention

At their first visit, more than half (61%) of children had no knowledge or incorrect knowledge of why they take their medications (Fig. 2). This included responses in which the child reported that they did not know why they took medicines or reported taking medication for another ailment such as cough or malaria. Initially, only 10% of children used HIV-specific terms to describe why they take medications, and 16% used basic health and wellness descriptions. By the last visit recorded before data abstraction, the number of children who had no knowledge or incorrect knowledge of fwhy they take their medicine dropped to 18%. Of 153 children who did not know why they took medications initially, 42% became fully disclosed and used HIV-specific language, while 34% adopted language specific to the disclosure program.

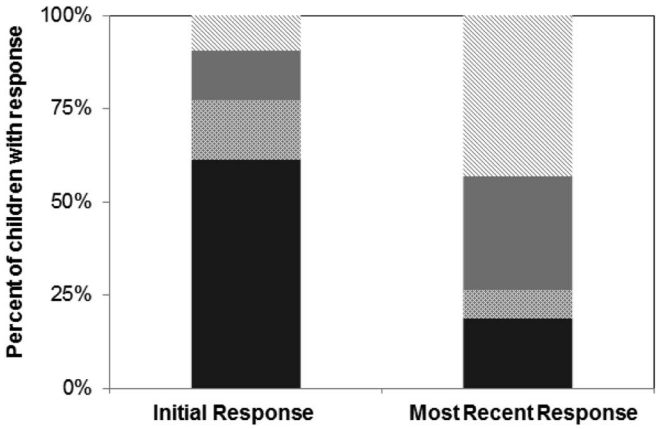
Clinical Outcomes

The 92 children included in the preanalysis or postanalysis of VL and adherence measures had been on ARVs for at least 18 months at the time of enrollment into the intervention and had at least one VL or adherence measurement during 2 periods of assessment time: (1) 12 months before enrollment in the intervention and (2) 0–12 months after intervention enrollment or 12–24 months after intervention enrollment. A total of 59 children contributed data to the VL analysis. Although we found no significant difference between pre-enrollment and postenrollment VL measurements 0–12 months after enrollment ($P = 0.896$), we did find that VL measurements significantly decreased from pre-enrollment measurements by 0.5 $\log_{10}$ copies per milliliter ($P = 0.004$) by 12–24 months after enrollment into the disclosure program. We also observed a decrease in

TABLE 2. Correlates of Disclosure

	N (%) or Mean (SD)					
	Partially Disclosed (N = 164)	**Fully Disclosed (N = 150)**	**OR**	***P***	**aOR***	***P***
Demographics						
Female	74 (46)	73 (47)	1.05	0.838		
Age at data abstraction, yr	11.2 (1.88)	12.7 (1.56)	1.58	**<0.001**	1.60	**<0.001**
Age rat enrollment, yr	8.7 (1.92)	9.54 (1.75)	1.28	**<0.001**		
Years in HIV care†	6.1 (2.29)	7.3 (1.90)	1.33	**<0.001**		
Years on ART	5.8 (2.05)	7.0 (2.00)	1.36	**<0.001**	1.20	**0.008**
Clinical Characteristics						
CD4‡						
Most recent CD4 count, cells/mm^3	852 (386)	801 (302)	1.00	0.569		
Most recent CD4 percent	33.6 (8.79)	31.8 (7.72)	0.98	0.409		
VL§						
VL, log copies/mL	2.5 (1.29)	2.16 (1.13)	0.76	**0.032**		
VL ≤100 copies/mL	73 (46)	42 (63)	2.00	**0.020**	1.85	**0.027**
Disclosure Characteristics						
Months enrolled in disclosure intervention	29.5 (9.64)	36.6 (8.88)	1.08	**<0.001**	1.06	**<0.001**
No. of visits during intervention‖	3.9 (2.20)	5.1 (2.28)	1.28	**<0.001**		
Average months between recorded visits‖	4.7 (2.64)	5.3 (2.67)	1.14	**0.001**		

P-values <0.05 are bolded.
*Analyses adjusted for age, time on ART, VL, and time enrolled in disclosure intervention.
†Among 242 children (partial = 116 and full = 126) who had HIV enrollment dates.
‡Among 117 children (partial = 99 and full = 18) who had CD4 measurements taken ≤1 year before disclosure or the date of data abstraction, whichever came first.
§Among 227 children (partial = 160 and full = 67) who had a VL recorded ≤1 year before disclosure or the date of data abstraction, whichever came first.
‖Among 278 children (partial = 136 and full = 142) who had more than 1 entry recorded.
aOR, adjusted odds ratio.



Category	Example Responses
Complete or accurate knowledge of HIV	"Because I am HIV positive" "For HIV and my body to be strong"
Adopts language from the intervention	"To keep the bad guys sleeping" "To make my soldiers strong"
Uses basic sickness or health descriptions	"To stay healthy and be strong" "To not be sick"
No or incorrect knowledge of HIV	"To cure pimples in my body" "I have a cough"

FIGURE 2. Changes in children's responses to the question "why do you take your medicine?" from enrollment to the time of data abstraction among 278 children with more than 1 entry in the disclosure tracking form.

VL measurements between 0–12 months after enrollment and 12–24 months after enrollment ($P = 0.053$). When evaluating sustained viral suppression at or below 1000 copies per milliliter during the 12-month period before and after enrollment, we saw no effect of enrollment in the intervention on virologic failure. Although not statistically significant, we observed slightly improved viral suppression at or below 100 copies per milliliter when comparing viral suppression before enrollment to 12–24 months after enrollment ($P = 0.103$). By 12 months after intervention, 18 (30%) children had reached full disclosure, and 8 more children reached full disclosure by 24 months. We saw no statistically significant association between full disclosure status at 12 months and mean VL values or proportion of children virally suppressed during the 12–24-month period after intervention enrollment.

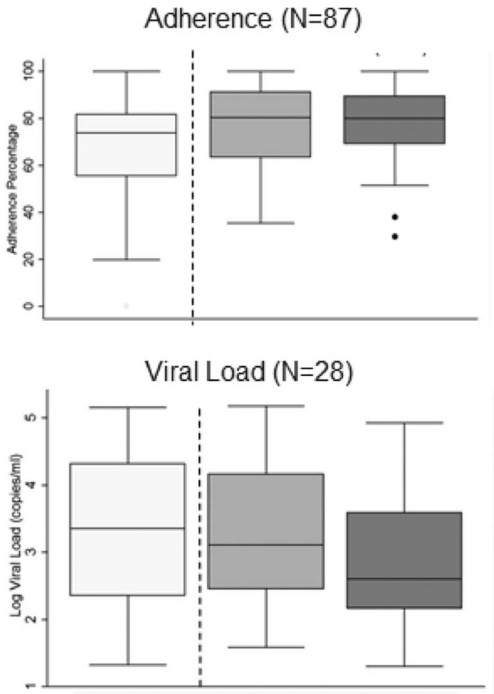
Data from 89 children contributed to the adherence analysis. At enrollment, 83 of these children were on first line regimens and 6 were on second line regimens. When evaluating calculated adherence percentage measurements before and after enrollment, we observed a significant adherence percentage increase over pre-enrollment measurements by 8% ($P < 0.001$) by 0–12 months after enrollment into the disclosure program and by 10% ($P < 0.001$) by 12–24 months after enrollment (Fig. 3). There was no significant difference between adherence percentages 0–12 months and 12–24 months after enrollment. When evaluating adherence measures categorically (mean adherence ≥80%), we also observed a significant increase in the proportion of children adherent to medications during the 12 months ($P < 0.001$) and 24 months ($P < 0.001$) after enrollment. By 12 months and 24 months after intervention, 22 and 31 children, respectively, had reached full disclosure. We did not observe statistically significant differences between full disclosure status and adherence measurements between the 12 months before enrollment and 12 months or 24 months after enrollment into the disclosure program. We saw no significant differences in CD4 counts or percent over these periods.

DISCUSSION

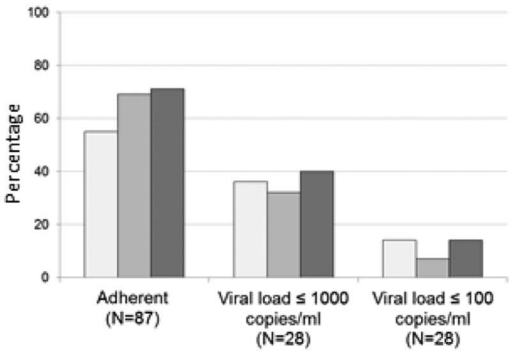
This evaluation provides additional support to previously published qualitative results indicating that this HIV disclosure intervention was beneficial to pediatric patients, their primary caregivers, and health providers. Previous publications cited caregiver and HCW descriptions of how the disclosure intervention improved their care of HIV-infected children and reports of children's improved adherence to care and treatment.[25,26] The analysis presented here contributes clinical outcome, quantitative data describing statistically significant improvements in adherence measurements before and after enrollment into the intervention. Children exhibited better adherence by 12 and 24 months after the initial exposure to the intervention. Children also showed improved VL measurements between pre-enrollment and postenrollment into the intervention, although these changes were not statistically significant when evaluated at a threshold of ≤1000 copies per milliliter or ≤100 copies per milliliter, measuring virologic success. Interestingly, when evaluating continuous measures of VL and adherence, we saw improved adherence measurements preceding improvements in VL. Although nonintervention studies have also shown that disclosure of HIV status is associated with improved adherence to ART regimens among children and adolescents,[6,10] our study is the first to evaluate changes in adherence longitudinally before and after the introduction of a disclosure intervention.

In evaluating knowledge of why they take their medicine over time, we found that there was a dramatic decrease in the number of children who did not know why they took their medicines. Our data, captured from routine tracking of pediatric patient knowledge which is a component of the intervention, depict the evolution of patient thinking about adherence and can directly relate it to the intervention's communication and education strategy, thus unpacking the "black box" of programmatic interventions.[27,28] After exposure to the intervention, most children changed responses and either related their partial understanding to terminology described in the disclosure book (to keep bad guys asleep and/or soldiers strong) or had documented full disclosure. We found that almost half of the children enrolled in the program had reached full disclosure by the time of data abstraction. This is almost 4.5 times the number of children who knew their status at enrollment. Similarly to other studies, we saw that younger

Panel A: Continuous Graphical Comparisons



Panel B: Categorical Graphical Comparisons



Panel C: Statistical Comparisons

Characteristic	N	Mean 1 or N1	Mean 2 or N2	p-value
Adherence (Calculated %)				
Period 1 vs. 2	87	68.9	77.0	<0.001
Period 1 vs. 3	88	68.2	78.0	<0.001
Period 2 vs. 3	88	76.9	78.2	0.428
Adherent to ARVs (≥80%)				
Period 1 vs. 2	87	25	45	<0.001
Period 1 vs. 3	88	25	46	<0.001
Period 2 vs. 3	88	45	46	0.866
Viral load (log copies/ml)				
Period 1 vs. 2	29	3.28	3.26	0.896
Period 1 vs. 3	42	3.18	2.71	0.004
Period 2 vs. 3	44	3.33	3.03	0.053
Suppressed viral load (≤1000 copies/ml)				
Period 1 vs. 2	29	10	10	1.000
Period 1 vs. 3	42	18	20	0.753
Period 2 vs. 3	44	15	19	0.343
Suppressed viral load (≤100 copies/ml)				
Period 1 vs. 2	29	4	2	0.261
Period 1 vs. 3	42	5	11	0.103
Period 2 vs. 3	44	7	8	1.000

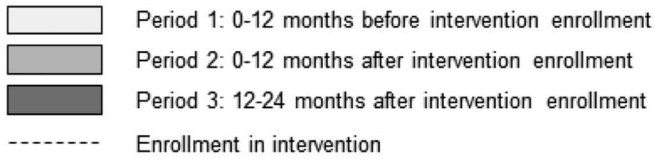


FIGURE 3. Panel A, Mean summary of adherence or VL measurements during the period specified. Includes only children who have measurements collected during all 3 periods. Panel B, Percent of children adherent (defined as mean adherence ≥80%) or with sustained viral suppression (defined as all VL measurements ≤1000 copies/mL or ≤100 copies/mL) during the period specified. Includes only children who have measurements collected during all 3 periods. Panel C, Paired *t*-tests and McNemar tests comparing adherence and VL measurements during the periods specified for all children with data recorded during the 2 periods specified.

children were fully disclosed less frequently than older children.[13,14,29–32]

Guidelines and current literature suggest that disclosure should be a guided step-by-step process, progressing from partial to full disclosure depending on caregiver readiness and child's maturity.[33,34] However, this is the first study of a disclosure intervention implemented at scale (nationally) to provide a description of the length and steps in that process. Our study found that the average length of time from partial to full disclosure was almost 2.5 years. Interestingly, our study did not find that the time to full disclosure differed by age. Rather, the time required to reach full disclosure may instead reflect the frequency that children attend clinic visits, the need to overcome caregiver barriers to disclosure, and variable child readiness for full disclosure, regardless of age.

This evaluation does not have the generalizability of a randomized control trial. The data on which the findings presented in this article are based were drawn from routinely collected patient information, based on health care service delivery as routinely implemented in busy practice settings. Thus, we were limited on the variables we were able to evaluate, the time when variables were collected, and the number of participants we were able to include. Unfortunately, no data on who performed disclosure was collected,

and we were unable to assess the location where disclosure happened. However, despite these limitations, the results of this study are promising and demonstrate that disclosure can impact clinical outcomes and improve HIV knowledge in children and adolescents. Analysis of each of 3 key variables indicates a consistent picture of a disclosure intervention that facilitates the disclosure process in such a way as to improve adherence and decrease VL. The fact that the intervention was successful in nonresearch settings suggests that while some specific intervention content adaptation would be necessary for different cultural contexts, major adaptations for "real world" implementation would not.

CONCLUSIONS

There is an urgent need to develop interventions to assist HCWs with the challenging but crucial process of HIV disclosure to children and adolescents. Throughout Sub-Saharan Africa, HCWs are reporting challenges with HIV disclosure. The Namibia HIV disclosure intervention seems to have improved disclosure rates, child knowledge of why they take their medicine, VL, and adherence measurements for children enrolled in the disclosure program. The Namibian disclosure intervention may provide a helpful example of what could be adapted and used in other settings.

ACKNOWLEDGMENTS

The authors thank the clinic staff and healthcare workers who provided assistance for data collection at each study site and Hetta Shongolo for her assistance with data abstraction. They also thank Larissa Feris and Joanna Bove for assistance with data collection and cleaning and the Namibia Ministry of Health and Social Services Study Group for providing ongoing consultation and support to ensure that the evaluation has programmatic relevance. The authors are grateful to the Kizazi group of the Global Center for Integrated Health of Women, Adolescents and Children (Global WACh) which provided feedback on study design and data analysis.

REFERENCES

1. UNAIDS. Fact sheet: global statistics 2015. 2015. Available at: unaids.org. Accessed May 3, 2016.
2. Idele P, Gillespie A, Porth T, et al. Epidemiology of HIV and AIDS among adolescents: current status, inequities, and data gaps. *J Acquir Immune Defic Syndr.* 2014;66(suppl 2):S144–S153.
3. Kasedde S, Kapogiannis BG, McClure C, et al. Executive summary: opportunities for action and impact to address HIV and AIDS in adolescents. *J Acquir Immune Defic Syndr.* 2014;66(suppl 2):S139–S143.
4. Amzel A, Toska E, Lovich R, et al. Promoting a combination approach to paediatric HIV psychosocial support. *AIDS.* 2013;27(suppl 2):S147–S157.
5. Battles HB, Wiener LS. From adolescence through young adulthood: psychosocial adjustment associated with long-term survival of HIV. *J Adolesc Health.* 2002;30:161–168.
6. Bikaako-Kajura W, Luyirika E, Purcell DW, et al. Disclosure of HIV status and adherence to daily drug regimens among HIV-infected children in Uganda. *AIDS Behav.* 2006;10(4 suppl l):S85–S93.
7. Oberdorfer P, Louthrenoo O, Puthanakit T, et al. Quality of life among HIV-infected children in Thailand. *J Int Assoc Physicians AIDS Care (Chic).* 2008;7:141–147.
8. Ferris M, Burau K, Schweitzer AM, et al. The influence of disclosure of HIV diagnosis on time to disease progression in a cohort of Romanian children and teens. *AIDS Care*. 2007;19:1088–1094.
9. Vreeman RC, Gramelspacher AM, Gisore PO, et al. Disclosure of HIV status to children in resource-limited settings: a systematic review. *J Int AIDS Soc.* 2013;16:18466.
10. Cluver LD, Hodes RJ, Toska E, et al. "HIV is like a tsotsi. ARVs are your guns": associations between HIV-disclosure and adherence to antiretroviral treatment among adolescents in South Africa. *AIDS*. 2015;29(suppl 1):S57–S65.
11. Haberer JE, Cook A, Walker AS, et al. Excellent adherence to antiretrovirals in HIV+ Zambian children is compromised by disrupted routine, HIV nondisclosure, and paradoxical income effects. *PLoS One*. 2011;6:e18505.
12. Arrive E, Dicko F, Amghar H, et al. HIV status disclosure and retention in care in HIV-infected adolescents on antiretroviral therapy (ART) in West Africa. *PLoS One*. 2012;7:e33690.
13. John-Stewart GC, Wariua G, Beima-Sofie KM, et al. Prevalence, perceptions, and correlates of pediatric HIV disclosure in an HIV treatment program in Kenya. *AIDS Care*. 2013;25:1067–1076.
14. Vreeman RC, Scanlon ML, Mwangi A, et al. A cross-sectional study of disclosure of HIV status to children and adolescents in western Kenya. *PLoS One*. 2014;9:e86616.
15. Meless GD, Aka-Dago-Akribi H, Cacou C, et al. Notification of HIV status disclosure and its related factors in HIV-infected adolescents in 2009 in the Aconda program (CePReF, CHU Yopougon) in Abidjan, Cote d'Ivoire, the PRADO-CI study. *J Int AIDS Soc.* 2013; 16:18569.
16. Wiener L, Mellins CA, Marhefka S, et al. Disclosure of an HIV diagnosis to children: history, current research, and future directions. *J Dev Behav Pediatr.* 2007;28:155–166.
17. Domek GJ. Debunking common barriers to pediatric HIV disclosure. *J Trop Pediatr.* 2010;56:440–442.
18. DeMatteo D, Wells LM, Salter Goldie R, et al. The "family" context of HIV: a need for comprehensive health and social policies. *AIDS Care*. 2002;14:261–278.
19. Klitzman R, Marhefka S, Mellins C, et al. Ethical issues concerning disclosures of HIV diagnoses to perinatally infected children and adolescents. *J Clin Ethics*. 2008;19:31–42.
20. Bunupuradah T, Kosalaraksa P, Vibol U, et al. Impact of antiretroviral therapy on quality of life in HIV-infected Southeast Asian children in the PREDICT study. *AIDS Patient Care STDS.* 2013;27:596–603.
21. Vreeman RC, Nyandiko WM, Ayaya SO, et al. The perceived impact of disclosure of pediatric HIV status on pediatric antiretroviral therapy adherence, child well-being, and social relationships in a resource-limited setting. *AIDS Patient Care STDS.* 2010;24:639–649.
22. Beima-Sofie K, John-Stewart G, Shah B, et al. Using health provider insights to inform pediatric HIV disclosure: a qualitative study and practice framework from Kenya. *AIDS Patient Care STDS.* 2014;28: 555–564.
23. Reynolds NR, Ofori-Atta A, Lartey M, et al. SANKOFA: a multisite collaboration on paediatric HIV disclosure in Ghana. *AIDS.* 2015;29 (suppl 1):S35–S45.
24. Cantrell K, Patel N, Mandrell B, et al. Pediatric HIV disclosure: a process-oriented framework. *AIDS Educ Prev.* 2013;25:302–314.
25. O'Malley G, Beima-Sofie K, Feris L, et al. "If I take my medicine, I will be strong": evaluation of a pediatric HIV disclosure intervention in Namibia. *J Acquir Immune Defic Syndr.* 2015;68:e1–e7.
26. Brandt L, Beima-Sofie K, Hamunime N, et al. Growing-up just like everyone else: key components of a successful pediatric HIV disclosure intervention in Namibia. *AIDS*. 2015;29(suppl 1): S81–S89.
27. Altman L, Kuhlmann AK, Galavotti C. Understanding the black box: a systematic review of the measurement of the community mobilization process in evaluations of interventions targeting sexual, reproductive, and maternal health. *Eval Program Plann.* 2015;49:86–97.
28. Salter KL, Kothari A. Using realist evaluation to open the black box of knowledge translation: a state-of-the-art review. *Implement Sci.* 2014; 9:115.

29. Biadgilign S, Deribew A, Amberbir A, et al. Factors associated with HIV/AIDS diagnostic disclosure to HIV infected children receiving HAART: a multi-center study in Addis Ababa, Ethiopia. *PLoS One*. 2011;6:e17572.
30. Moodley K, Myer L, Michaels D, et al. Paediatric HIV disclosure in South Africa—caregivers' perspectives on discussing HIV with infected children. *S Afr Med J.* 2006;96:201–204.
31. Kallem S, Renner L, Ghebremichael M, et al. Prevalence and pattern of disclosure of HIV status in HIV-infected children in Ghana. *AIDS Behav.* 2011;15:1121–1127.
32. Oberdorfer P, Puthanakit T, Louthrenoo O, et al. Disclosure of HIV/AIDS diagnosis to HIV-infected children in Thailand. *J Paediatr Child Health.* 2006;42:283–288.
33. Lesch A, Swartz L, Kagee A, et al. Paediatric HIV/AIDS disclosure: towards a developmental and process-oriented approach. *AIDS Care*. 2007;19:811–816.
34. Abebe W, Teferra S. Disclosure of diagnosis by parents and caregivers to children infected with HIV: prevalence associated factors and perceived barriers in Addis Ababa, Ethiopia. *AIDS Care*. 2012;24:1097–1102.