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Perceived discrimination and stigma toward children affected by HIV/AIDS and their HIV-positive caregivers in central Haiti

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Abstract

In many settings worldwide, HIV-positive individuals have experienced a significant level of stigma and discrimination. This discrimination may also impact other family members affected by the disease, including children. The aim of our study was to identify factors associated with stigma and/or discrimination among HIV-affected youth and their HIV-positive caregivers in central Haiti. Recruitment of HIV-positive patients with children aged 10–17 years was conducted in 2006–2007. Data on HIV-related stigma and/or discrimination were based on interviews with 451 youth and 292 caregivers. Thirty-two percent of caregivers reported that children were discriminated against because of HIV/AIDS. Commune of residence was associated with discrimination against children affected by HIV/AIDS and HIV-related stigma among HIV-positive caregivers, suggesting variability across communities. Multivariable regression models showed that lacking social support, being an orphan, and caregiver HIV-related stigma were associated with discrimination in HIV-affected children. Caregiver HIV-related stigma demonstrated a strong association with depressive symptoms. The results could inform strategies for potential interventions to reduce HIV-related stigma and discrimination. These may include increasing social and caregiver support of children affected by HIV, enhancing support of caregivers to reduce burden of depressive symptoms, and promoting reduction of HIV-related stigma and discrimination at the community-level.

Keywords

discrimination; stigma; HIV; Haiti; youth; caregivers

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Introduction

Haiti is the most impoverished country in the western hemisphere and also has one of the highest prevalence estimates of HIV outside of sub-Saharan Africa (2.2%) (UNAIDS, 2008). In addition to the significant physical and economic burden of HIV disease, those who are HIV-infected in resource-poor settings may also face a significant degree of discrimination (Liechty & Bangsberg, 2003). In rural Haiti, being affected by HIV/AIDS can result in ostracism, blaming the victim for the disease, withholding of food, social isolation, and denial of human dignity (Fitzgerald & Simon, 2001). In a study of 93 expectant fathers recruited from four health dispensaries in Haiti's Artibonite Valley, over half held at least some beliefs that could be characterized as stigmatizing toward people with HIV/AIDS, with approximately 30% showing attitudes indicating high levels of stigma (Magee, Small, Frederic, Joseph, & Kershaw, 2006).

Stigma has been defined as a perception of "differentness" stemming from one's affiliation with a group considered undesirable (Goffman, 1963). Among the varied approaches to understanding stigma, it has been conceptualized as a convergence of interrelated components, such that it occurs when differences are labeled, linked to negative stereotypes, and people are categorized as separate, such that discrimination results (Link & Phelan, 2001). Given the lack of consensus concerning the definition of stigma and the prior dominant conceptualization of it as an individualistic process, recent conceptual models of HIV/AIDS stigma conceive of it as a social and cultural phenomenon rooted in social conditions (Parker & Aggleton, 2003). According to a framework proposed by Parker and Aggleton (2003), stigma is part of a complex social struggle used to create and perpetuate social inequalities, such that it is through understanding and acting on these social processes that the problem can be addressed.

Building on this framework of stigma and discrimination (Parker & Aggleton, 2003), our aim was to study social processes (e.g., support) and structural factors (e.g., educational attainment, poverty, orphan-hood) in relation to HIV-related stigma and discrimination. Prior studies have shown that social support and higher socio-economic status (SES) are protective for elevated stress levels (Adler & Newman, 2002; Cohen, Underwood, & Gottlieb, 2000; Kawachi & Berkman, 2001; Szanton, Gill, & Allen, 2005). Therefore, we were particularly interested in whether support as well as educational attainment and income, as indicators of SES, might be protective of HIV-related stigma. Likewise, depression has been linked to HIV/AIDS stigma in other contexts (Dowshen, Binns, & Garofalo, 2009), but to our knowledge has not been previously investigated in Haiti.

Although, the impact of stigma and discrimination among HIV-affected caregivers and/or their children has been documented (Cluver & Gardner, 2007; Cohen, 2005; Cree, Kay, Tisdall, & Wallace, 2006; Reyland, Higgins-D'Alessandro, & McMahon, 2002), we do not know of literature that directly examines factors associated with HIV-related stigma and discrimination as the primary outcome. By identifying factors associated with HIV-related stigma and discrimination among families affected by HIV, we can develop interventions to address and/or prevent HIV-related stigma, possibly curtailing the psychosocial impact on families affected by HIV, such as isolation (Cree et al., 2006) and depression (Dowshen et al., 2009; Wu et al., 2008). In addition to the distress caused by stigma and discrimination, the isolation and silence surrounding the illness can have a negative effect on HIV prevention efforts (Ehiri, Anyanwu, Donath, Kanu, & Jolly, 2005; Kaplan, Scheyett, & Golin, 2005). Therefore, understanding factors associated with HIV-related stigma and discrimination can inform interventions to mitigate their potential impact, which is important from a clinical as well as a public health perspective.

In this study, we examined the associations of demographic and social factors with HIV-related stigma and discrimination among children affected by HIV in central Haiti. We hypothesized that HIV-related discrimination among HIV-affected children would be associated with social support, self-perceived orphan status, caregiver education, household income, and HIV-positive caregiver's experience of stigma. Secondly, we evaluated factors related to stigma among HIV-positive caregivers. We hypothesized that caregiver education, household income, social support, role functioning, and depressive symptoms would be associated with stigma in HIV-positive caregivers.

Methods

Our study focused on caregivers' perceptions of stigma and discrimination related to HIV/AIDS affecting themselves and their children. Study recruitment took place between February 2006 and January 2007, based on a listing of HIV-positive patients or deceased patients who had received care at six (out of seven) of Zanmi Lasante's sites in central Haiti since the inception of the HIV program in 1998. At the time of the study, the seventh site (Cerca La Source) was newly opened and had not yet recruited enough patients for participation in the study. The six study sites included: Belladere; Boucan Carre; Cange; Lascahobas; Hinche; and Thomonde. These locations were all Zanmi Lasante clinical sites (in collaboration with Haiti's Ministry of Health with the exception of Cange) where primary care and comprehensive HIV care (e.g., antiretroviral therapy) were offered. The overall catchment area for these clinics covered the Central Department of Haiti, which is largely rural with one small urban center (Hinche). All patients receiving HIV care and who had children between 10 and 17 years of age at these sites were invited to participate in the study.

Eligibility criteria for youth included: age between 10 and 17 years and being affected by HIV/AIDS. For this study, HIV-affected youth are defined as having at least one caregiver who was HIV-positive; having a caregiver who had died of HIV/AIDS; or being HIV-positive themselves. Of the 576 eligible youth identified (i.e., all youth who were in the eligible age range and were children of the caregivers who were invited to participate in the study), 492 youth (85%) and their caregivers agreed to participate. The primary reason for not participating was that the youth were living out of town to engage in school or work opportunities. Informed consent was given by their caregivers and assent was provided by the youth. Due to missing responses about stigma in children, the effective sample size was 451. Since caregivers could have more than one child between the ages of 10 and 17 in the study, there were only 330 parents or guardians of participating youth. Of these caregivers, analyses were further restricted to 292 who were HIV-positive (e.g., HIV-negative guardians of children whose parents had died of HIV/AIDS were excluded). Participants responded to a baseline survey prior to recruitment and enrollment in a feasibility study of a psychosocial intervention for HIV-affected youth. For each child-parent pair, a structured interview was performed at baseline by clinic social workers that were trained in administration of study questionnaires with the children and at least one of their parents/guardians who identified themselves as the youths' primary caregivers. The study received ethics approval by the Institutional Review Board (IRB) at Harvard Medical School and the Zanmi Lasante Ethics Committee.

Discrimination and stigma endpoints

We assessed caregivers' perceptions of HIV-related discrimination in youth by asking caregivers "Do you feel the children or orphans of parents who are HIV positive are treated differently from other children because of having AIDS in the family or being orphaned?" This item was adapted from a questionnaire on HIV-related stigma and discrimination from the Horizons Survey Instrument Bank (Population Council, 2005). For the HIV-positive

parents, HIV-related stigma was measured with a subset of items from a scale developed by Berger and colleagues for individuals with HIV/AIDS (Berger, Ferrans, & Lashley, 2001). For this scale, HIV-positive caregivers were asked to respond to statements reflecting HIV-related stigma, such as “People with HIV are treated like outcasts” on a four-point scale: “Not true,” “Not really true,” “Partly true,” and “Completely true.”

Covariates and social and health variables of interest

Demographic data regarding children and their parents included information on: gender; marital status of the caregiver; age of caregiver; child age; caregiver education; household income; and community of residence. Self-reported orphan status and child social support (i.e., having a confidant and/or friends) were also assessed. Caregiver social support was assessed by whether or not the parent had a confidant, someone to go to for money, and someone to count on if he/she needed a place to stay. We used two role functioning items related to work performance from the AIDS Clinical Trials Group (ACTG) Short Form (SF-21) (Wu, Revicki, Jacobson, & Malitz, 1997). They were: “Does your health keep you from working at a job, doing work around the house or going to school?” and “Have you been unable to do certain kinds or amounts of work, housework or school work because of your health?” Answer options were “Yes, all of the time,” “Yes, some of the time,” and “No.” To measure caregiver depressive symptoms, we summed the 15 items of the depression sub-scale from the Hopkins Symptom Checklist (Derogatis, Lipman, Rickels, Uhlenhuth, & Covi, 1974). This measure is based on a four-point scale in response to the degree in which depressive symptoms had bothered or distressed them in the past week: “Not at all,” “A little,” “Quite a bit,” or “Extremely.” This depression measure has demonstrated good reliability and validity in a number of cross-cultural contexts (Kaaya et al., 2002; Mollica et al., 1986).

Data analysis

Descriptive statistics were calculated for demographic and health information from the children and their caregivers in relation to the perceived discrimination and stigma outcomes. Chi-square tests were used to assess the relationship between each of the demographic and social variables with the dichotomous measure of perceived discrimination toward HIV-affected children. Multivariable logistic regression models were fit, including demographic variables: child gender, child age; caregiver gender, age, marital status; number of years of schooling; average monthly household income; and commune of residence. In addition to a model with these covariates, other variables related to support, stigma experienced by HIV-positive caregivers, and the child’s assessment of his/her status as an orphan were added separately and then simultaneously into models with child discrimination resulting from HIV/AIDS stigma as the outcome. A final model included all variables plus caregiver depressive symptom score to evaluate whether its inclusion might attenuate the other associations. Because more than one child from the same family could be included in the sample, we used proc genmod in SAS which allowed us to account for correlations between siblings by using an exchangeable variance–covariance structure.

In the analyses of HIV-positive caregivers’ experience of stigma, we used the Berger Stigma Scale as a continuous variable as our endpoint of interest. Therefore, *t*-tests and analysis of variance (ANOVA) were used to examine bivariate associations between demographic, social support, and role functioning items. For multivariable models, we performed linear regression using proc mixed in SAS. Covariates in all models focusing on stigma toward the caregiver included the caregiver’s gender, marital status, educational attainment, age, household income, and the commune of residence. Other associations were assessed between support variables (having someone to provide money, someplace to stay, having a confidant), whether his/her health keeps the person from working, whether he/she was

limited in work performance because of his/her health, and caregiver depressive symptoms, in relation to score on the Berger Stigma Scale. All analyses were conducted with SAS 9.1.3 (SAS Institute Inc., Cary, NC).

Results

Discrimination toward children affected by HIV/AIDS

Of participating youth in our study, seven (1.4%) of the adolescents and 292 (88.8%) of the primary caregivers were HIV-positive. Regarding the 487 adolescents for whom we had data on their orphan status (missing $n = 5$), over half of these youth ($n = 281$; 58%) had both parents alive, while 62 (13%) had lost one parent, 15 (3%) had lost both parents to HIV/AIDS, and 129 (26%) reported being unsure of whether one or more parents were alive.

In our sample, 32% of caregivers reported that children affected by HIV/AIDS were discriminated against. In bivariate analyses, being a female caregiver, commune of residence (Lascahobas, Thomonde), caregiver not knowing the household's monthly income, caregiver HIV-related stigma, the child lacking a confidant, and child considering him/herself an orphan were associated with an increased likelihood of perceived discrimination experienced by children affected by HIV/AIDS (see Table 1).

In multivariable logistic regression models we found the caregiver's score on the Berger Stigma Scale to be a strong predictor of caregiver report of child discrimination (adjusted OR 4.4, 95% CI: 2.6–7.4) (Table 2, Column 1). We modeled child social support using our composite variable that combined the child's number of friends with whether or not he/she had a confidant (Table 2, Column 2). Compared to children who reported having a confidant and at least one friend, having no confidant and no friend was associated with a two times higher likelihood of the caregiver perceiving discrimination toward children (adjusted OR 1.8, 95% CI: 0.9–3.5) and having either at least one friend or having a confidant was associated with a 20% higher risk of perceived discrimination (adjusted OR 1.2, 95% CI: 0.9–1.7) (Table 2, Column 2). A child who considered himself/herself an orphan was 40% more likely to have his/her caregiver report that children were discriminated against compared to caregivers of children who had at least one living biological parent (adjusted OR 1.4, 95% CI: 1.0–1.8) (Table 2, Column 3).

When all of the social variables were included in the model simultaneously, estimates remained stable regarding the associations between social variables – caregiver's Berger Stigma Scale score, child support from a friend or confidant, and whether or not the child considered himself/herself an orphan – and perceived discrimination toward children stigmatized because of HIV/AIDS (Table 2, Column 4). Demographic factors that were significantly or marginally associated with caregiver report of child discrimination included age of child, age of caregiver, self-reported level of household income, and commune of residence (see Table 2). The additional inclusion of caregiver depressive symptoms either did not affect or only negligibly affected the magnitude of the other associations in the model.

Stigma toward caregivers with HIV/AIDS

Both role functioning items from the SF-21 focusing on the caregiver's inability to work were associated with his/her score on the Berger Stigma Scale. Caregivers who reported that their health did not keep them from working had an average stigma score of 41.9 (SD 10.6), while caregivers reporting their health kept them from working part of the time or all of the time had higher mean stigma scores of 46.1 (SD 12.4) and 48.5 (SD 13.8), respectively ($p < 0.01$) (Table 3). Demographic variables associated with stigma experienced by HIV-

positive caregivers included gender, level of education, and commune of residence (see Table 3).

After adjusting for demographic variables, linear regression models indicated a strong relationship between limitations in one's ability to work and score on the Berger Stigma Scale ($\beta = 5.2$, 95% CI: 2.3–8.1; $\beta = 6.7$, 95% CI: 2.6–10.8 health interfered with work some or all of the time, respectively) (Table 4, Column 3). The other variable that was strongly associated with stigma scores was the caregivers' depressive symptom score ($\beta = 11.2$, 95% CI: 8.0–14.4) (Table 4, Column 5). A final model simultaneously included demographic variables, the composite caregiver support variable, the two SF-21 role functioning variables, and the Hopkins measure of depressive symptoms and demographic variables. Of the non-demographic variables, only the Hopkins measure of depressive symptoms remained significantly related to stigma score ($\beta = 10.0$, 95% CI: 6.7, 13.4) (Table 4, Column 6).

Discussion

HIV-related perceived stigma and discrimination against children affected by HIV/AIDS was fairly prevalent according to caregivers' report (32%) in the study population. HIV-positive caregivers reported significant levels of stigma that varied across geographical areas in central Haiti. Stigma against caregivers was highly associated with their reporting discrimination in children affected by HIV/AIDS. In addition, lack of child social support and the child considering himself/herself an orphan were factors associated with perceived discrimination toward children. Generally, discrimination has been associated with a number of adverse physical and mental health consequences (Krieger, 1999; Paradies, 2006; Williams, Neighbors, & Jackson, 2003), therefore, it is important to address HIV-related stigma among HIV-positive caregivers and their children with respect to preventing short-term as well as long-term negative health outcomes.

Perceived discrimination among HIV-affected children as reported by caregivers was strongly associated with HIV-related stigma among HIV-positive caregivers. This finding suggests that reducing stigma among HIV-positive caregivers may have an impact on the degree of discrimination children affected by HIV/AIDS experience. By relying on caregiver report, there is potential for bias in a positive direction, whereby caregivers who experience greater HIV-related stigma may perceive a greater degree of discrimination against children affected by HIV. However, after controlling for caregiver depressive symptoms in the multivariable analysis, a key mediating variable potentially related to this perception, the association between HIV-related stigma and caregiver report of discrimination against children affected by HIV was not attenuated.

Lack of child social support and the child considering himself/herself an orphan were factors associated with perceived discrimination toward children, conferring an increase in risk by nearly twofold and 40%, respectively. The present study showed that a child having at least one friend and/or a confidant was inversely associated with perceived HIV-related discrimination toward children. Social support is considered to be protective during major stressful life events (Cohen&Syme, 1985) and it has been suggested that it may confer protection with respect to the mental health impact of HIV (Murphy, Moscicki, Vermund, & Muenz, 2000; Turner-Cobb et al., 2002). Our findings, suggesting that discrimination is a challenge for children who are orphaned, echoes common sentiment expressed in the literature (Foster, Makufa, Drew, Mashumba, & Kambeu, 1997; Foster & Williamson, 2000; Funkquist, Eriksson, & Muula, 2007).

Our analyses further indicated that caregivers' disability related to his/her health as well as depressive symptoms were strongly related to his/her experience of HIV-related stigma. Caregivers who were unable to work or perform some of their work had almost a seven-point higher score on the Berger Stigma Scale. Although the direction of the association is unclear from our study, the idea that stigma is influenced by whether the disease is perceptible to others is informed by prior hypotheses regarding stigma in Haiti (Castro & Farmer, 2005). Castro and Farmer (2005) have argued that people who live with the disease without obvious symptoms or limitations may be better able to avoid stigma associated with HIV.

Regarding perceived stigma in the caregivers themselves, we found that depressive symptomatology was highly associated with experience of HIV-related stigma, such that people with the most depressive symptomatology had approximately 11 points higher score on the Berger Stigma Scale on average. The addition of the Hopkins' depressive symptoms scale to the model containing the role functioning items, made the associations between the variables pertaining to caregivers' work capacity lose significance. Prior literature indicates that depression is associated with disability, irrespective of physical health limitations (Judd et al., 2008; Murray & Lopez, 1996). Interventions that promote reduction in depressive symptomatology may also have an impact on degree of disability experienced by HIV-positive individuals with elevated depressive symptoms levels (Lopez, Mathers, Ezzati, Jamison, & Murray, 2006). In addition, prior evidence suggests that reducing depressive symptoms in the parents may have a positive impact on the children's well-being and health outcomes (Beardslee, Gladstone, Wright, & Cooper, 2003; Timko et al., 2008).

The variability in levels of perceived discrimination as experienced by children affected by HIV and their HIV-positive caregivers' experience of stigma across communities in Haiti's central plateau, suggests that stigma in the context of HIV is not a "constant" and can be affected by the broader environment. Interventions that serve to reduce community-wide stigma of HIV need to be explored as they may improve the quality of life of HIV-affected families and promote prevention of transmission as well (McCoy, Malow, Edwards, Thurland, & Rosenberg, 2007).

Given that educational initiatives have shown promise in reducing HIV/AIDS-related stigma (Barss et al., 2009; Fawole, Asuzu, Oduntan, & Brieger, 1999) and the high prevalence of perceived stigma reported in our study, these tools may be useful components of future interventions. Based on the association between caregiver and child stigma, our results also suggest that a family oriented approach to HIV-related services may be appropriate. In addition, findings regarding children who lack support or who considered themselves orphaned may also be important for program development. Public health interventions to address stigma and discrimination among children affected by HIV/AIDS and their HIV-positive caregivers may involve enhancing social support for youth, particularly by peers and supportive adults. Addressing the stigma and social isolation that surround HIV in high prevalence settings can have a potential impact on preventing HIV and stemming the tide of the epidemic (Ehiri et al., 2005; Kaplan et al., 2005). In addition, given the strong connection between parental depressive symptoms and HIV/AIDS stigma, these and future findings can help inform psychosocial interventions for children and their caregivers affected by HIV/AIDS in Haiti.

There are a number of limitations in the present study. First, the cross-sectional design prohibits causal inference in terms of the direction of associations. In addition, caregivers were asked about discrimination toward children affected by HIV generally, rather than being asked about their own children. Although this approach has disadvantages, asking the question in this manner may have fostered more valid answers by reducing the possibility

that a caregiver may wish to report socially desirable responses when referring to his/her own children. The results were also limited in terms of generalizability to the community, since this was a clinic-based study. Questions were also based on self-report rather than observed acts of discrimination. Due to concerns that some parents had about the potential of a negative impact on their children (both psychologically for the youth as well as the experience of HIV-related stigma at school and in the community), many of the caregivers had not disclosed their HIV/AIDS status to their children. Therefore, we did not use information about discrimination reported directly by children. Future research is needed to confirm these findings and appropriate randomized intervention studies would need to be implemented to identify if the suggested strategies may reduce the burden of HIV-related stigma and discrimination. However, if the results are confirmed, it could suggest some possible avenues for reducing HIV-related stigma and discrimination among children affected by HIV/AIDS and HIV-positive caregivers.

In summary, HIV-related stigma is not necessarily given in high HIV burden settings. Although further study is needed to determine causality, strategies to address this stigma may include offering interventions addressing community-based stigma, reducing disability associated with HIV through adequate access to treatment, enhancing social and caregiving support for youth affected by HIV, and reducing the level of depression among HIV-positive individuals.

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Table 1

Descriptive statistics for caregiver and child variables with parental report of discrimination toward children with HIV/AIDS.

	Child's discrimination, as reported by the parent (<i>N</i> = 451)		
	Overall number (%)	Report of "Yes" for discrimination number (%)	<i>p</i> -Value – χ^2 test
Whole sample	451 (100)	146 (32.4)	
Caregiver gender			
Female	325 (72.1)	114 (35.1)	0.05
Male	126 (27.9)	32 (25.4)	
Marital status			
Married/with a partner	282 (58.0)	77 (29.0)	0.08
Single	61 (12.6)	19 (31.7)	
Separated/widowed	143 (29.4)	50 (40.3)	
Caregiver schooling in years			
≤ 3	247 (54.8)	82 (33.2)	0.28
4–6	108 (23.9)	39 (36.1)	
≥ 7	96 (21.3)	25 (26.4)	
Caregiver age			
≤ 29	42 (9.4)	11 (26.2)	0.17
30–39	198 (44.2)	73 (36.9)	
40–49	151 (33.7)	47 (31.1)	
≥ 50	57 (12.7)	13 (22.8)	
Household income (gouds/month)			
0–250	76 (16.9)	20 (26.3)	0.02
251–750	63 (14.0)	14 (22.2)	
751–1500	69 (15.4)	18 (26.1)	
1501–2000	45 (10.0)	14 (31.1)	
> 2000	121 (27.0)	46 (38.0)	
Don't know	75 (16.7)	34 (45.3)	
Commune			
Belladere	55 (12.2)	15 (27.3)	<0.001
Boucan Carre	104 (23.1)	15 (14.4)	
Cange	79 (17.5)	36 (45.6)	
Hinche	91 (20.2)	21 (23.1)	
Lascohobas	56 (12.4)	31 (55.4)	
Thomonde	40 (8.9)	22 (55.0)	
Other	26 (5.8)	6 (23.1)	
Child gender			
Female	222 (49.4)	70 (31.5)	0.73
Male	227 (50.6)	75 (33.0)	
Child age			
10–12	211 (47.2)	70 (33.2)	0.12

Child's discrimination, as reported by the parent (<i>N</i> = 451)			
	Overall number (%)	Report of "Yes" for discrimination number (%)	<i>p</i> -Value – χ^2 test
13–15	156 (34.9)	55 (35.3)	
16–17	80 (17.9)	18 (22.5)	
Caregiver Berger Scale			
High (\geq median)	204 (49.8)	98 (48.0)	<0.0001
Low (< median)	206 (50.2)	35 (17.0)	
Child confidant			
No	102 (22.7)	40 (39.2)	0.09
Yes	347 (77.3)	105 (30.3)	
Child number of friends			
No friends	19 (4.2)	7 (36.8)	0.66
One or more	428 (95.8)	137 (32.0)	
Child support ^a			
No confidant nor friend	18 (4.0)	4 (22.2)	0.14
Friend or confidant	83 (18.6)	22 (27.9)	
Both confidant and friend	364 (77.4)	59 (18.0)	
Child considers himself/herself an orphan			
Yes orphan	247 (55.0)	99 (40.1)	
No	47 (10.5)	13 (27.7)	0.0004
Not orphan, both parents alive	155 (34.5)	33 (21.3)	

^aThis measure combines whether the child has a confidant (yes, no) with the child's number of friends (one or more friends, no friends).

Note: Because of missing values on independent variables not all numbers in Column 1 add up to 451.

Table 2

Multivariable models for associations between family characteristics and caregiver report of discrimination toward children affected by HIV/AIDS (odds of caregivers report “yes” that children affected by HIV/AIDS are discriminated against).

	OR (95% CI)	OR (95% CI)	OR (95% CI)	OR (95% CI)	OR (95% CI)
Child gender					
Female	1.0 (0.9, 1.2)	1.0 (0.8, 1.2)	1.0 (0.9, 1.2)	1.0 (0.8, 1.2)	1.0 (0.8, 1.2)
Male	1.0	1.0	1.0	1.0	1.0
Child age					
10–12	1.2 (0.9, 1.5)	1.1 (0.9, 1.4)	1.2 (0.9, 1.5)	1.1 (0.9, 1.4)	1.1 (0.9, 1.5)
13–15	1.3 (1.0, 1.8)	1.3 (1.0, 1.7)	1.4 (1.0, 1.8)	1.3 (1.0, 1.7)	1.3 (1.0, 1.7)
16–17	1.0	1.0	1.0	1.0	1.0
Caregiver gender					
Female	1.2 (0.6, 2.4)	1.2 (0.6, 2.3)	1.2 (0.6, 2.3)	1.2 (0.6, 2.3)	1.1 (0.6, 2.2)
Male	1.0	1.0	1.0	1.0	1.0
Marital status					
Separated/widowed	1.4 (0.8, 2.4)	1.3 (0.8, 2.4)	1.3 (0.7, 2.3)	1.3 (0.7, 2.3)	1.3 (0.7, 2.3)
Single	1.6 (0.7, 3.6)	1.7 (0.8, 3.9)	1.6 (0.7, 3.7)	1.8 (0.8, 4.0)	1.8 (0.8, 4.1)
Married or with partner	1.00	1.0	1.0	1.0	1.0
Caregiver education					
≤ 3	1.6 (0.9, 3.0)	1.6 (0.9, 3.0)	1.6 (0.9, 3.1)	1.6 (0.9, 3.1)	1.6 (0.8, 3.0)
4–6	2.6 (1.2, 5.5)	2.6 (1.2, 5.6)	2.6 (1.2, 5.4)	2.6 (1.2, 5.6)	2.6 (1.2, 5.5)
≥ 7	1.0	1.0	1.0	1.0	1.0
Caregiver age					
≤ 29	2.3 (0.7, 7.8)	2.3 (0.7, 7.7)	2.3 (0.7, 7.7)	2.3 (0.7, 7.7)	2.3 (0.7, 8.0)
30–39	3.3 (1.2, 8.9)	3.4 (1.3, 9.3)	3.3 (1.2, 8.8)	3.4 (1.3, 9.1)	3.4 (1.3, 9.4)
40–49	2.7 (1.0, 7.3)	2.7 (1.0, 7.3)	2.7 (1.0, 7.2)	2.7 (1.0, 7.2)	2.7 (1.0, 7.3)
≥ 50	1.0	1.0	1.0	1.0	1.0
Household income (gouds/month)					
0–250	1.0	1.0	1.0	1.0	1.0
251–750	0.9 (0.3, 2.3)	0.8 (0.3, 2.1)	0.9 (0.3, 2.3)	0.8 (0.3, 2.1)	0.9 (0.3, 2.3)
751–1500	0.8 (0.3, 2.1)	0.7 (0.3, 1.8)	0.7 (0.3, 2.1)	0.7 (0.3, 1.8)	0.7 (0.3, 1.9)
1501–2000	1.1 (0.4, 3.2)	1.0 (0.4, 2.9)	1.1 (0.4, 3.3)	1.0 (0.4, 2.9)	1.1 (0.4, 3.1)

	OR (95% CI)	OR (95% CI)	OR (95% CI)	OR (95% CI)	OR (95% CI)
> 2000	1.7 (0.7, 4.1)	1.5 (0.6, 3.6)	1.7 (0.7, 4.3)	1.6 (0.6, 3.8)	1.7 (0.7, 4.2)
Don't know	2.9 (1.2, 6.7)	2.6 (1.2, 5.9)	2.9 (1.2, 7.0)	2.7 (1.2, 6.1)	2.7 (1.2, 6.4)
Commune					
Belladere	2.9 (0.9, 9.1)	2.9 (0.9, 9.0)	3.0 (1.0, 9.6)	3.0 (1.0, 9.2)	3.3 (1.0, 10.8)
Cange	5.4 (2.1, 14.0)	5.6 (2.1, 14.5)	5.0 (1.9, 13.0)	5.2 (2.0, 13.6)	5.8 (2.1, 15.5)
Hinche	2.1 (0.7, 6.1)	1.8 (0.6, 5.4)	2.2 (0.8, 6.2)	1.9 (0.6, 5.5)	2.0 (0.7, 6.2)
Laschobas	8.1 (2.9, 22.5)	8.4 (3.0, 23.2)	7.5 (2.7, 21.0)	7.8 (2.8, 21.8)	8.8 (3.0, 25.6)
Thomonde	9.1 (2.5, 32.3)	8.4 (2.3, 30.6)	9.6 (2.7, 34.4)	8.9 (2.4, 32.5)	8.9 (2.4, 32.9)
Other	1.8 (0.5, 7.0)	1.5 (0.4, 6.2)	1.9 (0.5, 7.3)	1.5 (0.4, 6.4)	1.7 (0.4, 7.0)
Boucan Carre	1.0	1.0	1.0	1.0	1.0
Berger Stigma Scale					
High (\geq median)	4.4 (2.6, 7.4)	4.4 (2.7, 7.4)	4.5 (2.6, 7.6)	4.5 (2.7, 7.6)	4.4 (2.6, 7.4)
Low (< median)	1.0	1.0	1.0	1.0	1.0
Child support ^d					
No confidant nor friend	-	1.8 (0.9, 3.5)	-	1.8 (0.9, 3.6)	1.9 (0.9, 3.7)
Friend or confidant	-	1.2 (0.9, 1.7)	-	1.2 (0.9, 1.7)	1.2 (0.9, 1.7)
Both confidant and friend		1.0		1.0	1.0
Child considers himself/herself an orphan					
Yes			1.4 (1.0, 1.8)	1.3 (1.0, 1.7)	1.4 (1.0, 1.8)
No			1.2 (0.7, 2.2)	1.2 (0.7, 2.0)	1.2 (0.7, 2.1)
No, mother or father alive			1.0	1.0	1.0
Hopkins Symptom Checklist (depressive symptoms)					
High quartile	-	-	-	-	1.4 (0.7, 2.6)
Lowest three quartiles	-	-	-	-	1.0

^dThis measure combines whether the child has a confidant (yes, no) with the child's number of friends (one or more friends, no friends).

Table 3

Descriptive statistics for demographic, support, and health variables in relation to stigma of parents affected by HIV/ AIDS.

	Berger scale – parental stigma (N = 292)		
	Number (%)	Mean Berger Score (SD)	p-Value (ANOVA or t-test)
Overall	292 (100)	44.8 (12.1)	
Caregiver gender			
Female	215 (73.6)	46.0 (12.0)	0.007
Male	77 (26.4)	41.6 (12.1)	
Marital status			
Married/with a partner	162 (55.7)	45.2 (12.6)	0.19
Single	43 (14.8)	41.7 (11.5)	
Separated/widowed	86 (29.5)	45.6 (11.3)	
Parent schooling in years			
≤ 3	171 (58.6)	46.6 (11.6)	0.006
4–6	66 (22.6)	41.1 (11.8)	
≥ 7	55 (18.8)	43.8 (13.1)	
Parent age			
≤ 29	29 (9.9)	44.8 (11.4)	0.18
30–39	134 (45.9)	46.2 (12.5)	
40–49	93 (31.8)	44.3 (12.5)	
≥ 50	36 (12.3)	41.3 (9.7)	
Household income (gouds/month)			
0–250	54 (18.6)	44.9 (13.7)	0.25
251–750	37 (12.8)	45.6 (10.4)	
751–1500	51 (17.6)	45.0 (10.8)	
1501–2000	24 (8.3)	50.2 (13.3)	
> 2000	71 (24.5)	44.1 (11.4)	
Don't know	53 (18.2)	42.8 (12.9)	
Commune			
Belladere	35 (12.0)	50.5 (14.4)	<0.0001
Boucan Carre	62 (21.2)	46.2 (11.0)	
Cange	53 (18.2)	48.1 (8.3)	
Hinche	60 (20.6)	37.0 (11.7)	
Lascohobas	43 (14.7)	47.4 (11.4)	
Thomonde	23 (7.9)	43.0 (13.2)	
Other	16 (5.5)	41.3 (9.5)	
Someone to provide support for money			
No	169 (57.9)	45.6 (12.8)	0.23
Yes	123 (42.1)	43.8 (11.2)	
Someone to provide support for someplace to stay			
No	126 (43.2)	44.5 (13.1)	0.71

Berger scale – parental stigma (<i>N</i> = 292)			
	Number (%)	Mean Berger Score (SD)	<i>p</i> -Value (ANOVA or <i>t</i> -test)
Yes	166 (57.8)	45.1 (11.4)	
Caregiver has a confidant			
No	118 (40.1)	43.7 (12.7)	0.18
Yes	174 (59.6)	45.6 (11.7)	
Combined caregiver support ^a			
No support	51 (17.5)	43.3 (12.8)	0.60
One support item	87 (29.8)	46.1 (13.4)	
Two support items	86 (29.5)	44.5 (11.5)	
Support on all three items	68 (23.3)	44.8 (10.5)	
Health keeps from working			
No	127 (43.5)	41.9 (10.6)	0.001
Yes, some of the time	122 (41.8)	46.6 (12.4)	
Yes, all the time	43 (14.7)	48.5 (13.8)	
Unable to do some of work because of health			
No	113 (38.7)	42.2 (10.5)	0.002
Yes, some of the time	142 (48.6)	45.7 (12.8)	
Yes, all the time	37 (12.7)	49.8 (12.8)	
Hopkins Symptom Checklist (depressive symptoms)			
High quartile	68 (23.3)	53.1 (11.2)	<0.0001
Lowest three quartiles	224 (76.7)	42.3 (11.3)	

^aThis item combines three social support questions: caregiver support for money (yes/no); a place to stay (yes/no); and having a confidant (yes/no).

Note: Because of missing values on independent variables, not all numbers in Column 1 add to 292.

Table 4

Multivariable linear regression models for demographic and other variables associated with parental self-reported discrimination on the Berger Stigma Scales.

	Mean difference (95% CI)	Mean difference (95% CI)	Mean difference (95% CI)	Mean difference (95% CI)	Mean difference (95% CI)	Mean difference (95% CI)
Caregiver gender						
Female	2.9 (-0.4, 6.2)	2.9 (-0.5, 6.3)	3.9 (0.6, 7.1)	3.6 (0.3, 6.9)	0.9 (-2.2, 4.0)	1.4 (-1.8, 4.7)
Male	(reference)	(reference)	(reference)	(reference)	(reference)	(reference)
Marital status						
Married/with a partner	(reference)	(reference)	(reference)	(reference)	(reference)	(reference)
Single	-0.6 (-5.1, 3.9)	-0.6 (-5.1, 4.0)	0.1 (-4.3, 4.6)	-0.6 (-5.0, 3.8)	0.6 (-3.6, 4.8)	0.8(-3.4, 5.0)
Separated/widowed	-0.7 (-3.8, 2.4)	-0.8 (-3.9, 2.4)	-0.7 (-3.8, 2.3)	-1.0 (-4.0, 2.1)	-0.7 (-3.5, 2.2)	-1.1 (-3.9, 1.8)
Caregiver education (years)						
≤ 3	1.3 (-2.3, 4.9)	1.7 (-2.0, 5.3)	0.9 (-2.6, 4.5)	0.9 (-2.7, 4.5)	0.1 (-3.3, 3.5)	-0.5 (-3.4, 3.5)
4-6	-1.0 (-5.2, 3.2)	-1.0 (-5.2, 3.3)	-1.4 (-5.5, 2.8)	-1.1 (-5.3, 3.0)	-1.0 (-4.9, 2.9)	-1.8 (-5.7, 2.1)
≥ 7	(reference)	(reference)	(reference)	(reference)	(reference)	(reference)
Caregiver age (years)						
≤ 29	2.6 (-3.3, 8.6)	2.2 (-3.8, 8.3)	2.2 (-3.6, 8.1)	3.0 (-2.9, 8.8)	4.5 (-1.0, 10.1)	4.0 (-1.5, 9.5)
30-39	5.0 (0.3, 9.5)	5.0 (0.4, 9.6)	4.7 (0.2, 9.2)	5.0 (0.5, 9.5)	5.6 (1.3, 9.8)	4.9 (0.7, 9.1)
40-49	4.0 (-0.6, 8.6)	4.2 (-0.4, 8.8)	3.5 (-1.0, 7.9)	3.9 (-0.6, 8.4)	4.1 (-0.1, 8.4)	3.4 (-0.8, 7.6)
≥ 50	(reference)	(reference)	(reference)	(reference)	(reference)	(reference)
Household income (gouds/month)						
0-250	(reference)	(reference)	(reference)	(reference)	(reference)	(reference)
251-750	0.5 (-4.6, 5.6)	0.9 (-4.3, 6.0)	-0.5 (-5.5, 4.5)	-0.5 (-5.5, 4.6)	2.6 (-2.1, 7.4)	1.5 (-3.3, 6.2)
751-1500	-1.2 (-5.9, 3.5)	-0.7 (-5.5, 4.1)	-1.8 (-6.4, 2.8)	-2.1 (-6.8, 2.5)	0.3 (-4.1, 4.7)	0.2 (-4.3, 4.6)
1501-2000	4.7 (-1.0, 10.4)	5.3 (-0.4, 11.1)	5.9 (0.3, 11.5)	5.3 (-0.3, 10.9)	5.3 (0.04, 10.6)	5.4 (0.1, 10.7)
> 2000	-1.9 (-6.5, 2.6)	-1.7 (-6.3, 2.8)	-1.8 (-6.3, 2.6)	-2.2(-6.7, 2.2)	-0.4 (-4.7, 3.8)	-0.2 (-4.4, 4.0)
Don't know	0.9 (-3.9, 5.7)	1.5 (-3.4, 6.3)	0.4 (-4.3, 5.0)	0.3 (-4.4, 5.0)	1.7 (-2.7, 6.1)	1.6 (-2.8, 6.1)
Commune						
Belladere	2.8 (-2.3, 7.8)	2.7 (-2.4, 7.9)	1.9 (-3.1, 6.8)	2.2 (-2.8, 7.1)	5.9 (1.2, 10.7)	4.9 (0.1, 9.8)
Cange	2.8 (-1.5, 7.1)	2.9 (-1.5, 7.3)	3.1 (-1.1, 7.4)	3.4 (-0.8, 7.7)	6.2 (2.1, 10.3)	6.0 (1.8, 10.1)
Hinche	-9.6 (-14.3, -4.9)	-9.7 (-14.6, -4.8)	-9.3 (-13.8, -4.7)	-9.2 (-13.8, -4.6)	-6.2 (-10.6, -1.8)	-6.6 (-11.2, -2.0)

	Mean difference (95% CI)	Mean difference (95% CI)	Mean difference (95% CI)	Mean difference (95% CI)	Mean difference (95% CI)	Mean difference (95% CI)
Laschobas	0.4 (-4.2, 5.1)	1.1 (-3.6, 5.9)	1.9 (-3.1, 6.8)	2.2 (-2.5, 6.8)	4.4 (-0.03, 8.9)	5.7 (1.1, 10.2)
Thomonde	-2.4 (-8.1, 3.3)	-1.6 (-7.5, 4.2)	-2.7 (-8.2, 2.9)	-2.8 (-8.4, 2.9)	-3.1 (-8.4, 2.1)	-2.1 (-8.3, 4.1)
Other	-4.8 (-11.4, 1.8)	-5.1 (-11.9, 1.7)	-4.2 (-10.7, 2.3)	-4.1 (-10.6, 2.4)	-2.0 (-8.2, 4.2)	-2.6 (-8.1, 2.9)
Boucan Carre	(reference)	(reference)	(reference)	(reference)	(reference)	(reference)
Combined caregiver support ^a						
No support		1.0 (-3.6, 5.6)	-	-	-	1.4 (-2.9, 5.6)
One type of support		0.9 (-3.0, 4.8)	-	-	-	2.4 (-1.3, 6.0)
Two types of support		-1.9 (-5.8, 2.0)	-	-	-	0.1 (-3.5, 3.7)
Support on all three		(reference)				(reference)
Health keeps from working						
No			(reference)			(reference)
Yes, some of the time			5.2 (2.3, 8.1)			3.2 (-1.2, 7.5)
Yes, all the time			6.7 (2.6, 10.8)			1.9 (-4.7, 8.4)
Unable to do some of work because of health						
No				(reference)		(reference)
Yes, sometimes				4.8 (1.9, 7.7)		0.8 (-3.5, 5.2)
Yes, always				6.8 (2.4, 11.1)		2.6 (-4.3, 9.6)
Hopkins Symptom Checklist (depressive symptoms)						
High quartile					11.2 (8.0, 14.4)	10.0 (6.7, 13.4)
Lowest three quartiles					(reference)	(reference)

^aThis item combines three social support questions: caregiver support for money (yes/no); a place to stay (yes/no); and having a confidant (yes/no).