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# Psychosocial support intervention for HIV-affected families in Haiti: Implications for programs and policies for orphans and vulnerable children

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# ABSTRACT

Given the increased access of antiretroviral therapy (ART) throughout the developing world, what was once a terminal illness is now a chronic disease for those receiving treatment. This requires a paradigmatic shift in service provision for those affected by HIV/AIDS in low-resource settings. Although there is a need for psychosocial support interventions for HIV-affected youth and their caregivers, to date there has been limited empirical evidence on the effectiveness of curriculum-based psychosocial support groups in HIV-affected families in low-income countries. Therefore, the purpose of this study is to examine the feasibility and assess the preliminary effectiveness of a psychosocial support group intervention for HIV-affected youth and their caregivers in central Haiti. The study was conducted at six Partners In Health-affiliated sites between February 2006 and September 2008 and included quantitative as well as qualitative methods. HIV-affected youth (n = 168) and their caregivers (n = 130) completed a baseline structured questionnaire prior to participation in a psychosocial support group intervention. Ninety-five percent of families completed the intervention and a follow-up questionnaire. Psychological symptoms, psychosocial functioning, social support, and HIV-related stigma at baseline were compared with outcomes one year later. Qualitative methods were also used to assess the participants' perspectives of the intervention. Comparing pre- and post-intervention assessment, youth affected by HIV experienced decreased psychological symptoms as well as improved psychosocial functioning and social support. Caregivers (95% HIV-positive) demonstrated a significant reduction in depressive symptoms, improved social support, and decreased HIV-related stigma. Although further study is needed to assess effectiveness in a randomized controlled trial, corroborative findings from qualitative data reflected reduced psychological distress, less social isolation and greater hope for the future for families affected by HIV/AIDS following the intervention.

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# Introduction

Since the establishment of the Global Fund to Fight AIDS, Tuberculosis, and Malaria (GFATM) and the U.S. President's Emergency Plan for AIDS Relief (PEPFAR) in 2002 and 2003, respectively, the number of individuals receiving antiretroviral therapy (ART) in the developing world has dramatically increased. By 2008, more

than four million people in low- and middle-income countries were receiving ART, reflecting a ten-fold increase in five years (WHO, UNAIDS, & UNICEF, 2009). Although there is still major progress that needs to be made in access to ART in the developing world, HIV is no longer a fatal disease but a chronic illness that requires lifelong care and support. The care should focus on not only attending to the physical consequences of having a chronic illness but the psychosocial needs for people living with HIV and their families.

Children affected by HIV often face considerable uncertainty about their parent's disease, having concerns about the recurrence of significant and life-threatening symptoms or premature death. Girls in particular may take on the role of caregiver in the household, caring for their ill parent or assuming greater responsibilities

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in supervising younger children in their family (Romer, Barkman, Schulte-Markwort, Thomalla, & Riedesser, 2002). In addition, children affected by HIV must often cope with HIV-related stigma in the community (Reyland, Higgins-D'Alessandro, & McMahon, 2002). Children orphaned by HIV in particular suffer from the tremendous loss of one or both parents in their lives (Cluver & Gardner, 2007). These factors are compounded by poverty in resource-limited settings, where economic instability is coupled with uncertainty related to their parent's HIV status (Cluver, Gardner, & Operario, 2009). Child abuse and neglect have also been associated with emotional distress among children orphaned by HIV in South Africa (Cluver & Gardner, 2007). Related to the broad range of stressors that can impact children affected by HIV in the developing world, these youth may experience psychological distress, such as depression and anxiety, or may be more likely to engage in high risk behavior related to problems with conduct, unprotected sex, and substance abuse (Brown & Lourie, 2000; Cluver, Operario, & Gardner, 2009; Nyamukapa et al., 2010).

Evidence has been accruing in recent years that psychosocial support initiatives for HIV-affected youth have been effective. Earlier evidence was based on a randomized controlled trial in the U.S. by Rotheram-Borus, Stein, and Lin (2001), who implemented and evaluated the Project TALC (Teens and Adults Learning to Communicate) intervention in New York City. After six years of follow-up, youth reported less substance use; in turn, lower levels of substance use were related to higher future expectations and reduced HIV risk behaviors. Positive relationships between youth and parents were associated with lower emotional distress and optimistic future expectations (Rotheram-Borus, Lee, Lin, & Lester, 2004; Rotheram-Borus, Stein, & Lester, 2006). An adapted version of Project TALC has also been evaluated in Thailand using a randomized controlled trial; the authors observed a positive effect of the intervention on general as well as mental health status among HIV-affected families in this middle-income country setting (Li et al., 2010).

In addition, a mentoring program for youth-headed households affected by HIV resulted in a reduction in depressive symptoms among intervention participants in Rwanda (Brown et al., 2007). In a randomized controlled trial in Uganda, a school-based peer group support intervention with youth orphaned by HIV demonstrated reductions in depression, anger, and anxiety (Kumakech, Cantor-Graae, Maling, & Bajunirwe, 2009). In contrast, an art therapy intervention program among HIV-affected youth in South Africa did not result in reductions in depression or behavior problems. However, there appeared to be a protective effect on self-efficacy among bereaved youth. HIV-related stigma and violence at community and household levels were associated with poor psychological health outcomes in this population (Mueller, Alie, Ionas, Brown, & Sherr, 2011).

In light of the increasing evidence of effectiveness of psychosocial interventions among youth affected by HIV and contrasting evidence on the potential impact on psychological symptoms, the current study addresses a gap in our understanding of how to reduce psychological distress among the broader population of children affected by HIV in the community. Given the effectiveness of the TALC intervention in the U.S. and the middle-income country setting of Thailand, the present study examines the use of this curriculum-based intervention in a low-income country setting. As described below the intervention was adapted for families who have experienced HIV as a chronic condition with increasing access of ART in the developing world. Finally, although family-based interventions have been effective with primary prevention of HIV among youth as well as with HIV-positive youth (Bhana, McKay, Mellins, Petersen, & Bell, 2010), the present study provides preliminary data on the effectiveness of a family-focused intervention for the broader community of HIV-affected youth, with a primary focus on the potential impact on psychological distress and psychosocial functioning among HIV-affected youth and their caregivers. The purpose of this paper is to document the feasibility of implementing such a program in central Haiti and to describe preliminary findings of the effect of this intervention on psychosocial health-related outcomes, including psychological symptoms, HIV-related stigma, social support, and psychosocial functioning, among HIV-affected youth and their parents.

# Methods

Setting

The setting for this project is in central Haiti, where Partners In Health/Zanmi Lasante (PIH/ZL), a non-governmental organization (NGO), is based. The study was implemented at six PIH/ZL sites providing ART in Haiti's Central Department from February 2006 to September 2008, five of which are public facilities operated by the Haitian Ministry of Health with support from PIH/ZL. In 1998, PIH/ZL started the HIV Equity Initiative, a program to provide ART free of charge to people in the late stages of AIDS. This program, one of the first in the developing world, demonstrated the feasibility of providing therapy in such a setting and documented dramatic recoveries among the patients (Farmer et al., 2001). ART was provided for free at PIH/ZL for those who required treatment during the study.

Study population and design

In an effort to broaden the HIV care at PIH/ZL to address psychosocial issues, including those that impact HIV-affected children, an intervention was introduced to "high risk" families at six hospitals and clinics in the Central Department. Caregiverchild pairs were identified as high risk and included in the intervention if at least one of the following criteria was present: 1) child's psychological symptoms impacted his/her psychosocial functioning (child or caregiver report); 2) youth affected by HIV/ AIDS was being abused (child or caregiver report); 3) child did not live with mother and father (child or caregiver report); 4) youth affected by HIV/AIDS was being underfed due to his/her 'HIVaffected' status (child or caregiver report); 5) child reported 'having no friends'; and 6) caregiver reported 'thoughts of suicide' (for him/herself). These criteria were identified as clinically relevant in the local context through review of results by the Haitian psychologist directing psychological services at Zanmi Lasante of a baseline survey administered by trained Haitian social workers (Smith Fawzi et al., 2010).

Based on responses from 492 youth and their caregivers in a baseline survey, 210 youth met these criteria. A detailed description of the recruitment process for the 492 youth at baseline, implemented between February 2006 and January 2007 prior to the intervention has been documented previously (Smith Fawzi et al., 2010). Among these 210, there were only two refusals to participate (one caregiver and one youth). However, due to children being out of the catchment area (primarily for secondary school or living with other family members due to economic reasons), 168 of these youth participated in the intervention. For these 168 youth, 130 caregivers participated (due to some caregivers having more than one child participating in the intervention). All of the HIV-positive participants (over 95% of caregivers and less than 5% of youth) that required HIV treatment received ART through clinical services at PIH/ZL.

For this study population, pre- versus post-intervention assessments (one year apart) were compared for levels of

psychological symptoms, degree of psychosocial functioning, and extent of social support from friends and family among youth. For caregivers, severity of depressive symptoms, level of role functioning, degree of social support, and HIV-related stigma were compared pre- and post-intervention (see measures section below for detail). Institutional Review Board (IRB) approval was obtained from Harvard Medical School (Office for Research Subject Protection) and the Zanmi Lasante ethics committee.

# Intervention

A psychosocial support group intervention for youth affected by HIV and their caregivers was based on "Project TALC" developed by Rotheram-Borus et al. (2001). The intervention relies on social cognitive theory with a focus on enhancing coping skills and increasing social support. This original curriculum was adapted by a Haitian professional psychologist and social workers for use in central Haiti using focus groups and qualitative interviews. One adaptation involved the timing of the support groups—rather than meetings held once a week for six months, the sessions were implemented over a one year period (held bi-monthly). The groups included 12-15 participants (or parent-child pairs) and were facilitated by trained professional social workers. The organization and format of the sessions were largely retained from the initial TALC project. The adapted curriculum included the first two of the three phases of the intervention. Phase 1 consisted of eight group sessions of HIV-positive caregivers, focusing on healthy lifestyles, coping with negative feelings, disclosing their HIV status, along with other challenges of being HIV-positive.

Phase 2 included an initial set of sessions with HIV-positive parents/caregivers and children meeting separately followed by eight sessions of children meeting with their caregivers. For the caregivers during the first part of Phase 2, caregivers met for six sessions and discussed ways to support their children, in particular focusing on awareness of children's needs, active listening, and building problem-solving skills. Children during the first part of Phase 2 met for seven sessions and focused on strategies for reducing emotional stress, developing a broader range of coping strategies, and reducing HIV risk behavior. During the second part of Phase 2, children and their caregivers met together for eight sessions and focused on parent—child communication, conflict resolution, as well as prevention of risk behaviors related to early pregnancy, transmission of HIV and other STDs, as well as drug and alcohol abuse.

Given that a large percentage of the caregivers were HIVpositive (95%), Phase 3 from the original curriculum was not adapted for the present feasibility study. Other changes from the original curriculum included providing food at meetings, incorporating Haitian Creole proverbs, as well as revising and removing sections that were not relevant to the local context. In particular, the sections on preparing for your parent's death and custody planning were omitted in light of access to ART in the study population. Elements that were added to the original curriculum included: greater detail on 'taking care of myself,' such as the importance of adherence to ART; additional content on HIV prevention and reduction of risk behaviors among the youth; and a greater focus on HIV-related stigma and the cultural meanings of HIV within the Haitian context. Since open discussion and dialog with one's children was a new concept for many parents in this setting, talking with one's healthcare provider was used as an 'entry point' for understanding how to talk with one's children. The adapted curriculum in Haitian Creole is available by request from the authors.

#### Measures

A one-hour structured questionnaire was administered by trained Haitian social workers with HIV-affected youth and their caregivers at baseline and after the intervention (one year later upon completion of the intervention) that included assessment of socio-demographic, economic, and psychosocial variables. The measures were translated into Haitian Creole by the Haitian psychologist directing psychological services at Zanmi Lasante. Assessments for youth included measures from the peer-reviewed literature and were as follows: 1) Goodman's Strengths and Difficulties Questionnaire (SDQ) to assess level of psychological symptoms (Goodman, 2001); 2) extended version of the SDQ to examine degree of psychosocial functioning; a lower level of psychosocial functioning was defined as the caregiver or child self-report of difficulties related to emotions, concentration, behavior, or getting along with others (Goodman, 1999); and 3) Provisions of Social Relation (PSR) to assess extent of social support from family and friends (Turner, Frankel, & Levin, 1983). For caregivers, we used the following measures: 1) depression sub-scale from the Hopkins Symptom Checklist-25 (HSCL-25) (Derogatis, Lipman, Rickels, Uhlenhuth, & Covi, 1974); 2) social support assessment by Gielen, McDonnell, Wu, O'Campo, and Faden (2001) to examine having a confidant, network size, and level of instrumental support; 3) ACTG Short Form-21 (SF-21) to assess role functioning of parents/ caregivers (i.e. the extent to which health status keeps them from performing daily activities) (Crystal, Fleishman, Hays, Shapiro, & Bozzette, 2000); and 4) HIV-related stigma questionnaire developed by Berger, Ferrans, and Lashley (2001).

Although validating these measures in Haitian Creole was outside the scope of the present study, the reliability and validity of these measures have been reported in the original publications (Berger et al., 2001; Crystal et al., 2000; Derogatis et al., 1974; Gielen et al., 2001; Goodman, 1999, 2001; Turner et al., 1983). In particular, the measures of psychological symptoms, the SDQ and HSCL-25 have demonstrated validity and reliability in other cultural or resource-limited settings (Bolton, 2001; Du, Kou, & Coghill, 2008; Kaaya et al., 2002; Mullick & Goodman, 2001).

### Qualitative methods

During the intervention, at the conclusion of each support group session, group facilitators held a brief focus group to compile feedback on participants' impressions of the session, their suggestions for improvement, and the information that they had learned during each session. This information was compiled by social workers at the end of each phase of the support groups and used to improve the adapted version of the TALC curriculum. In addition, at the conclusion of the intervention period, individual interviews were held with five caregivers and five youth from each study site to examine the participants' overall perspectives of the psychosocial support groups. Although there are limitations with purposive sampling in terms of generalizability, recruitment for these final interviews was based on this sampling method to demonstrate the range of experiences the participants may have had during the intervention. The analysis was based upon a grounded theory approach (Glaser & Strauss, 1967) in which there was no a priori assumption about themes that would emerge from the data. Themes were empirically derived from the data and reflected a high frequency and level of agreement among the participants.

# Statistical analysis

Descriptive statistics, frequencies, means, ranges and standard deviations were calculated at baseline. Univariate analyses

**Table 1** Baseline descriptive characteristics for HIV-affected youth, ages 10-17 (n=168).<sup>a</sup>

Characteristic		n (%) or Mean (SD, range)
Gender	Female	100 (59.5%)
	Male	68 (40.5%)
Age	10-13	75 (45.2%)
	14-17	91 (54.8%)
Education level	Ever attended school	160 (95.2%)
Current guardian	Mother	133 (79.2%)
	Father	53 (33.3%)
	Stepmother	9 (5.8%)
	Stepfather	26 (16.7%)
	Grandmother	32 (20.3%)
	Grandfather	19 (12.0%)
	Aunt	23 (14.7%)
	Uncle	15 (9.6%)
	No parent	18 (10.7%)
	No adult	1 (0.6%)
Child experienced death	Yes, one parent	16 (9.8%)
of parent from HIV	Yes, both parents	3 (1.8%)
	Unsure	48 (29.3%)

<sup>&</sup>lt;sup>a</sup> Sample size is less than 168 in some cases due to missing data.

comparing pre- and post-test assessments of psychosocial variables were performed using the paired *t*-test for continuous variables and McNemar's test for categorical variables. Mixed effect models (PROC MIXED) were used to run linear regression for continuous variable outcomes, and logistic regression was performed using the GENMOD procedure in SAS to account for the correlation between siblings within families. An exchangeable variance—covariance structure was used. Socio-demographic variables, including age, sex, and socioeconomic status (SES), were controlled for in the multivariate analyses. Statistical analysis was performed using SAS version 9.1 (SAS Institute, Cary, NC).

#### Results

# Descriptive statistics

Among the youth enrolled in psychosocial support groups in this study, nearly 60% were female, with older children (ages 14–17 years) representing a slightly larger portion of the sample (54.8%) compared to the younger age group (10–13 years). Socio-demographic and economic characteristics indicated that the youth lived in extreme poverty. Among their parents/caregivers, who were predominantly female (76.2%) with a mean age of 39.4 years, over 70% reported a monthly income of less than or equal to \$50/month. Most families lived in substandard housing, with 14.6% living in a house with a thatched roof and less than half (42.3%) having a latrine. Food insecurity was significant with over 90% spending at least half of their income on food and 41.1% indicating that they spent all of their income on food (see Tables 1 and 2).

# Univariate analyses of psychological symptoms

While the youth showed very high levels of self-reported psychological symptoms at baseline, univariate analyses comparing the pre- versus post-intervention assessment indicated significant changes. For the overall SDQ score, based on self-report, the mean total score decreased from 14.7 to 11.1 (p < 0.0001). The most common symptom reported at baseline among the youth enrolled in groups was headaches/stomachaches (90.5%), which decreased to 45.2% (p < 0.0001) at followup. The most prevalent self-reported depressive symptoms reflecting social withdrawal among the youth significantly

**Table 2** Baseline socio-demographic profile of caregivers of HIV-affected youth (n = 130).<sup>a</sup>

Characteristic		n (%) or Mean (SD, range)
Age		39.4 (9.4, 21–84)
Gender	Female	99 (76.2%)
	Male	31 (23.9%)
Residence	Countryside	51 (40.2%)
	Small town	34 (26.8%)
	Large city	42 (33.1%)
Education level	Never attended school	53 (40.8%)
Current marital status	Married	25 (19.2%)
	Living with a partner	44 (33.9%)
	Single	19 (14.6%)
	Separated	18 (13.9%)
	Divorced	0 (0%)
	Widowed	24 (18.5%)
Occupation	Subsistence farming	41 (32.3%)
occupation .	Market vendor	28 (22.1%)
	Tailor	2 (1.6%)
	Domestic servant	1 (0.8%)
	Professional (teacher, nurse,	2 (1.6%)
	doctor, etc.)	2 (1.0%)
	None/not working	52 (40.3%)
Family income (USD)	No income and "don't know"	38 (29.2%)
per month	\$0.05—\$6.25	10 (7.7%)
per monen	\$6.26-\$12.50	9 (6.9%)
	\$12.51-\$18.75	7 (5.4%)
	\$18.76-\$25.00	8 (6.2%)
	\$25.01-\$37.45	13 (10.0%)
	\$37.46-\$43.70	4 (3.1%)
	\$43.71-\$50.00	4 (3.1%)
	>\$50	37 (28.5%)
	Mean family income	\$25.01-\$37.45
Mean family size living in	wican family meome	6.2 (2.8, 2–18)
household Number of children under		
18 living in household		3.6 (2.0, 1–11)
Number of rooms in household		2.3 (1.0, 1–5)
Income spent on food	Less than 50% of income spent on food	9 (9.5%)
	Approximately 50% of income spent on food	8 (8.4%)
	Most of income spent on food	39 (41.1%)
	All income spent on food	39 (41.1%)
Type of roof	Aluminum roof	109 (83.9%)
	Thatched or hay roof	19 (14.6%)
	Concrete roof	1 (0.8%)
	Wood roof	0
	Hay roof	1 (0.8%)
Latrine	Have a latrine	55 (42.3%)
Radio	Have a radio	23 (17.7%)
HIV status	Respondent is HIV-positive	124 (95.4%)

<sup>&</sup>lt;sup>a</sup> Sample size is less than 130 in some cases due to missing data.

decreased at follow-up, which included getting along better with adults than with children of own age (79.2%–60.7%; p = 0.001) and preferring to be alone than with people of own age (61.9%–43.2%; p = 0.0007). However, while nearly 90% of youth initially reported constant fidgeting or squirming, youth indicated similar levels at follow-up (88.3%). Similarly, 61.3% of youth reported worrying a lot at baseline and did not demonstrate significant change at follow-up (63.9%) (see Fig. 1). Among the parents/caregivers, the mean total score for the HSCL depression sub-scale decreased from 38.9 to 32.1 (p < 0.0001). One of the most prevalent depressive symptoms reported at baseline among caregivers that showed the largest decline at follow-up was feeling everything is an effort (74.6%-43.9%; p < 0.0001). Other prevalent symptoms that showed significant decreases from baseline to follow-up were feeling worthless (56.2%–26.2%; *p* < 0.0001) and loneliness (70%–41.5%; p < 0.0001) (see Fig. 2).

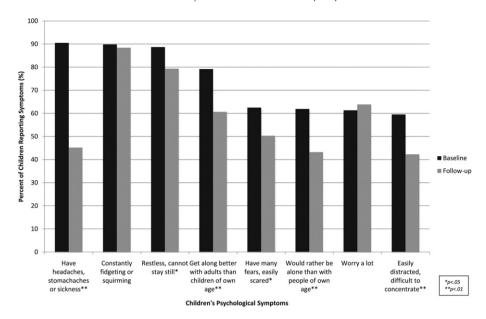


Fig. 1. Most prevalent psychological symptoms reported by children.

#### Multivariate analyses

After adjusting for demographic variables, linear regression models indicated a significant change in the level of children's psychological symptoms. When comparing pre- versus post-intervention assessment, we observed a significant change in the level of the children's self-report of psychological symptoms ( $\beta=3.42$ ; SE = 0.54; p<0.0001). This was also indicated in the caregiver report of their child's psychological symptoms ( $\beta=3.80$ ; SE = 0.54; p<0.0001). Improvement in social support from friends ( $\beta=1.39$ ; SE = 0.67; p=0.04) and relatives ( $\beta=1.10$ ; SE = 0.38; p=0.005) was also indicated in the multivariate analysis. Similarly, after adjusting for demographic variables, we observed a significant change in the level of the caregivers' depressive symptoms, comparing pre- versus post-intervention assessment ( $\beta=5.61$ ; SE = 1.08; p<0.0001). We also saw a significant change in the

caregiver's perception of stigma, comparing pre- versus post-intervention assessment and adjusting for demographic variables ( $\beta = 10.66$ ; SE = 1.58; p < 0.0001) (see Table 3).

Findings from the multivariate analyses also suggested improvements in psychosocial functioning of youth, comparing baseline to follow-up data. We observed a 68% reduction in self-reported impairment in psychosocial functioning, comparing preversus post-intervention assessment (adjusted OR = 0.32; 95% CI: 0.18-0.57; p=0.0001). This was also evident in the caregiver's report of their child's psychosocial functioning (adjusted OR = 0.20; 95% CI: 0.10-0.34; p<0.0001). Of the social variables, the children's report on the number of friends ('0' versus '1 or more') showed a significant change, comparing preversus post-intervention assessment (adjusted OR = 0.41; 95% CI: 0.23-0.72; p=0.002). Availability of a confidant among youth also demonstrated an improvement, although this finding was of marginal

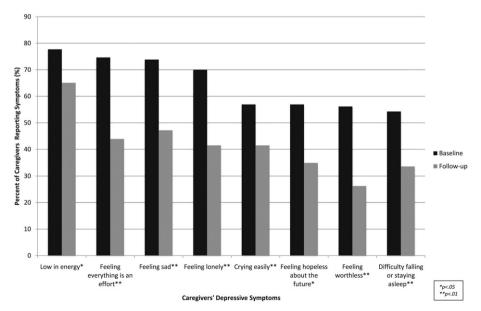


Fig. 2. Most prevalent depressive symptoms reported by caregivers.

 Table 3

 Linear regression models of effect of intervention on children's and caregivers' psychosocial continuous outcomes.

	n	Parameter estimate (standard error)	<i>P</i> -value	n	Parameter estimate (standard error)	P-value	n	Parameter estimate (standard error)	P-value
Children's psychol	ogical symp	toms (self-reported)							
Intervention	151			149			110		
Follow-up		3.74 (0.50)	< 0.0001		3.58 (0.50)	< 0.0001		3.42 (0.54)	< 0.0001
Baseline		0	_		0	_		0	_
Gender		_	_		-0.62 (0.57)	0.27		-0.64(0.63)	0.31
Age		_	_		-0.17 (0.12)	0.16		0.25 (0.14)	0.08
SES		_	_		_ ` `	_		-0.76(0.74)	0.31
Children's psychol	ogical symp	toms (caregiver-reported)						, ,	
Intervention	151	, ,		149			110		
Follow-up		4.19 (0.46)	< 0.0001		4.09 (0.46)	< 0.0001		3.80 (0.54)	< 0.0001
Baseline		0 ` ′	_		0	_		0	_
Gender		_	_		-0.81(0.54)	0.13		-0.75(0.59)	0.21
Age		_	_		-0.24(0.11)	0.03		-0.38 (0.13)	0.005
SES		_	_		_	_		-0.08 (0.84)	0.93
Children's social st	upport from	friends						,	
Intervention	151	<b>,</b>		149			110		
Follow-up		1.85 (0.52)	0.0005		1.77 (0.53)	0.001		1.39 (0.67)	0.04
Baseline		0	_		0	_		0	_
Gender		_	_		-0.94 (0.58)	0.12		-1.11 (0.72)	0.12
Age		_	_		-0.11 (0.13)	0.40		-0.22 (0.16)	0.19
SES					_	_		1.50 (0.79)	0.06
Children's social st	upport from	relatives						, ,	
Intervention	151			149			110		
Follow-up		1.70 (0.36)	< 0.0001		1.53 (0.35)	< 0.0001		1.10 (0.38)	0.005
Baseline		0 ` ′	_		0	_		0	_
Gender		_	_		-0.88 (0.61)	0.15		-1.09(0.57)	0.06
Age		_	_		0.25 (0.13)	0.06		0.06 (0.13)	0.63
SES		_	_		_ ` ` `	_		-0.27(0.63)	0.67
Caregiver stigma p	perception							, ,	
Intervention	130			128			95		
Follow-up		11.33 (1.33)	< 0.0001		11.32 (1.34)	< 0.0001		10.66 (1.58)	< 0.0001
Baseline		0	_		0	_		0	_
Gender		_	_		-2.12 (2.02)	0.30		-1.09(2.27)	0.64
Age		_	_		-0.22 (1.76)	0.90		-3.06 (1.98)	0.13
SES		_	_		_ ` ` `	_		0.36 (1.90)	0.85
Caregiver depressi	ve sympton	15						, ,	
Intervention	130			128			95		
Follow-up		6.60 (0.98)	< 0.0001		6.61 (0.99)	< 0.0001		5.61 (1.08)	< 0.0001
Baseline		0	_		0	_		0	_
Gender		_	_		-1.44 (1.68)	0.39		-1.74 (1.85)	0.35
Age		_	_		1.91 (1.44)	0.19		0.10 (1.59)	0.95
SES		_	_		_	_		-3.12 (1.56)	0.05

statistical significance (adjusted OR 0.53; 95% CI: 0.28-1.02; p = 0.06) (see Table 4).

# Qualitative findings

Complementary qualitative data supported the quantitative data in the potential improvement in quality of life of the HIV-affected youth and their caregivers. One of the caregivers reported a renewed sense of hope after the intervention: "My heart was closed, I had asked my body to die... The support groups gave us courage to live with our illness, and they gave us hope." Another caregiver expressed that the groups helped them learn how to cope: "I used to feel sorry for myself, as if I was at a loss for life, but when I started the groups I started listening to other people and that helped me a lot... the groups have helped me to learn how to cope with my problems."

In addition, HIV-affected youth also described a greater ability to cope with adversity and plan for the future: "As a teenage girl, I learned how to protect myself and cope with things on my own and continue with school." Youth had also expressed interest in protecting themselves from HIV: "I learned so much in the support groups, such as how I can protect myself from illnesses you can get from having sex and how I can chase bad ideas from my head." These qualitative findings corroborate the results from the quantitative

data that demonstrated a reduction in psychological distress and an improvement in psychosocial functioning among the HIV-affected youth and their caregivers comparing pre- and post-intervention assessment.

A second complementary theme that emerged was a greater confidence in coping with HIV-related stigma in the community. One caregiver stated: "Before I had a lot of problems because my friends and neighbors talked badly about me. They called me 'SIDAyis' (person with HIV). Now I feel comfortable, I don't let things like this give me problems anymore." Another mother reported: "I felt embarrassed because people said bad things about me, I was very discouraged. Now I feel as though I have more strength, and I don't think about what others have to say about me." Youth also expressed similar feelings: "Before I started in the support groups, my experience was that I thought everyone was always talking about my mother, but now I am not afraid of anyone and I do not let them bother me."

Another theme that emerged from both caregiver and youth interviews was greater capacity to communicate with each other and a stronger sense of family cohesion. One youth mentioned: "Before I always used to be afraid to speak to my mother about my thoughts, but now I feel more comfortable speaking with her." Another stated: "I really liked the work that we did in the support groups. I now understand my mother better and I am able to better support her." Caregivers expressed similar sentiment: "We learned how we can

Table 4 Generalized linear models of effect of intervention on children's and caregivers' psychosocial categorical outcomes.

	п	Parameter estimate (standard error)	P-value	Odds ratio (95% confidence interval)	Parameter estimate (standard error)	P-value	Odds ratio (95% confidence interval)	Parameter estimate (standard error)	P-value	Odds ratio (95% confidence interval)
Children's psychosocial	151								_	
functioning (self-reported)		1 35 (0 34)	-0.001	0.30 (0.10, 0.40)	1 35 (0 35)	-0.0001	0.20 (0.10, 0.47)	1.14 (0.20)	0.0001	0.33 (0.10, 0.57)
Intervention		-1.25 (0.24)	< 0.001	0.29 (0.18, 0.46)	-1.25 (0.25)	< 0.0001	0.29 (0.18, 0.47)	-1.14 (0.29)	0.0001	0.32 (0.18, 0.57)
Gender		_	_	_	0.47 (0.27)	0.08	1.60 (0.95, 2.70)	0.58 (0.31)	0.06	1.79 (0.97, 0.3.32)
Age		_	_	_	0.67 (0.27)	0.01	1.96 (1.16, 3.31)	0.96 (0.32)	0.003	2.61 (1.40, 4.84)
SES	454	_	_	_	_	_	_	0.90 (0.33)	0.006	2.46 (1.29, 4.70)
Children's psychosocial functioning (caregiver-reported)	151									
Intervention		-1.57(0.26)	< 0.0001	0.21 (0.13, 0.35)	-1.57(0.26)	< 0.0001	0.21 (0.12, 0.35)	-1.62(0.34)	< 0.0001	0.20 (0.10, 0.34)
Gender		_	_	_	-0.42(0.28)	0.14	0.66 (0.38, 1.14)	-0.45(0.32)	0.16	0.64 (0.34, 1.20)
Age		_	_	_	0.19 (0.28)	0.50	1.21 (0.70, 2.09)	0.26 (0.33)	0.44	1.30 (0.68, 2.46)
SES		_	_	_	_	_	_	1.42 (0.33)	< 0.0001	4.15 (2.18, 7.87)
Children's social support: confidant	151									
Intervention		-0.66(0.28)	0.02	0.52 (0.30, 0.89)	-0.66(0.28)	0.02	0.52 (0.30, 0.90)	-0.63(0.33)	0.06	0.53 (0.28, 1.02)
Gender		_ ` `	_	_	-0.13 (0.31)	0.67	0.88 (0.48, 1.60)	-0.03 (0.33)	0.92	0.97 (0.51, 1.85)
Age		_	_	_	-0.14 (0.31)	0.65	0.87 (0.48, 1.59)	-0.18(0.34)	0.59	0.83 (0.43, 1.63)
SES		_	_	_	_	_	_	0.36 (0.33)	0.27	1.44 (0.75, 2.742)
Children's social support: friends	151							(,		, , , , ,
Intervention		-1.21 (0.23)	< 0.0001	0.30 (0.19, 0.47)	-1.19(0.24)	< 0.0001	0.31 (0.19, 0.48)	-0.89(0.29)	0.002	0.41 (0.23, 0.72)
Gender		_	_	_	-0.09 (0.27)	0.73	0.91 (0.53, 1.56)	0.05 (0.31)	0.86	1.06 (0.57, 2.00)
Age		_	_	_	-0.35 (0.28)	0.21	0.70 (0.41, 1.21)	-0.39 (0.33)	0.24	0.68 (0.35, 1.30)
SES		_	_	_	_	_	_	0.94 (0.32)	0.004	2.55 (1.35, 4.82)
Caregivers' role functioning: type 1 <sup>a</sup>	130									
Intervention	150	-0.51 (0.24)	0.03	0.60 (0.38, 0.95)	-0.53 (0.24)	0.03	0.59 (0.37, 0.95)	-0.39(0.29)	0.1728	0.67 (0.39, 1.19)
Gender		_	_	_	0.17 (0.29)	0.55	1.19 (0.67, 2.11)	0.43 (0.44)	0.33	1.53 (0.65, 3.62)
Age		_	_	_	0.55 (0.37)	0.13	1.74 (0.85, 3.57)	0.13 (0.34)	0.69	1.14 (0.59, 2.22)
SES		_	_	_	-	-	-	-0.33 (0.32)	0.30	0.72 (0.38, 1.35)
Caregivers' role functioning: type 2 <sup>b</sup>	130							0.55 (0.52)	0.50	0.72 (0.50, 1.55)
Intervention	150	-0.54 (0.23)	0.02	0.58 (0.37, 0.92)	-0.55 (0.24)	0.02	0.58 (0.36, 0.92)	-0.53 (0.29)	0.07	0.59 (0.33, 1.04)
Gender		-0.54 (0.25)	- 0.02	-	0.20 (0.30)	0.49	1.23 (0.68, 2.21)	0.27 (0.34)	0.43	1.31 (0.67, 2.55)
Age		_	_	_	0.40 (0.36)	0.43	1.49 (0.73, 3.03)	0.12 (0.42)	0.78	1.13 (0.49, 2.57)
SES		_	_		0.50)	- 0.27	1.43 (0.73, 3.03)	-0.42 (0.32)	0.78	0.66 (0.35, 1.24)
Caregivers' social support: financial	130	_	_	_	_	_	_	-0.42 (0.32)	0.20	0.00 (0.55, 1.24)
Intervention	130	-0.64 (0.24)	0.007	0.53 (0.33, 0.84)	-0.66 (0.25)	0.008	0.52 (0.32, 0.84)	-0.16 (0.27)	0.56	0.85 (0.50, 1.45)
Gender		-0.04 (0.24)	0.007	0.33 (0.33, 0.04)	-0.06 (0.25) -0.01 (0.30)	0.008	0.99 (0.55, 1.80)	-0.16 (0.27) -0.10 (0.37)	0.30	0.83 (0.30, 1.43)
		_	_	_	` ,	0.98	, ,	-0.10 (0.37) -1.02 (0.39)	0.80	0.36 (0.17, 0.78)
Age SES		_	_	_	-0.85 (0.32)		0.43 (0.23, 0.80)	` ,	0.01	, , ,
SES		_	_	_	_	_	_	0.56 (0.36)	0.12	1.75 (0.86, 3.54)

<sup>&</sup>lt;sup>a</sup> Health keeps individual from having a job, doing housework, or going to school.
<sup>b</sup> Health makes individual unable to do certain kinds or amounts of work, housework or school work.

talk with our children so that they will listen. Before I was in the groups, I spoke with my children as my parents did to me (in an authoritative way). Now, when I speak with my children they listen to me and I listen to them." Another caregiver-reported a transition from using corporal punishment to non-violent approaches to conflict: "Before the [support groups] I used to treat my children very badly; I would hit them... and yell at them. But now, thanks to our good God, the support groups have brought a different feeling to me and my children are now my friends because I treat them much better."

# Discussion

Although HIV is no longer a death sentence for those who have access to ART, youth affected by HIV and their parents/caregivers face significant challenges in their daily lives as they cope with chronic illness. The present study demonstrated that a psychosocial support group intervention for HIV-affected youth and their caregivers was feasible in central Haiti, where people often travel for long distances to access healthcare facilities, as reflected by a high retention rate (95%). Factors that promoted retention in the groups included: participant satisfaction with content of support groups; the coverage of transportation costs; changing the frequency of the sessions from once per week to twice per month; and the provision of food at the sessions. Although other studies have demonstrated the feasibility of psychosocial support programs for HIV-affected youth in developing countries (Brown et al., 2007; Kumakech et al., 2009), this study documents the feasibility of implementing a structured curriculum and family-based psychosocial support group intervention for HIV-affected youth and their caregivers in a low-income country.

Preliminary results demonstrated a decreased burden of psychological symptoms among HIV-affected youth. In particular, significant reductions were observed for somatic and depressive symptoms, such as having headaches or stomachaches or preferring to be alone than with people their own age. One consideration regarding a reduction in somatic symptoms in youth (i.e. headaches or stomachaches) is the potential for these symptoms to be explained by circumstances other than the intervention, such as food insecurity and/or underlying HIV disease. However, it is unlikely that this significant reduction in headaches/stomachaches could be completely explained by these factors, since the prevalence of HIV among the youth was low (less than 5%) and aside from the food provided at bi-monthly meetings, food aid was not a part of the specific program. Although some families may have received food assistance or cash transfers through PIH's broader program on social and economic rights, this would have not necessarily changed prior to or during the psychosocial intervention period.

In addition, improvement was observed for 'easily distracted, difficulty concentrating.' Although there was a significant reduction in 'having many fears, easily scared' (62.5%-50.3%; p=0.01), there was no significant reduction in 'worrying a lot' (61.3%-63.9%). This persistent anxiety may be due in part to the high levels of food insecurity in this population. Given that the intervention did not focus on improvement in socioeconomic conditions, it is possible that these symptoms persisted given youths' uncertainty about the economic situation in their families (Weinreb et al., 2002; Whitaker, Phillips, & Orzol, 2006).

A number of depressive symptoms among the caregivers also decreased significantly, including feeling sad, crying easily, and feeling hopeless about the future. In some cases, symptoms were reduced by more than half, such as feeling worthless (56.2%—26.2%). Notably, caregivers had a marked decrease in "thoughts of ending your life" from 27.7% to 8.1%. Other studies of group psychosocial support in resource-poor settings have demonstrated improvements in depressive symptoms among adults

(Bolton et al., 2003) as well as youth (Bolton et al., 2007). In particular, Bolton et al. (2007) observed a significant reduction in depressive symptoms among youth who were survivors of war and displacement in northern Uganda related to participation in group interpersonal psychotherapy.

HIV-related stigma also demonstrated a reduction comparing pre- versus post-intervention assessment among the HIV-positive parents. This effect may also significantly improve the quality of life for HIV-positive patients. In a study of HIV-related stigma in five countries in sub-Saharan Africa (Lesotho, Malawi, South Africa, Swaziland, and Tanzania), HIV-positive individuals experienced a significant reduction in overall perceived stigma, workplace stigma, as well as negative self-perception and improvement of self-esteem following a stigma reduction intervention (Uys et al., 2009).

Youth showed improvement in psychosocial functioning comparing pre- and post-intervention assessment. At initial follow-up (up to two years), Rotheram-Borus et al. (2001) reported a lower level of problem behaviors in youth enrolled in the TALC program, suggesting a higher level of psychosocial functioning. For example, six years after the intervention Rotheram-Borus et al. (2004) observed that adolescents who participated in the TALC program were more likely to be employed or in school (82.6%) compared to those in a control group (68.9%).

There are a number of limitations in our study, including the small sample size, particularly for the number of caregivers (n = 130). In addition, there was some loss to follow-up during the intervention for the caregivers (from n = 130 to 123) and youth (from n = 168 to 155), although these losses are small in magnitude (95% and 92% retention, respectively). The study can only offer preliminary results on the effectiveness of the intervention, given that the design is a pre- versus post-test analysis, rather than a randomized controlled trial (RCT). Although performing a RCT was outside the scope of the present study, having a control group would have provided a more definitive evaluation of the intervention. However, it is unlikely that broader improvements in the environment could account for the decrease in psychological symptoms in the study population. During the time of the intervention and follow-up interviews the target area was affected by a severe hurricane season that resulted in significant flooding and concomitant economic vulnerability.

An alternative explanation for the positive findings could be related to access to ART among the HIV-positive members of the groups. While this is unlikely to have affected the children's responses, since less than 5% were HIV-positive; this may have affected our findings among the caregivers, which were over 95% positive. However, recruitment occurred among patients who had initiated ART starting as early as 1998. Since enrollment was based on patients starting ART between 1998 and 2007 (a ten year period), we anticipate that the effects of initiation of ART may have not entirely explained the positive findings from our study.

Qualitative findings suggesting improvement in psychological well-being also corroborate the quantitative results. Although there is also limitation in the qualitative findings: since participants were asked at the end of the intervention to provide feedback on the intervention, they may have also been responding to the "performative" demands of the narrative in this context of open-ended discourse, potientially biasing the results toward more positive reflections on the intervention. This was also demonstrated through feedback from annual surveys among women affected by lymphatic filariasis enrolled in support groups conducted in Haiti. Women generally provided positive feedback of the intervention (Coreil & Mayard, 2006), which may be related to the significant adaptation of this intervention to the Haitian setting, as well as the general expectation that participants should frame their responses

in a positive manner. Constructive feedback from these groups reflected an interest in more practical activities related to crafts, sewing, cooking, and forming a credit association (Coreil & Mayard, 2006). Similarly, at the end of the current program, participants voiced a strong interest in employment and microfinancing opportunities. Future psychosocial support groups should consider addressing the important issue of economic security for families affected by HIV.

Also, given the need for professional social workers for this adapted intervention, for resource-limited settings it is likely that this intervention may need to be linked with a clinical facility or other service-related program that either provides care free of charge or is government sponsored. However, further study would allow programs to evaluate the effectiveness of groups facilitated by professional social workers versus lay community health workers. Finally, the present study was limited in examining outcomes post-intervention. Future studies would benefit from following the group participants for a longer follow-up period after the end of the psychosocial support group meetings to assess the potential for an effect of the intervention in the long-term.

In conclusion, the results demonstrated feasibility and preliminary effectiveness of a psychosocial support group intervention for HIV-affected youth and their caregivers in a low-income country. In addition, prior to the study there were limited empirical data on the burden of psychological symptoms among HIV-affected youth and their caregivers in central Haiti. The findings demonstrated very high rates of symptoms at baseline in this at-risk population. Through the implementation of a psychosocial support intervention, significant reductions in psychological symptoms among youth and depressive symptoms among caregivers were observed.

However, symptoms of anxiety persisted among this youth. It is possible that pervasive poverty and food insecurity in central Haiti may play a role in the sustained level of anxiety. In addition, from the multivariate analyses, lower socioeconomic status was associated with a higher level of caregiver depressive symptoms, lower self-report of social support from children's friends, and a lower level of psychosocial functioning among the youth. This suggests that after controlling for the effect of the intervention, that low socioeconomic status continued to have an impact on psychosocial well-being in this population that bears a high burden of poverty. Although caregivers reported improved financial social support following the intervention (i.e. self-report of having someone whom you can get money from when you need it), this was insufficient to offset the highly vulnerable economic situation experienced by the families.

Psychosocial support programs in low-resource contexts may also consider implementing and evaluating an additional program component to address the underlying economic and food insecurity that are common in these settings. Although future studies should evaluate additional program components of improving economic security, these preliminary findings suggest it is feasible to implement a family-focused, curriculum-based psychosocial support group intervention that may reduce the burden of psychological symptoms and potentially impact psychosocial functioning among HIV-affected families in Haiti and similar resource-limited settings.

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