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Disclosure of their Status to Youth with Human Immunodeficiency Virus Infection in the Dominican Republic: A Mixed-Methods Study

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Abstract

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A mixed-methods study was conducted to determine the proportion of HIV-infected children who knew their status, identify characteristics associated with children's knowledge of their status, and describe caregivers' and adolescents' experiences relevant to disclosure in the Dominican Republic (DR). Of 327 patients aged 6–18 years treated in the principal DR pediatric HIV facilities, 74 (22.6%) knew their status. Patients aged 13 years or older and/or who had participated in non-clinical activities for HIV-infected children were more likely to know their status. Caregivers who had disclosed cited healthcare providers' advice, children's desire to know and concerns that children might initiate sexual activity before knowing or discover their status by accidental or malicious disclosure. Non-disclosing caregivers worried that children would be traumatized by disclosure and/or stigmatized if they revealed it to others. Adolescents supported disclosure by 10–12 years of age, considered withholding of children's HIV diagnosis ill-advised, and recommended a disclosure process focused initially on promoting non-stigmatizing attitudes about HIV.

INTRODUCTION

Of the estimated 35.3 million people worldwide living with HIV/AIDS in 2012, 3.3 million were children under 15 years of age [1, 2]. After Sub-Saharan Africa, the Caribbean is the second most HIV-impacted region in the world [1–3]. Approximately 24% of the 61,000 people with HIV infection in the Caribbean live in the Dominican Republic (DR). As combination antiretroviral therapy (ART) has become more readily available worldwide since 2003, including in low- and middle-income countries (LMICs) like the DR, pediatric patients not expected to survive childhood now often reach adulthood [4,5]. Increased survival makes disclosure of their status to HIV-infected youth particularly important, and has been recommended for over a decade worldwide [6, 7]. Eventual transition to effective self-management, adult care and preventive behaviors requires that HIV-infected youth learn their status.

Yet most HIV-infected children do not know their status; youth living in LMICs are even less likely to know than those in industrialized countries [8–10]. Most have received either no information or deceptive information. Little is known about patterns of disclosure to HIV-infected children in Caribbean LMICs. Previous studies in other LMICs have found that caregivers are reluctant to disclose their diagnosis to HIV-infected youth because they fear it may adversely affect the child emotionally or require skills caregivers do not feel they possess [8,9,11–15]. Of 31 HIV-infected youth receiving treatment in 2002 (before ART introduction in the DR's principal children's hospital, Robert Reid Cabral Children's Hospital [CCH]), only 5 knew their status [16].

The only theory- and evidence-based intervention published before 2013 to support disclosure of their status to HIV-infected children was developed in Puerto Rico by Blasini *et al* [17]. We proposed to adapt this intervention and pilot it in the first binational (Haiti and DR) pediatric HIV study funded by the National Institutes of Health [18]. To estimate the number and proportion of ART patients who did not know their status and were thus eligible for study participation, inform the process of intervention adaptation and explore the disclosure experience in the DR, a mixed-methods study was conducted. Proportion of ART

patients who did not know their status and characteristics associated with status knowledge were assessed by quantitative data analysis. Focus groups were conducted to explore disclosure experiences, preferences and insights of youth and caregivers.

METHODS

Population

Anonymized data were obtained in two HIV comprehensive care pediatric clinics (CCH, in Santo Domingo, and Clinica de Familia La Romana [CDF] in 2011. These clinics have provided comprehensive care including ART since 2004 to the hundreds of HIV-infected children in the DR. Of the 1,386 pediatric patients receiving care through the Ministry of Health's programs in 2011, 559 (40.3%) were enrolled in these two centers; 517 (92.5%) received ART (DR Ministry of Health). Data were abstracted from medical and other clinic records of patients aged 6–18 years or obtained from their caregivers by clinic pediatricians. Data included gender, age, community or institutional residence, route of infection, ART use, knowledge of HIV infection status and participation in non-clinical activities for HIV-infected children. Data were collected using standardized data-abstraction forms in 2011 in CDF or CCH clinic record rooms or examining rooms by CDF or CCH staff.

Disclosure of their HIV status to minors without caregiver consent in the DR is limited to specific circumstances [19]; accidental disclosure is strongly discouraged. Whether patients know their status is relevant to many patient care encounters. Therefore, clinic personnel and caregivers regularly document whether children know their diagnosis. Information regarding participation in non-clinical activities for HIV-infected children was also documented and available to clinic pediatricians.

Medical Record Data Analysis

Abstracted data were anonymized by clinic personnel and provided to FIU researchers, who entered and analyzed the data using Epi Info for Windows 3.5.4 (Atlanta, GA, 2011) [20]. Strength of associations was determined using prevalence ratios (PRs) as estimates of relative risk. Chi-square or Fisher's exact two-tailed tests ($\alpha=0.05$) were used to determine whether differences were statistically significant; 95% confidence intervals (CIs) were calculated to assess precision of prevalence estimates and PRs. Stratified analyses were conducted to control for confounding. Breslow-Day Chi-square tests were used to ascertain whether PRs differed significantly by stratum.

Focus Groups

Settings—During 2012, four focus groups of 6–10 participants each were conducted with adolescents aged 12–19 years of age who knew their status (two in CDF with participants of both sexes and one each in CCH of boys and girls) after parental consent and participant assent were obtained. Four focus groups were conducted with caregivers of youth who knew (2) and caregivers of youth who did not know their status (2). Youth and caregivers were invited to participate in focus groups when they awaited appointments or medications or at support groups in CDF and CCH. Youth aged 12–19 years who knew their status and were enrolled in either clinic were eligible to participate in focus groups. The criteria for caregiver

focus group participation were being the primary caregiver for a child with HIV infection aged 6–17 years enrolled in either clinic, and being at least 18 years old. Caregivers included family and non-family members. Caregiver focus groups were scheduled for weekends and did not coincide with other activities. Youth focus groups were scheduled on the same days, but were independent of, support groups. Focus groups took place in conference or meeting rooms at the clinics.

Data Collection—The focus groups were conducted by MCP-I, a pediatrician experienced in focus group facilitation who had never met any of the caregivers or youth. A guide was prepared for the focus group with open-ended questions (Appendix) customized according to participant type (adolescent, caregiver of patient who knew, etc.). The guide explained the focus group purpose, how to participate, ground rules and procedures to ensure confidentiality. Questions for discussion explored advantages and disadvantages of disclosure of their status to HIV-infected children, the best age for disclosure, disclosure experiences, strategies and insights, and thoughts about the future of HIV-infected children. All groups were digitally recorded by an FIU note-taker who subsequently transcribed the entire recorded discussions verbatim. No clinic staff was present for the focus groups or permitted to hear any part of the digital recording. Limited demographic data were collected verbally by the facilitator prior to the focus group from all caregivers as most had less than seven years of education and struggled to read. Participation was by invitation, voluntary and not incentivized.

Qualitative Data Analysis Plan—Transcripts from focus groups were imported into NVivo (a qualitative data analysis program [QSR International Pty Ltd. Version 10, 2012]). Using grounded theory, thematic analysis was conducted for each focus group using open coding. Coders identified recurrent themes as they emerged from the data. Transcript data were analyzed by two Spanish-English bilingual coders who did not participate in the conduct of the focus group. Once transcripts had been coded independently by both coders, they met to compare categories and agree on the major themes. Disagreements were discussed until consensus was reached. The coding of the transcripts was finalized using the major themes. Coder agreement was assessed using the Kappa coefficient [21]; .85 or higher was considered an acceptable of agreement.

Human Participant in Research Protection

The Florida International University (FIU) Institutional Review Board (IRB) reported that the proposed analysis of anonymized clinic medical record data did not constitute human participant research. The focus group study component was approved by the FIU IRB. Informed consent and assent were obtained verbally. Caregivers and youth were given information forms about the study (including study explanation, risks, benefits and investigator and IRB contact information) which did not mention HIV, AIDS or any other potentially stigmatizing subject. These terms were replaced with the words “the chronic condition”.

RESULTS

Anonymous Data Analysis

Of 327 children aged 6–18 years enrolled in CCH and CDF whose data were abstracted, 182 (55.7%) were female; 326 received ART. Their mean age was 11.1 (SD±3.2, median=11) years; 118 (36.1%) were less than 10 years old, 91 (27.8%) were 10 to 12 years old, and 118 (36.1%) were 13 to 18 years old (adolescents). Most (322 [98.5%]) patients lived in the community with family and/or friends and five in orphanages; 320 (97.9%) had been infected perinatally and 104 (31.8%) had participated in non-clinical activities for children and adolescents with HIV infection. For 83 (81.4%) the non-clinical activity was a one-week sleepover camp for children with HIV, for 13 (12.7%), support groups, for 6 (5.9%), other types of meetings, and for one, a retreat.

Only 74 (22.6%; 95%CI=18.4–27.5%) knew their HIV infection status. Knowledge of status did not differ significantly by sex. Likelihood of knowing their status was over six times as high among adolescents (49.6%) than among younger patients (7.7%); PR=6.4; 95%CI=3.9–10.7, $p<.001$) (Appendix: Table 1). However, most adolescents (just over half [50.4%]) did not know their status. Patients who had participated in any non-clinical activities for HIV-infected children were over three times more likely to know their status (46.1%) than children who had never participated in these activities (12.1%; PR=3.8; 95%CI=2.5–5.7, $p<.001$). The proportion of CCH patients who knew their status (19.5%, Appendix, Table 1) did not differ significantly from the proportion reported in a 2002 study of CCH patients (16.1%) [16]. However, it was significantly lower than the proportion of CDF patients who knew their status (30.3%; PR=1.6; 95%CI=1.04–2.3; $p=.03$).

When stratified by age categories (adolescents vs. younger children [those aged less than 13 years]), participation in any non-clinical activity for HIV-infected children was significantly associated with status knowledge in both age categories (Appendix, Table 2). However, non-clinical activity participation was more strongly associated with status knowledge in younger patients. Children aged less than 13 years who had participated in non-clinical activities were almost six times more likely to know their status than counterparts who had not participated in such activities (PR=5.7; 95%CI=2.1–15.7, $p<.001$). In contrast, adolescents who had participated in such activities were 2.7 times more likely to know their status than other adolescents (95%CI=1.9, 4.0; $p<.001$). This difference in the strength of the association between non-clinical activity participation and status knowledge by age group did not achieve statistical significance ($p=.18$).

The strength of the association between camp participation and status knowledge was almost identical in adolescents (PR=1.7) and younger patients (PR=1.8) and was only statistically significant in adolescents. However, the associations between support group participation and status knowledge were significant in both age-groups and far stronger in younger patients (PR=15.7) than in adolescents (PR=2.3) ($p<.001$). Most CCH patients who had participated in a non-clinical activity had participated in support groups; most CDF non-clinical activity participants had been to camp. When controlled for the interaction between type of non-clinical activity and clinic, only age group and participation in any non-clinical activity remained significantly associated with status knowledge.

Focus Groups

Focus Group Participant Characteristics—Forty-one caregivers and 36 adolescents (90.2% and 62.9% female, respectively) participated in the focus groups in 2012. Median and modal ages of adolescent focus group participants at the time they learned their diagnosis were both 12 years. Fifteen (41%) lived with their grandmothers, 5 with fathers, 4 with mothers, 4 with both biological parents, and 8 with other relatives. Caregivers ranged in age from 23 to 66 years (median age=42 years). Caregivers of patients who did **not** know their status were more likely to be younger and more likely to be the patient's mother than caregivers of patients who knew their status (median ages=36 versus 48.5 years, $p=.02$; proportion who were the child's mother 55.0% versus 28.6%, $p=.09$). Most (21 [53.7%]) caregivers had 0–6 years of education. The rest had attended school from 7–13 years.

Focus Group Findings—Coders agreed on nine major recurrent themes: Worries, Social Stigma, Child's Reaction to Disclosure, Support, Adherence, Future Plans, Emotion and Outlook (Appendix). For the purposes of this study, we focused primarily on the Disclosure theme, which was most relevant to the questions: 1) what were the reasons for disclosure and non-disclosure (caregivers); and 2) what were the best ways to disclose (adolescents). The rate of coder agreement ($\kappa > .92$) was high.

Reasons for disclosure: Caregivers who had disclosed cited several reasons for having done so, and suggested that healthcare providers including psychologists played a major role in the decision to disclose. Some stated that the providers suggested when to disclose. Others received help from providers in the disclosure process:

“My [child] was in the camp and they gave a talk and told us that around 9 years old we had to tell and I took advantage of the moment and I told my [child] and she took it well.”

“Well, my daughter was already 12 years old, it was necessary that she know. I accepted the advice of a psychologist and she asked me if she could tell her and I said yes. I took her and she told her and she took it well.”

“My child (female) started to ask and was very persistent and I went to the counselor and she sent me to the psychologist. The two of us talked to her and the psychologist told her in my presence (at 12 years old). She took it well at first, very normal. When we left there, the questions started, and she still asks, how much longer, how much longer does she have to take the medication.”

Reasons given for disclosure were that the child asked too many questions or did not want to take their medications, or the caregiver wanted to be the person to disclose the status to the child, before someone else did. In general, caregivers who disclosed reported that the child took it well.

“No, I told my [daughter]. Mine knew at 7 years. Because she asked me many questions, about the medication. And I told her ‘because you have this and this and this just like me.’ She didn't get mad.”

“In the case of my daughter, I have raised her to be normal, and she, there came a time that she asked me why I gave her the medication. ‘Mommy, why is it that you give me those medications?’ The moment had arrived. ‘I give you those medications so that you don’t get sick’. But she insisted, ‘but so I do not get sick from what?’ And I had to bring her to the psychologist so that they could help me with the situation because she is very sharp, she talks a lot, asks a lot of questions, she is very curious.”

Reasons for non-disclosure: Caregivers who had not yet disclosed the child’s status gave several reasons for their decision, the main one being the age of the child. The caregivers did not want to disclose the status until the child was at an age which would facilitate the child’s coping and understanding of their condition. Ages considered appropriate for disclosure ranged from 10 to 16 years:

“You have to prepare the children beginning at 6 years old to be able to tell them [of their condition] at ten, eleven years of age”.

“[I would tell] during adolescence, when they begin falling in love, because it has to be made clear.”

Caregivers also expressed concern about the child’s emotional wellbeing, worrying that disclosure might lead to sadness and low self-esteem in the child. Often caregivers would tell the child that they had some other illness to explain the need for medication. The illnesses mentioned by caregivers included cancer, thalassemia, sickle cell or other anemia, tuberculosis, or asthma.

“I haven’t told him because when children are happy, why create something else in their minds? I think that in that moment, when one is telling them something like that, their happiness will go away, and they are left alone thinking about that. The boy thinks that the medications are for tight chest, (asthma), because we’ve had to take him to the hospital several times for that.”

“... it could traumatize him, I tell him, ‘you are ill because of your lungs and you have to take the [medications] because if not you will die’, but I don’t have the courage to tell him this and this and this. Because, I see him, he is a boy, with his happiness, his innocence, jumping and playing... It is very hard to tell him.”

Lastly, they expressed concern that younger children might disclose their status to others, leading to rejection by peers and others in the community, suggesting that disclosure should happen when the child is old enough to cope with rejection. Although caregivers acknowledged some advantages to disclosure, such as the child “adapting” to their status, and taking care of themselves, the fear of rejection and discrimination was compelling.

“One reason why I have not told my child is because I fear that he will tell some little friend in school and [that friend] would go telling others; I want to tell him... when he is prepared, in case someone wants to say something to him, he would already know how to handle it.”

Caregivers of youth who knew their status indicated that their lives were more challenging after disclosure to their children, and that major adjustments had to be made in all aspects of

family life. But independent of disclosure, they indicated that their lives were complex and stressful due to their experiences of dealing with illness, treatment and/or death in family members, and poverty. They shared feelings of despair, guilt, blame, denial, sadness and fear, and experiences of rejection and stigmatization. Most extended family members knew, but caregivers expressed caution about telling “outsiders.” Conversely, those who had not yet informed their children of their status dreaded the moment, the emotional toll that this would exact from the child and the likelihood of mistreatment by others. Caregivers generally recommended that providers be the ones to disclose their status to children. They worried about the future, particularly the possibility that the DR Ministry of Health would have to stop providing ART at no cost to persons with HIV infection. Regardless of whether they had disclosed or not, caregivers indicated that they would have preferred “never to have to tell.”

Youth recommendations

How disclosure should occur: In the two focus groups conducted in each clinic, the youth were asked to identify what factors helped or would have helped in disclosure. The age that adolescents suggested for disclosure ranged from 7 to 16 years of age. Virtually all concurred on disclosure between 10–12 years of age, because the child is old enough to have some awareness about the disease, but young enough that they are unlikely to be sexually active. Participants suggesting disclosure at much younger ages clarified that they meant the caregiver should begin to discuss the disease, but not necessarily disclose, suggesting that disclosure is a process, beginning with educating the child and preparing him/her to not have discriminatory attitudes towards persons with HIV, before informing the child that, indeed, s/he has HIV her/himself. One participant said:

“... the younger the better. Not that they tell you (abruptly): ‘You have it.’ But that they talk to you about it (HIV), they say: ‘hey, you can’t reject someone just because they have it’. For example, maybe your friend has it and confides in you, you can’t be like, ‘no, I’m going to catch it from you’, or anything... because that way you grow up with that and for you it’s nothing, (it’s) normal. But imagine that they come and they tell you that, out of the blue at 12 years old; you are going to feel bad! You are going to say ‘not me!’”

Participants also suggested that caregivers and healthcare professionals should be present at the time of disclosure. The most common response was that it should be the mother (caregiver) who actually says the words but others suggested a family member or person to whom the child is closest, with a doctor present, to answer any questions and help the child understand their disease and what it means for them.

“I think it’s good that this issue is dealt with by professionals, like doctors or a psychologist. But the best way would be, you first find out from your family, because it’s a way to create communication in your own home so that you feel confident to tell, to tell them anything...”

An important theme was having a positive outlook and helping the child feel ‘normal’ and confident. Participants expressed that this helps the child to continue coping with emotions regarding their disease, and to confront stigma and discrimination. One participant said:

“Give your child confidence. Because there are mothers that do not give confidence... there are children who never tell them how they feel inside. Because there are people who will say: ‘no, you move over, because you have such and such thing’ and they’ll get depressed.”

Another participant emphasized the importance of making the child feel valued:

“They try to get one to live, that one becomes part of this world that we can get to still be somebody, because there are people that think that because I have this, I am a lost cause”.

Adolescents described non-clinical activities for HIV-infected youth, particularly the summer camps, as helpful in disclosure. All who had attended summer camps cherished the experience. They indicated that the camps provided emotional support during and after disclosure and “normalized” the experience of having HIV infection. Among the comments describing the camps were:

“... (you) meet new people... who share... your same condition and you do not feel that different, that discriminated.” “You share with your friends, who are just like you and... you’re not afraid of taking the medications in front of everybody... sometimes I am ashamed of doing it in front of people who do not know my condition”.

When asked about the purpose of summer camp, participants suggested

“I believe the organizers’ idea is we can learn to live with this, that we will not see this as a hassle... but as a part of our lives that we need to cope with.” Others commented *“(in) summer camps... we are all equal... there is no distinction because you are black or white. No, no, no! You are family!”*

How disclosure should not occur: Some of the negative factors of disclosure were disclosing at the wrong age, not preparing the child or withholding information about the disease, keeping it a secret from the child, or deceiving the child. Most youth agreed that if the child is too young, they are not mature enough to understand and might tell others inappropriately. On the other hand, all agreed that disclosure after 14 years of age is irresponsible, because youth might have begun sexual activity, and if they don’t know their status or how to avoid transmission, they might infect others.

“Well, I would tell [the caregivers] to tell the children. Because this is something that they don’t tell them... So when they begin ‘carrying on’, having a girlfriend, or whatever, they realize [what they have] at 18 or 19 years old. This is, like, stupid to me ... because one is already living that experience. One says, ‘it’s because they are maybe waiting for the right time’ (while) perhaps they already have a girlfriend and are having sexual relations”.

Some of the participants found out about their HIV status ‘by accident’; they learned it independently of the caregiver (looking up their medications on the internet, or by being taunted by classmates who learned their status from a neighbor). Others were deceived and told it was something else (e.g. sickle cell anemia). In contrast to disclosure in general, which was considered helpful, this type of disclosure was reported universally as a negative

experience. In these situations, the participants expressed that one may feel that s/he is the “last to know”, disrespected and/or angry.

“They didn’t want to tell me at home, I don’t know why. They didn’t know how I was going to react, and here, I don’t remember what she’s called, the psychologist, I asked her [about my condition] and she asked me if I really wanted to know honestly what I have. I told her yes. She explained it to me. I took it, I took it okay. So when I got home I asked everyone about it and no one told me anything. Everyone left....”

DISCUSSION

Most children (77.4%) receiving ART in the principal DR pediatric centers were unaware of their status. This is consistent with findings from other LMICs which suggest even less disclosure of their status to HIV-infected children than in industrialized countries [8–10]. Studies of HIV-infected children in Ethiopia, Uganda, Zambia, India and Ghana reported that 82.6%, 71%, 62.2%, 86%, and 79%, respectively, did not know their diagnosis [12–15, 22]. In Puerto Rico, 80% of children had received only partial or no disclosure prior to participating in the only intervention for disclosure whose safety and efficacy had been described in the peer-reviewed literature before 2013 [17].

Although adolescents were more likely to know their status than younger children, most did not know they were infected. This is concerning, because Dominicans report early sexual debut; 50% of male and 38.4% female respondents aged 15–19 years in the 2007 Demographic and Health Survey had had sexual intercourse; 14% of female and 21.1% of male respondents reported sexual debut before age 15 years [23,24]. Knowledge of HIV-infected status in perinatally-infected youth is associated with improved ART adherence and possibly delayed disease progression [14, 25]. It may also be associated with increased condom use. HIV transmission from status-naïve antiretroviral-experienced adolescents may result in new infections with strains that have accumulated mutations and become resistant to first-line ART regimens [26].

Knowledge of HIV status was associated with participation in non-clinical activities for children with HIV including camp the most frequently reported non-clinical activity. These camps were not designed to facilitate disclosure of HIV status to children, but as settings to provide support and opportunities for youth development [27]. Focus group participants reported enjoying camp participation and valued being with other HIV-infected youth. Camps for HIV-infected children reportedly promote formation of caring connections, recreation, and increase knowledge, attitudes, and skills relevant to medication adherence [27]. Caregivers who have misgivings about disclosure may feel reassured about the child’s reactions if s/he is in the supportive camp environment after disclosure (Personal Communication, Noemi Paniagua-Torres, CDF Coordinator, Community-Based Care). It is encouraging that summer camp participation, an activity associated with positive outcomes in children with HIV [27], was also associated with knowledge of infection status in the DR.

Results from focus groups suggest that caregivers fear that knowledge of HIV infection status will result in both emotional and social consequences for the child and family,

although most adolescents reported feeling better after disclosure. Most youth also described disclosure as a process that should start at an early age with education designed to promote non-discriminatory, accepting attitudes towards HIV, and learning their status at 10–12 years of age. In the DR, HIV discrimination remains a well-documented concern [28–30]. HIV discrimination (including loss of employment and housing and denial of health care due to HIV positive status), reduces willingness of adults who know they are infected to disclose their status even to close friends and sex partners. Others who suspect they are infected may decline testing. Criminalization of “knowingly exposing” or “having exposed” a sex partner to HIV without informing them of the exposure [19] may be a disincentive to acceptance of testing. As such, HIV discrimination in the DR is believed to possibly contribute to HIV transmission [28–30].

Although perinatally-infected children in the DR suffer less overt discrimination than adults, they and their caregivers report exclusion from school attendance and recreational activities. As noted in a qualitative study “...at schools, if they say they are HIV positive they are forbidden entrance (denied admission), maybe by ignorance of some professors and directors... (and/or) because if other children know they all will leave (the school)... It goes as far as not wanting the HIV positive kid to play with other kids, etc.” [28]. Worldwide, studies of HIV-infected children suggest that concerns regarding discrimination should children divulge their status to others prompt caregivers to delay disclosure [9]. However, some evidence suggests that sharing their status with trusted friends is associated with delayed HIV disease progression [31].

This study had limitations. Among the weaknesses of the anonymized clinic data analysis was its cross-sectional design. Also, caregivers who consented to disclosure may have also more readily consented to non-clinical activity participation. Moreover, specific reasons for disclosure or non-disclosure, and age at disclosure to the relatively small group of participants who did know their status were unavailable in the anonymized data. Differences in disclosure levels were seen related to types of non-clinical activity participation between Santo Domingo and La Romana (DR’s largest and third largest city, respectively); disclosure levels may vary in other centers, reducing the generalizability of these findings to the DR. As in other focus group studies, despite the participants’ apparent frankness, relevant issues may not have emerged because they were too painful or embarrassing to discuss in groups, particularly for HIV-infected mothers. These include feeling that they “caused” their children’s illness and concerns that children would judge, reject or lose respect for them if they knew they were infected perinatally. For caregivers whose child’s HIV status was only one of several secrets (e.g., child’s abandonment, orphaning, and/or adoption), these topics, which may have affected disclosure and been relevant to the disclosure decision, may not have emerged.

Despite these limitations, these results have implications for future research and interventions. This is the first large study of knowledge of their status in HIV-infected children in a Caribbean or Spanish-speaking low or MIC [8–10, 16] and the only study of any size since the ART scale-up. “Familism”, a strong value in many cultures, particularly in Latin American and Caribbean LMICs, promotes withholding diagnoses by family members

even from adult patients to “protect” them, and hiding one’s own diagnosis [32, 33]. Familism may thus hinder disclosure to children in the context of “protecting” them.

Results of this study informed the adaptation of the Blasini Disclosure Model [17] currently being piloted in CCH and CDF, and in the Groupe Haïtien d’Etude du Sarcome de Kaposi et des Infections Opportunistes in Haiti [18]. Specifically, it confirmed the existence of a large population of HIV-infected youth including older adolescents who do not know their status. It suggested an important role for camps and support groups for HIV-infected children in supporting disclosure. Our results suggest that strategies for disclosure must focus on safety, particularly in LMICs, where protection against discrimination is limited [19, 28–30]. Increased focus on caregiver capacity building and protection from adverse consequences of disclosure related to stigma and discrimination are warranted. Dominican children and adolescents with HIV infection have emerged as activists, demanding schooling, treatment and, specifically, knowledge of their status [34]. Their insights from this mixed-method study are contributing to an island-wide effort to explore how best to respond to HIV-infected youth’s need to be respectfully and sensitively informed of their status, and to build their caregivers’ capacity to support disclosure.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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