

## Brief report

# Depression in Caregivers of Status-Naïve Pediatric HIV Patients Participating in a Status Disclosure Study in Haiti and the Dominican Republic: Preliminary Report

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## Summary

A pilot study is underway to assess safety and acceptability of an intervention to disclose their HIV infection status to status-naïve pediatric antiretroviral therapy patients in Hispaniola [the island shared by Haiti and the Dominican Republic (DR)]. Of 22 Haiti and 47 DR caregivers recruited to date, 68.2% Haiti and 34.0% DR caregivers had clinically significant depressive symptomatology at the time of enrollment ( $p = 0.008$ ). Depressive symptom prevalence was higher in Haiti caregivers who were female (81.3% vs. 0 in males;  $p = 0.02$ ) and in DR caregivers who were patients' mothers (50.0%) or grandmothers (66.7%; 56.0% combined) than others (9.1%), ( $p < 0.001$ ). Internalized stigma was more commonly reported by Haiti (85.7%) than DR (53.2%;  $p = 0.01$ ) caregivers; 56.4% of Haiti and DR caregivers reporting internalized stigma vs. 26.1% of caregivers denying it had depressive symptoms ( $p = 0.02$ ). Depression is common in Hispaniola caregivers possibly affecting disclosure timing. Study participation presents opportunities for addressing caregiver depression.

**Key words:** HIV, disclosure, antiretroviral therapy, depression, caregivers, mother-to-child transmission.

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## Introduction

Second to sub-Saharan Africa, the Caribbean has the highest HIV prevalence worldwide [1]. Of 16000 HIV-infected children in the Caribbean, most live in Hispaniola, the island shared by Haiti [12000 (75%)] [1–3] and the Dominican Republic (DR) (approximately 10%). Another 15% live in other Caribbean nations. Reportedly, 2265 children in Haiti and 1083 in the DR receive antiretroviral therapy (ART) [1]. ART has transformed perinatally

acquired HIV infection from a disease with high childhood mortality to one which may be consistent with survival into adulthood in industrialized and low- and middle-income countries, including Haiti and the DR [4–7]. Most HIV-infected pediatric patients worldwide do not know their status [8, 9]. An intervention to prepare HIV-infected children and their caregivers for disclosure developed in Puerto Rico [10, 11] is being pilot tested in Haiti and the DR. We reviewed completed enrollment assessments to describe depression in caregivers of status-naïve pediatric ART patients in Hispaniola.

### Methods

The study is underway in three facilities (two in the DR and one in Haiti) where over 40% of the DR's and Port-au-Prince, Haiti's pediatric ART patients are treated (Unpublished data, 2013: Ministry of Health, Santo Domingo, DR; Haitian Group for the Study of Kaposi's Sarcoma and Opportunistic Infections, Port-au-Prince, Haiti). Patient-caregiver pairs are eligible for study participation if the patient is aged 10–18 years, status naïve, receiving ART in a participating clinic and with a caregiver aged 18 years or older, if neither child nor caregiver is acutely ill or severely cognitively impaired. Caregivers whose children meet inclusion criteria are invited privately during routine visits to hear about the study. Questionnaires administered verbally to caregivers include the Center for Epidemiologic Studies Depression Scale-20 [12], a 20-item scale for detection of clinically significant depressive symptomatology, the Food Insecurity Two-Question Screening Test [13] and an adapted HIV Stigma and Discrimination Index [14–16].

### Results

The study began in Haiti 7 months after beginning in the DR. Of 50 Haiti and 64 DR eligible caregivers invited to participate to date, 48 (96.0%) Haiti

and 55 (85.9%) DR caregivers accepted ( $p=0.07$ ; Table 1). Complete enrollment data available for 22 Haiti and 47 DR caregivers (total=69) showed that 15 (68.2%) Haiti and 16 (34.0%) DR caregivers had clinically significant depression symptoms ( $p=0.008$ ), higher than normative populations (15–19% [12];  $p<0.01$ ). Most caregivers (86.4%, Haiti; 87.2%, DR) were female, ranging in age from 18 to 73 years (medians=41.7 and 38.5 years, respectively). All 22 Haiti and 78.7% DR caregivers reported food insecurity ( $p=0.03$ ).

Depressive symptom prevalence did not vary significantly by children's age or sex, or caregivers' age, HIV status, food insecurity or household income in either country. However, depressive symptom prevalence was higher among Haiti female than male caregivers (81.3% vs. 0;  $p=0.02$ ). Haiti mothers were more likely to report depressive symptomatology than other Haiti caregivers, but this difference was not significant (80.0 vs. 58.3%;  $p=0.26$ ). Single Haiti caregivers were more likely than married or cohabiting counterparts to have depressive symptomatology [9/10 (90.0%) vs. 6/12 (50.0%);  $p=0.058$ ].

In contrast, DR married or cohabiting caregivers were more likely to have depressive symptoms [11/21 (52.4%)] than those who were single [5/26 (19.2%);  $p=0.02$ ]. Depression symptom prevalence was higher among DR caregivers who were patients' mothers [8/16 (50.0%)] or grandmothers [6/9 (66.7%); 14/25 (56.0%) combined] than other DR caregivers [2/22 (9.1%)  $p<0.001$ ].

In both countries, internalized stigma was more common than external stigma and discrimination; both were more commonly reported by Haiti caregivers (85.7% internalized, 71.4% external) than DR caregivers [53.2% internalized ( $p=0.01$ ); 47.8% external ( $p=0.07$ )] (Table 1). Internalized HIV-related stigma did not vary significantly by HIV status in Haiti caregivers; 85.7% of HIV-infected and 80.0% of uninfected caregivers reported internalized stigma. Among DR caregivers, however, internalized stigma

TABLE 1

*Comparison by country of caregivers invited to participate in the pilot study of disclosure of their status to HIV-infected youth in Haiti and the Dominican Republic (DR)*

Characteristic	Haiti n/N* (%)	DR n/N* (%)	Prevalence ratio (95% confidence interval)	<i>p</i>
Agreed to study participation	48/50 (96.0)	55/64 (85.9)	1.1 (1.0, 1.3)	0.07
Clinically significant depressive symptoms	15/22 (68.2)	16/47 (34.0)	2.0 (1.2, 3.3)	0.008
Reported food insecurity	22/22 (100)	37/47 (78.7)	1.3 (1.1, 1.5)	0.03
Reported internalized stigma	18/21 (85.7)	25/47 (53.2)	1.6 (1.2, 2.2)	0.01
Reported external stigma	15/21 (71.4)	22/46 (47.8)	1.5 (1.0, 2.2)	0.07

\*n/N: Number of caregivers with the characteristic divided by total number of caregivers assessed for each characteristic. Enrollment data were only available for 22 of the Haiti and 47 of the DR caregivers who agreed to participate to date. Not all caregivers for whom there were enrollment data answered all questions.

varied by caregiver HIV-infection status; 70.0% of DR HIV-infected vs. only 33.0% of uninfected caregivers reported internalized stigma ( $p=0.02$ ).

Only internalized stigma was associated with significantly greater risk of depressive symptomatology. In both countries combined, 56.4% of caregivers reporting internalized stigma (vs. 26.1% of caregivers denying it) had depressive symptoms ( $p=0.02$ ). Suicidal ideation was more common among (but not exclusive to) caregivers with significant depressive symptomatology (25.9%) compared with those without depressive symptomatology (6.7%;  $p=0.046$ ).

### Discussion

Depressive symptomatology, external and internalized stigma and discrimination and food insecurity were common among Haiti and DR caregivers; all were more common among Haiti caregivers. Based on previous research in Hispaniola [15, 17–22], we anticipated that depression symptoms and victimization related to HIV-related stigma would be high among HIV-infected caregivers, particularly mothers. Depression in mothers is often associated with poor outcomes in their children [23]. In HIV-infected mothers, it has been linked with increased risk of behavioral problems in their children [24]. In both countries, internalized stigma was more common than overt, externalized discrimination and was associated with depression, as expected [15, 17–22].

However, the high prevalence of internalized stigma reported by HIV-uninfected Haiti caregivers and of depression symptoms in mostly HIV-uninfected DR grandmothers and caregivers with live-in partners was unexpected. Society-wide HIV-related stigma in urban Haiti remains a persistent, formidable problem, despite progress in rural areas [25, 26], impacting even uninfected caregivers. Individual-level interventions to combat HIV-related stigma are the most commonly pursued worldwide, and are essential to youth's preparation for disclosure [18, 27, 28]. However, it is essential to recognize that addressing societal, community and health-care facility factors that reinforce caregivers' internalized stigma are essential to HIV-infected children's survival worldwide [29–30]. It is also impossible to exaggerate the burden that food insecurity places on caregivers, and the role that food assistance can play in promoting ART adherence and response and well-being in HIV-affected families [31, 32].

Worldwide, grandmothers are primary caregivers of millions of HIV-affected youth. Yet few studies [33–36] have explored what must be a profoundly traumatic experience for a parent: enduring the death or severe stigmatized illness of her child, while assuming responsibility for similarly stricken grandchildren. Moreover, protective health effects

of marriage reported in men are not consistently observed in women; unsupportive live-in relationships may be more stressful to women than living alone [37, 38].

Our data suggest that depression in Hispaniola caregivers may be common. Severe caregiver depression should delay disclosure [10]. Disclosure study participation presents opportunities for assessing and responding to caregivers' needs, which remain largely unaddressed [39–43].

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