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Disclosure of their HIV status to perinatally infected youth using the adapted Blasini disclosure model in Haiti and the Dominican Republic: preliminary results

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Abstract

Objectives—To assess the safety, acceptability, and preliminary efficacy of a culturally-adapted disclosure intervention for perinatally HIV-infected combined antiretroviral therapy patients in Haiti and the Dominican Republic.

Design—A quasi-experimental trial was conducted comparing caregiver–youth pairs who completed the intervention [adapted Blasini disclosure model (aBDM)] to pairs who discontinued aBDM participation before disclosure. aBDM consists of five components: structured healthcare worker training; one-on one pre-disclosure intervention/education sessions for youth (describing pediatric chronic diseases including cancer, diabetes and HIV) and for caregivers (strengthening capacity for disclosure); a scheduled supportive disclosure session; and one-on-one postdisclosure support for caregivers and youth.

Methods—Caregivers of nondisclosed combined antiretroviral therapy patients aged 10.0–17.8 years were invited to participate. Data were collected by separate one-on-one face-to-face

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Conflicts of interest

There are no conflicts of interest.

interviews of caregivers and youth by study staff and medical record review by pediatricians at enrollment and 3 months after disclosure or after intervention discontinuation.

Results—To date, 65 Dominican Republic and 27 Haiti caregiver–youth pairs have enrolled. At enrollment, only 46.4% of youth had viral suppression and 43.4% of caregivers had clinically significant depressive symptomatology. To date, two serious study-related adverse events have occurred. Seven of the 92 (7.6%, 6 in the Dominican Republic) enrolled pairs discontinued participation before disclosure and 39 had completed postdisclosure participation. Median plasma HIV-RNA concentration was lower in youth who completed aBDM than in youth who discontinued participation before aBDM disclosure (<40 versus 8673 copies/ml; $P = 0.027$). Completers expressed considerable satisfaction with aBDM.

Conclusion—Preliminary results suggest safety, acceptability, and possible effectiveness of the aBDM.

Keywords

HIV; adolescent; antiretroviral therapy; disclosure; dominican republic; haiti; perinatally infected

Introduction

Second only to sub-Saharan Africa, the Caribbean remains the region with the highest HIV prevalence worldwide, as it has been for decades. Of the 3826 mostly perinatally infected Caribbean children receiving combined antiretroviral therapy (cART), most (3348, 87.5%) live in Hispaniola, the island shared by Haiti and the Dominican Republic (with 2265 and 1083 pediatric cART patients, respectively) [1]. Many of these patients are expected to survive to adulthood and become sexually active [2–5]. Disclosure of their status to children is strongly encouraged in low and middle-income, and industrialized countries [6,7]. Knowledge of their HIV status has been associated with delayed disease progression [8], improved cART adherence [9,10], and psychosocial outcomes [11,12]. Only one study has reported on cART virologic response in the context of disclosure, reporting 8% postdisclosure virologic failure [13].

Several other studies, however, have reported that disclosure had no impact on cART outcomes [14] or was associated with poorer adherence [15,16]. These are sobering, often overlooked findings. Studies also report varied psychosocial outcomes after disclosure, including behavior problems and post-traumatic stress disorder, and no change at all [17,18]. Caregivers who agree to disclosure often believe that it will support cART adherence [10], which is a first step towards transition to effective self-care. But the tacit assumption may be that youth do not need caregiver support for cART adherence once they know their status [19]. Decline in caregiver support after disclosure may contribute to the poorer adherence sometimes reported [15,16]. Conversely, disclosure methods that promote continuing caregiver involvement in youth's cART use may prevent postdisclosure deterioration in youth cART adherence and response.

Worldwide, most youth living with HIV do not know their status [20,21]. Groupe Haïtien d'Etude de Sarcome de Kaposi et Infections Opportunistes (GHESKIO) center's clinic

policy recommends that perinatally infected patients be told by the age of 15–16 years (GHEAKIO, unpublished data, Port-au-Prince, Haiti). National Dominican Republic guidelines recommend disclosure to pediatric cART patients in early adolescence [22]. But there is little structure in Hispaniola disclosure guidelines, and patterns of disclosure to youth living with HIV are poorly described. Disclosure of their status to the HIV-infected youth worldwide is complicated as there are concerns about their emotional consequences if they learn their status, and to the family or minor should he or she divulge the information [20,21]. Haiti and the Dominican Republic have protections to shield HIV-infected persons from discrimination, but HIV-related stigma and discrimination are common in both countries, impacting HIV-infected youth and their caregivers [23–28], and discouraging disclosure. We conducted exploratory research in Hispaniola's leading cART clinics to inform the adaptation of the Blasini disclosure model (BDM), an intervention to facilitate disclosure created in Puerto Rico [19], and pilot tested the adapted BDM's (aBDM's) safety and acceptability, feasibility of implementing it in diverse clinics, and preliminary efficacy in supporting cART adherence and response in three Hispaniola facilities.

Methods

Study population

The pilot study is underway in one Port-au-Prince, Haiti clinic (GHESKIO centers) and two Dominican Republic clinics (Robert Reid Cabral National Children's Hospital, in Santo Domingo, the capital of the Dominican Republic; and Clínica de Familia La Romana in the sugarcane-growing eastern Dominican Republic region). GHESKIO provides comprehensive care to over 30% of the Haitian pediatric cART patients (unpublished data, GHESKIO; January 2014) and the two Dominican Republic clinics to 40% of the Dominican Republic's pediatric cART patients (Ministry of Health, Santo Domingo, Dominican Republic; May 2013). Anonymized data of patients aged 6–18 years, including sex, age, cART use, and status knowledge, were abstracted by clinic staff and provided to Florida International University (FIU) investigators to identify factors associated with status knowledge, and to estimate the number of nondisclosed cART patients aged 10–17.8 years potentially eligible for the pilot study.

Adapted Blasini disclosure model pilot methodology

The BDM is based on the Tasker theory of disclosure, which describes a process from secrecy, to exploration, readiness for knowledge of status, and disclosure [19,29]. The BDM consists of: a training/support session for healthcare providers who will participate in disclosure; separate predisclosure intervention/education sessions describing pediatric cancer, diabetes, and HIV (for the youth) and building capacity for disclosure (for the caregiver); a scheduled supportive disclosure session; and separate one-on-one postdisclosure support sessions with psychologists for caregivers and youth (Fig. 1). BDM postdisclosure 'emotion screens' for undesirable (e.g. sadness, anger) and desirable emotions (e.g. 'normal', relief) are used at 1 and 2 weeks, and 1 and 3 months postdisclosure to detect whether potential threats to safety are emerging.

On the basis of exploratory data collected in the Dominican Republic [24] and Haiti (below), including focus groups in both, the BDM was adapted for Hispaniola, translating materials to English and Haitian Creole from the original Spanish language, and introducing other changes to improve usability and fidelity to intervention methodology. These included a multimedia training/retraining tool for staff, digital audio-recording of all one-on-one sessions with caregivers and youth for evaluation at FIU, and a video ‘Live to see it’ featuring young adult survivors of chronic pediatric illness, including HIV and type 1 diabetes, and animations of chronic illnesses and daily medication use. aBDM’s disclosure support tool – ‘Así Como’ (Spanish for ‘Just Like’) – a colorful picture book explaining cell-mediated immunity, the impact of HIV on CD4 T-lymphocytes, and cART’s role in ‘fighting’ HIV and protecting the immune system with comparisons to body building, armor, and other familiar concepts, was translated to Creole (Thankou), and was adapted with images relevant to Hispaniola youth.

Initial staff training was led by Dr Blasini for all Haiti and Dominican Republic staff in a hotel summit in the Dominican Republic, and reinforced with the multimedia tool, onsite simulation of enrollment instrument administration, and predisclosure intervention/education sessions by CBS and MCPI, and regular onsite retraining based on issues identified in audio-recordings (GI, PD, MCPI). To participate in the pilot study, caregivers consented to predisclosure intervention/education sessions and medical record review, and youth assented to participation in a program to learn about chronic illnesses. In the predisclosure intervention/education sessions, psychologists strengthen bonds with, and encourage and support caregivers, exploring barriers to disclosure. Youth sessions focused on the concept of chronic illness, normal life with a chronic illness, and the youth’s experience of his/her own illness; in both caregiver and youth predisclosure sessions, study staff explored progress from secrecy through exploration and readiness for disclosure [19,29]. The sessions provided caregivers and youth with ‘confidantes’ using Blasini instruments for structured open-ended interviews. The video (‘Live to see it’) was used in the last predisclosure session. The youth watched the video using ear bud earphones, which they were allowed to keep.

Once readiness was confirmed, separate caregiver consent and youth assent were obtained for supported disclosure. The youth was invited to bring person(s) he or she would like to accompany him or her (e.g. siblings, cousins, and/or friends). The caregiver chose a professional (e.g. pediatrician, psychologist) to disclose to the youth. Disclosure was done in less than 30 min using the ‘just like’ booklets; the youth’s questions were answered and they were assured that more questions would be addressed in one-on-one postdisclosure sessions. After disclosure, youth and caregivers were invited to support groups, summer camps, and other activities. Postdisclosure one-on-one emotion screens with psychologists explored specific feelings that youth and caregivers were experiencing (anxiety, fear, relief, ‘normal’, anger, sadness, etc.) and had open-ended questions for participants to comment on and suggest improvements in aBDM.

Adapted Blasini disclosure model evaluation

Acceptability was assessed by calculating proportions of caregiver–youth pairs who continued participation after enrollment through disclosure and 3-month postdisclosure evaluation, and by reviewing transcripts of openended interviews with caregivers and youth. Safety was assessed by active and passive surveillance for adverse events mentioned by youth, caregiver, or provider(s), and/or noted in medical record reviews, categorized by severity, and relatedness to study participation.

Expecting attrition of over 20% of enrolled pairs before disclosure, a quasi-experimental comparison was planned, comparing cART adherence and viral response (viral suppression) outcomes among those who proceeded with aBDM disclosure and completed participation to those who discontinued participation before aBDM disclosure. We anticipated enrolling 60 caregiver–youth pairs in each country with attrition down to 40–80 pairs (20–40 in each country), continuing to study completion at least 3 months after disclosure. The primary preliminary efficacy analysis of the aBDM was a comparison of cART adherence and viral suppression among enrolled youth who received disclosure in aBDM and continued to complete cART adherence and response among those who did not. Comparisons of indicators at enrollment versus postdisclosure indicators were also performed for completers. Adherence to cART was assessed by the AIDS Clinical Trials Group adherence questionnaire [30]. Response to cART was assessed by most recent CD4 T-lymphocyte (CD4) cell counts and plasma quantitative HIV-RNA measurements (‘viral loads’) [31,32] at enrollment and three months after disclosure (for youth who participated through aBDM disclosure) or three months after discontinuation of participation (for youth who did not have aBDM disclosure). These data were abstracted from medical records using a standardized form. Viral load measurements were conducted at the Dominican Republic national laboratory (for Dominican Republic patients) and GHESKIO (for the Port-au-Prince) patients.

Because the BDM suggests that disclosure be deferred in pairs in which the caregiver and/or youth are severely depressed until improvement of depression, enrollment evaluations included assessments of depression symptoms in caregivers using the 20-Question Center for Epidemiologic Studies Depression Screen (CESD-20) [33] and in youth using the Child Depression Inventory [34]. Because of the strong association between food insecurity and depression in the Dominican Republic, caregivers were administered the two-question Food-Insecurity questionnaire at enrollment and after disclosure [35,36].

Analyses

Strength of associations was assessed with prevalence or hazard ratios as estimates of relative risk (RR); 95% confidence intervals (CIs) and chi-square or Fisher’s exact two-tailed test (FET) were used to test for statistical significance for categorical variables [37,38]. The Kruskal–Wallis test for the two groups was used for statistical testing of continuous variables [38]. P values less than 0.05 were interpreted as statistically significant. Analyses were performed using Epi Info for Windows 3.5.3 (Atlanta, Georgia, USA; 2011) and OpenEpi [37,38]. Participants with missing data for a variable were excluded from analysis of that variable, but included in analyses of other variables for which they had data.

Human participant protections before analyses

Analysis of anonymized data abstracted from medical records of patients aged 6–18 years was considered not to meet the criteria for human participant research. Institutional review boards at FIU, GHESKIO (Port-au-Prince, Haiti), Cabral National Children's Hospital in Santo Domingo, Dominican Republic, and the Dominican Republic Ministry of Health Council for Bioethics in Health (CONABIOS, Santo Domingo, Dominican Republic) approved the pilot study. Detailed protocols to monitor safety and respond to adverse events regardless of study relatedness were implemented in the participating clinics.

Results

In the anonymized data analysis, of 737 children aged 6–18 years of age who received care in the partnering facilities (410 in Haiti and 327 in the Dominican Republic), 28.8 and 22.6%, respectively, knew their status ($P = .06$). In Haiti, female patients were more likely to know than male patients [74/225 (32.9%) versus 44/185 (23.8%); $P = 0.04$], but knowledge of status did not vary by sex in the Dominican Republic clinics. Youth over 12 years old were more likely to know their status than younger children (46.5 versus 2.4%, Haiti, $P < 0.001$; 49.6 versus 7.7%, Dominican Republic, $P < 0.001$); 28.3 and 43.9% of Haiti and Dominican Republic patients over 15 years old did not know their status. Haiti patients were less likely to receive cART [372 (78.5%) than the Dominican Republic patients [326 (99.1%)]; 248 Haiti and 208 Dominican Republic cART 10–18-year-old patients did not know their status.

To date, 27 Haiti and 65 Dominican Republic pairs (total = 92 pairs) have completed enrollment assessments. The 92 youth in these pairs tended to be slightly older than nondisclosed 10–18-year-olds in the anonymized data, but this difference was not statistically significant. Most enrolled youth were female (Table 1). The Haiti participants (youth) tended to be older than their Dominican Republic counterparts. Enrollment CD4 counts ranged from 8 to 1446 cells/mm³. Median CD4 count at enrollment for Haitian youth (540 cells/mm³) did not differ significantly from the median CD4⁺ cell count at enrollment in the Dominican Republic youth (576 cells/mm³). Enrollment HIV-RNA measurements ranged from less than 40 copies ('viral suppression') to 1 418 311 copies/ml. At enrollment, the Haiti youth were less likely than their Dominican Republic counterparts to have viral suppression (Table 1). At enrollment, 39.3% of caregivers reported that their child had never missed a cART dose. Caregiver depression screening scores were more likely to be abnormal in Haiti than in Dominican Republic counterparts (Table 1). Proportion of caregivers who reported food insecurity and median number of days with insufficient food for all household members were also higher in Haiti.

Only seven (7.6%, six of whom were Dominican Republic enrolled pairs) did not proceed to disclosure. Three pairs could not continue participation once enrolled because of one child's cognitive disability and a caregiver's severe maternal depression which led to her discontinuing cART and succumbing to AIDS (in the Dominican Republic) and a caregiver accepting employment that precluded participation (in Haiti). The other four were Dominican Republic caregiver – youth pairs in which the caregiver (three) or the youth (one) refused to consent or assent, respectively, to disclosure. Fourteen individuals from 13

pairs including two caregivers have had adverse events, out of which 6 were serious. Two serious events were related to study participation (one in each country): a child found sitting in bed with a rope around his neck (Dominican Republic) and severe depression (Haiti). Neither adverse event resulted in hospitalization or severe sequelae. Three less serious study-related events (two in Haiti and one in Dominican Republic participants) were also reported.

A total of 39 pairs (all from the Dominican Republic) had completed study participation. HIV-RNA levels in the Dominican Republic youth from pairs who discontinued ranged from 78 to 33 667 (median 8673 copies/ml) compared to median less than 40 copies/ml in postdisclosure participants ($P = 0.027$) (Table 2). Completers were more likely to be virally suppressed than discontinuers; this difference approached, but did not achieve statistical significance. CD4⁺ cell counts did not differ significantly by study discontinuation. Among the 39 pairs who completed aBDM intervention, the proportion of caregivers who had clinically significant depressive symptoms after disclosure was lower than the proportion at enrollment. Although most youth who completed aBDM expressed grief or anger about their diagnosis at 1 or 2 weeks postdisclosure, and only 4 completers described their emotional state as 'normal' at those screenings, over 26/39 (67%) completers characterized themselves as feeling 'normal' 3 months after disclosure.

Caregivers and youth who completed aBDM on the whole gave very positive reviews of the intervention; most suggestions for improvements came from the youth. Caregivers expressed gratitude for the opportunity to interact privately with the psychologist. Some transcripts were emotional; caregivers indicated that the psychologist was the only person with whom they could unburden themselves, as no one outside the clinic knew the youth's infection status. Youth in both countries suggested that the video was too long. In addition, the Dominican Republic youth suggested that the soothing music in the video should be replaced with 'reggaeton' and requested increased animation and special effects. The Haitian youth requested the ear buds to improve concentration and privacy while watching the video.

Discussion

The preliminary analyses of data from the pilot evaluation suggest that the aBDM is acceptable to caregivers in Hispaniola. Retention to date has been much higher than expected, suggesting that we will exceed our maximum expected number of completers ($N = 80$). Study-associated serious adverse events, although concerning, are infrequent, and suggest safety. Although these clinics have conducted multiple studies in the past, they are busy and typical of low and middle-income country clinical settings. Their ability to implement the aBDM (and administer various instruments) within the context of patient care suggests that integration of the model is feasible in varied settings. The very limited preliminary data relevant to cART response in our study suggest that aBDM completion is not associated with deterioration of cART response and may possibly be linked to higher likelihood of viral suppression.

Among the study's findings is the formidable level of unmet need for psychological, social, and structural support in both countries, particularly in Haiti. Food insecurity and malnutrition have been linked to depression and are identified as important barriers to cART adherence and response in Hispaniola; conversely, nutritional and other structural supports have been associated with retention in care and cART adherence [36,39–43]. The need for these supports in Hispaniola to support disclosure cannot be overstated. The depression and stigma that Hispaniola caregivers endure are not only a disincentive to disclosure of HIV-infected youth's status [18–22]. They may discourage resisting maltreatment under admittedly lax protections for HIV-affected people, reduce caregivers' willingness to seek assistance and/or adhere to their own treatment (as illustrated by the discontinuation of cART by a Dominican Republic caregiver), and can delay disclosure. Addressing these needs is critical to increasing disclosure. Moreover, caregiver capacity, strengthening needs to affirm that disclosure, is not 'finished' after the disclosure session, but requires additional education, reinforcement, and support to ensure that youth comprehend their condition and do not feel overwhelmed or abandoned, to affirm that youth still need caregivers' cART adherence support after disclosure, and that postdisclosure feelings of sadness and loss are normal responses to disclosure for both caregivers and youth [11,12,19,29].

The preliminary analysis, and the study itself, have important limitations. The study's ongoing nature and later initiation in Haiti than in the Dominican Republic resulted in sparse and pending data, particularly from Haiti; many associations with large effect sizes may have failed to achieve statistical significance because of this reason. Second, our study can only indirectly assess safety and efficacy of this specific disclosure model (compared to noncompletion or baseline) unlike a comparison with alternative disclosure strategies. Finally, attrition was much less than expected. As a result, the population of "discontinuers" for the quasi-experimental comparison with aBDP "completers" was far smaller than anticipated.

Despite these limitations, this is, to our knowledge, the first study to examine prospectively the impact of disclosure within a structured 'manualized' model on children's cART virologic response; another disclosure study that reported an impressive cART-related virologic failure rate of only 8% postdisclosure did not report the total number of youth disclosed or the predisclosure level of virologic failure [10]. Although the proportion of our population that achieved viral suppression 3 months postdisclosure is far more modest, our preliminary analysis suggests that a relatively brief intervention is not associated with increased virologic failure and that intervention completers are somewhat less likely to have virologic failure than discontinuers. These findings were seen in centers reporting high levels of antiretroviral resistance, virologic failure, and death in perinatally infected adolescents receiving cART [44] [unpublished data (Dominican Republic)].

The findings that two-thirds of youth report feeling 'normal' and caregivers are less likely to have depressive symptoms 3 months after intervention completion are also encouraging; only 8% of youth reported feeling normal at 3 months postdisclosure in the original BDM evaluation [19]. This pilot study also identified high levels of depression in youth and caregivers, widespread need for psychosocial support, and shortcomings of current resources

for these populations. These can and should be addressed as part of disclosure support for HIV-infected youth and in efforts to prepare youth for independence and self-care.

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Fig. 1. Adapted Blasini Disclosure model procedures and Tasker Theory of Disclosure
Adapted from Blasini *et al.* [19] and Tasker [29].

Table 1

Characteristics of caregivers and youth at enrollment in predisclosure activities (adapted Blasini disclosure model), and comparisons by country [Haiti ($N=27$) and Dominican Republic ($N=65$)].^a

Proportions with characteristic or 'median'	All (%)	Haiti (%)	DR (%)	Prevalence ratio 95% CI	P^b
Median age at enrollment (years)	12	13 (10–17.9)	12 (10–17.9)	–	0.039
Number (%) female	61/92 (66.3)	17/27 (63.0)	44/65 (67.7)	0.9 (0.7–1.3)	0.8
Food insecurity	71/88 (80.7)	23/23 (100)	48/65 (73.8)	1.4 (1.2–1.6)	0.006
Median number of days with insufficient food for all household members	6 (0–30)	7.0 (1–30)	3.0 (0–30)	–	0.040
Viral suppression ^c	32/69 (46.4)	7/22 (31.8)	25/47 (53.2)	0.6 (0.31–1.7)	0.097
Elevated Child Depression Inventory scores	18/81 (22.2)	8/21 (38.1)	10/60 (16.7)	1.9 (0.9–4.0)	0.18
Clinically significant depression symptoms in caregivers	36/83 (43.4)	18/26 (69.2)	18/57 (31.6)	2.2 (1.4, 3.5)	0.003

CI, confidence interval; DR, Dominican Republic.

^aExcludes missing and pending values.

^bFisher's exact test, two-tailed (categorical); Kruskal–Wallis test for two groups (continuous).

^cPlasma HIV-RNA concentration less than 40 copies/ml.

Table 2

Comparison of youth viral response to combined antiretroviral therapy after disclosure using the adapted Blasini disclosure model to combined antiretroviral therapy viral response after discontinuing participation and comparison of caregiver depression at enrollment versus postdisclosure^a.

Comparisons	Number (%)	Prevalence ratio (95% CI)	<i>p</i> ^b
Comparison of aBDM completers to aBDM discontinuers			
Viral suppression ^c , after completion of aBDM	26/37 (70.3)	3.5 (0.6–20.5)	0.09
Viral suppression ^c after discontinuation	1/5 (20.0)		
Median viral load after completion of aBDM (<i>N</i> =37 youth)	<40 copies/ml (range <40–980)	–	0.027
Median viral load after discontinuation (<i>N</i> = 5 youth)	8673 copies/ml (range <40–33667)		
Comparison, before and after aBDM completion ^d			
Caregiver depression symptoms after completion of aBDM	4/39 (10.3)	0.3 (0.1–0.9)	0.047
Caregiver depression symptoms at enrollment	12/39 (30.8)		

aBDM, adapted Blasini disclosure model; CI, confidence interval.

^aExcludes missing/pending values; restricted to DR population (no Haitian pairs completed participation).

^bFisher's exact test, two tailed (categorical); Kruskal–Wallis test for two groups (continuous).

^cPlasma HIV-RNA concentration less than 40 copies/ml.

^dBoth values (enrollment and post-completion, i.e., pre- and post-disclosure) confined to caregivers in pairs who completed aBDM.