Psychosocial Implications of HIV Serostatus Disclosure to Youth with Perinatally Acquired HIV

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Abstract

Recommendations suggest that older children and adolescents perinatally infected with HIV (PHIV+) be informed of their HIV diagnosis; however, delayed disclosure is commonly reported. This study examined the prevalence and timing of HIV disclosure to PHIV+ adolescents and the associations between the timing of disclosure and psychological functioning and other behavioral outcomes. Recruitment took place at four medical centers in New York City between December 2003 and December 2008. This sample included data from 196 PHIV+ youth and their caregivers: 50% of youth were male, 58% African American, 42% Hispanic, with a mean age of 12.71 years. According to caregiver reports, 70% of the PHIV+ youth knew their HIV diagnosis. Youths who had been told were more likely to be older; youths with a Spanish-speaking Latino caregiver and whose caregivers had a grade school education were told at an older age. Youths who had been told their HIV status were significantly less anxious than those who had not been told; there were no other differences in psychological functioning. Youths who knew their status for longer reported higher intentions to self-disclose to potential sex partners. In multivariate analyses only demographic differences associated with timing of disclosure remained. In summary, PHIV+ youth who had been told their HIV status did not show an increase of psychological problems and were more likely to have intentions to self-disclose to sexual partners. Yet, almost one third was entering puberty without important information regarding their illness. Caregivers need support to address factors impeding HIV disclosure.

Introduction

SINCE THE ADVENT OF ANTIRETROVIRAL TREATMENT (ART) and its widespread use in the United States (U.S.), fewer babies are born with HIV; those who are HIV infected, once expected not to outlive childhood, are now living into older childhood, adolescence, and early adulthood.^{1,2} More than 10 years have passed since the American Academy of Pediatrics (AAP) issued guidelines for disclosure of HIV serostatus to children and adolescents. Thus, HIV disclosure to a child has become "an increasingly common clinical issue."³ The AAP strongly recommended that older school-age children and adolescents living with HIV be informed of their HIV diagnosis. Adolescence is a developmental period characterized by considerable social, biological and physical change, during which youth gradually assume more autonomy and take on adult roles and behaviors.^{4,5} The AAP argued that adolescents fully informed of their status can tackle illness and issues of

dying and immediate future, consider the consequences of their sexual behavior, and participate in their own medical treatment.³ In the 12 years since the guidelines were published, caregivers and medical providers have continued to struggle with decisions about the timing and content of HIV disclosure conversations with an aging population of HIV-infected children.⁶

In spite of the AAP recommendations, early data suggest not all children were told their diagnosis prior to adolescence.⁷ Adolescence is a period often characterized by experimentation with sexual and drug risk behavior^{8,9} and other health risk behaviors such as nonadherence to medication in the context of increasing autonomy for medical treatment and care.¹⁰ Knowledge of HIV status may be critical to decision making around both health and sexual risk behaviors for adolescents, yet, the majority of studies on disclosure have been with younger cohorts of children.⁶ There have been few studies of diagnostic disclosure to adolescents. This study

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examines the prevalence and timing (i.e., age at disclosure and length of time known) of HIV disclosure to perinatally HIV-infected (PHIV+) older children and adolescents and the impact of disclosure on mental health function and other behavioral outcomes.

Studies that examine the association of serostatus disclosure and psychological functioning in youth born with HIV have shown mixed results. Disclosure has been associated with reduced rates of anxiety, depression, and other such internalizing behavior problems,^{11,12} and conversely, elevated internalizing behavior problems and higher rates of posttraumatic stress-disorder or related symptoms.^{13,14} Studies have also shown disclosure to have no association with psychological outcomes.^{5,15,16} Methodological limitations may in part explain the variation in results. The majority of studies with PHIV+ children have had relatively small samples, which may have limited their ability to detect associations between disclosure and psychological functioning.^{6,11,13,15} Furthermore, studies often had differing and wide age ranges (e.g., 6–16 years) that may have also reduced their sensitivity to detect an association between disclosure and psychological functioning.^{6,7,11,13} Psychological adjustment to learning one is HIV-positive likely takes time. Older youth who may have known their status longer may have had more time to adjust compared to younger youth. However, no studies have examined the association between length of time the youth has known his/her status and psychological functioning.

Given the limited number of studies of disclosure in adolescents, we may have an incomplete understanding of how the timing of disclosure can influence youth's intentions to disclose to future sexual partners. A subset of PHIV+ youth will become sexually active during adolescence,^{17,18} and HIV status disclosure to potential partners is an important public health concern given increased risk of HIV transmission, including transmission of ART resistant strains to partners.^{8,19} Youth who have known their HIV status for a longer (versus shorter) period of time may be more comfortable with their identity as people living with HIV and may be more comfortable talking with others about HIV, including potential sexual partners. Conversely, as youth adjust to the knowledge that they are living with HIV, they may experience stigma and rejection related to their HIV status and be less open about their status. Understanding the impact of timing of disclosure in PHIV+ youth on their decisions to disclose to their sexual partners may have important public health implications for ongoing interventions for this population.

HIV-related stigma in youth is also critical to understand. As in adults,^{20–22} the stigma youth may experience related to their HIV status could ultimately have negative implications for their physical and mental health.²³ Similar to youth with other stigmatized illness (e.g., epilepsy, psychiatric disorders), youth whose HIV status becomes public may experience or perceive discrimination and rejection from others, and subsequently withdraw.^{24–26} Even youth who have not told others about their HIV status may experience internalized stigma in the form of shame, self-blame, and stress related to hiding a potentially damaging “secret” from others as they engage with the negative evaluations of what it means to be HIV+ found within their immediate and broader social context.²⁷ Although numerous studies have explored stigma experiences among adults living with HIV,^{20–22} stigma

experiences of PHIV+ youth are not well understood. Therefore, as a contribution to the literature, we also examine the association of age at disclosure and years since disclosure on HIV-related stigma.

To extend previous research concerning the psychosocial effects of disclosure, the current study uses data from one of the largest U.S. cohort studies of perinatally HIV-infected youth to examine: (1) the prevalence and timing of HIV status disclosure; (2) the demographic correlates of disclosure; (3) the association of disclosure and timing of disclosure on psychological functioning; and (4) among the PHIV+ youth who know their status, the association of age at disclosure and length of time since disclosure on intentions to disclose one's status to future sexual partners and stigma perceptions.

Methods

Participants and procedures

Data for this article are from the baseline interview of Project CASA (Child and Adolescent Self-Awareness and Health Study). Participants were recruited from four medical centers in New York City (NYC) that provide family-focused primary and tertiary care to HIV-affected families between December 2003 and December 2008. Inclusion criteria were: (1) youth between 9 to 16 years old, (2) perinatal exposure to HIV confirmed by medical providers, (3) caregiver and youth had cognitive capacity to complete interviews, (4) caregivers were English or Spanish speaking, and (5) caregiver had legal capacity to sign consent for child participation. Foster care parents cannot consent for child participation in research in NYC and so these youth were excluded from study participation. Among 443 eligible participants identified, 6% could not be contacted by providers, and 11% refused contact with the researchers. Of the remaining 367 eligible participants, 340 (92%) were enrolled, including 206 PHIV+ youths, and 134 perinatally HIV-uninfected (PHIV–) youths. To preserve patient confidentiality, data were not collected on patients who were not eligible, who were not approached or who refused participation.

Institutional Review Board approval was obtained from all sites. All caregivers provided written informed consent for themselves and their target child. Youths provided written assent. Monetary reimbursement for time and transportation was provided to all participants. Caregivers and youths were interviewed simultaneously but separately over two 60- to 90-min interview sessions, approximately 2–4 weeks apart. Two sessions were required in order to make the interview length manageable and to reduce interviewee burden. Data for this article are from the 196 PHIV+ youths and their caregivers who completed both interview sessions (95% of PHIV+ youths enrolled). The primary reasons for failure to complete session 2 were caregiver death and/or relocation.

Measures

Demographic characteristics assessed included child and caregiver age, gender, ethnicity, and HIV status; caregiver work, education, relationship to child (e.g., birth parent versus adoptive parent related or adoptive not related); and household composition and income. The majority of participants were African American and Latino; thus, for data analytic purposes, three categories were created for caregivers

based on ethnicity and language (African-American-English, Latino-English, and Latino-Spanish). Mixed ethnicity and other non-Latino categories were excluded from the analyses given too few participants within each of these groups. All children in the study were English speaking. For the vast majority of child/caregiver dyads, the child and the caregiver were of the same race/ethnicity, therefore child's ethnicity was not analyzed as a separate variable.

The Child Depression Inventory (CDI)²⁸ is an extensively used and well-validated 27-item measure that assesses the intensity of depression symptoms in children. For each item, youth were asked to select one of three statements describing their feelings over the past two weeks. A total score was calculated ranging from 0 to 54. Cronbach α for our sample was 0.82.

The State Trait Anxiety Inventory-Child version (STAI-C)²⁹ is a measure used to assess trait anxiety and permitting the identification of children who are prone to generalized anxiety. Youth reported on a 3-point scale the degree to which they experience each anxiety symptom. Adequate reliability and validity have been established for this measure in previous studies.²⁹ Cronbach α for our sample was 0.90.

The Child Behavior Checklist—Parent version for ages 4 to 18 years (CBCL-P)³⁰ is a well-validated measure of 113 items on which caregivers were asked to rate on a 3-point scale how "true" the items were in describing their child's emotions and behaviors. Standardized scores, based on age and gender were computed. Adequate psychometric properties have been established for total Internalizing (e.g., anxiety, depression) and Externalizing (e.g., aggression, delinquency) behavior problem scales.³⁰ α for these scales in our sample were 0.89 and 0.92, respectively.

HIV disclosure and timing information was obtained by asking caregivers to report information on whether or not they or other people had disclosed to their child; this was done due to ethical concerns relating to inadvertently disclosing a youth's HIV status. According to caregivers, the majority of youth (80%) were told by either their caregiver and/or their clinician: 45% by caregiver, 35% by caregiver and clinician, 17% by another person and 3% worked it out by themselves. Disclosure was coded as either disclosed or not disclosed. Caregivers who said their child knew his/her status were asked to permit study staff to ask the child questions about disclosure. After obtaining permission, youth were asked about their age at disclosure. Years since disclosure was calculated by subtracting age at disclosure as determined by the youth from youth's age at the interview.

HIV-related stigma. A modified version of the Social Impact Scale³¹ was used for this study, and completed only by disclosed children whose caregivers gave us permission to discuss HIV with the child. Our final version includes 18-items assessing youth perception of HIV stigma with themes around social rejection and isolation, and internalized shame (e.g., I feel others avoid me because of my HIV, I feel I am less able to do things because of my HIV, I feel others think I am to blame for my HIV). A total score was computed by averaging items rated on a 4-point Likert scale (1 = strongly disagree, 2 = disagree, 3 = agree, and 4 = strongly agree; $\alpha = 0.84$ for this sample).

Youth intentions to self-disclose (for youth for whom we had permission to discuss HIV) were assessed with the following: Would you tell your partner that you are HIV+ if (1)

you were going to have sex, (2) you were going to have sex with a condom, (3) without a condom, (4) your partner was your steady boy/girlfriend, or (5) your partner was someone besides a steady boyfriend/girlfriend? These items were generated by the research team to learn about youth's intentions to self-disclose their status to potential romantic partners. Each question was rated on a 4-point scale (0 = definitely would not; 1 = probably wouldn't; 2 = probably would; and 3 = definitely would). Intentions to self-disclose reflects the mean of all five items ($\alpha = 0.92$ for this sample).

Statistical methods

We first examined demographic correlates of disclosure (y/n) using χ^2 tests and *t* tests for categorical and continuous correlates, respectively. We also determined age at HIV status disclosure and years since disclosure, and examined demographic correlates of these two continuous variables using *t* tests or analysis of variance (ANOVA) for two group and multiple group comparisons, respectively. When examining demographic correlates of number of years since disclosure, we also adjusted for the child's age except for when the demographic characteristic was youth's age group (Table 1). We next examined bivariate relationships between disclosure, age at disclosure, and years since disclosure and psychological functioning (i.e., depression, anxiety, internalizing and externalizing behavior problems). We used *t* tests to examine the relationship between disclosure status and psychological functioning; we computed partial correlations, adjusting for the youth's age, to examine the association between psychological functioning and years since disclosure; and we computed Pearson correlations to examine the association between psychological functioning and age at disclosure. Also, among those youth who knew their HIV status, we explored the associations between age at disclosure and years since disclosure and HIV stigma and intentions to self-disclose using partial correlations and Pearson correlations, respectively (Table 2).

Finally, we conducted multivariate analyses. We used multiple logistic regression to examine demographic characteristics associated with disclosure and multiple linear regression to examine the association between demographic characteristics, age at disclosure, and the number of years the youth knew their diagnosis. We included child's gender, age, caregiver type, caregiver's HIV status, caregiver's race/ethnicity and caregiver's primary language as covariates in these models. We next used multiple linear regression to examine the association of disclosure and the psychological functioning and social interaction variables that were significantly associated in bivariate analyses. Specifically, we examined the association of disclosure status on anxiety and externalizing behavior symptoms, while adjusting for the effects of demographic variables. We also examined the association between intentions to self-disclose and years since disclosure, while adjusting for key demographic variables.

Results

Sample description

Demographic characteristics of the sample are shown in Table 1. The sample had an equal number of males and females. The mean age was 12.71 years (standard deviation

TABLE 1. SAMPLE DESCRIPTION BY HIV DISCLOSURE STATUS, YEARS SINCE DISCLOSURE, AND AGE OF DISCLOSURE

	Disclosure status				Timing of disclosure			
	Total (n = 196) n (%)	Not disclosed (n = 58) n (%)	Disclosed (n = 138) n (%)	χ^2 p	Years since disclosure (n = 120) Mean (SD)	ANOVA ^a p	Age (yr) at disclosure (n = 120) Mean (SD)	t test/ ANOVA ^b p
<i>Demographics</i>								
Youth gender ^c				0.876		0.123		0.337
Male	98 (50)	28 (29)	70 (71)		4.9 (3.3)		9.1 (3.1)	
Female	98 (50)	30 (31)	68 (69)		3.6 (2.8)		9.6 (2.8)	
Youth age group (yr) ^c				<0.001		<0.001		0.022
9–10	51 (26)	32 (63)	19 (37)		1.5 (0.8)		8.7 (1.0)	
11–12	51 (26)	20 (39)	31 (61)		2.9 (2.4)		9.1 (2.5)	
13–14	60 (31)	6 (10)	54 (90)		5.3 (3.2)		8.8 (3.2)	
15–16	34 (17)	0 (0)	34 (100)		5.1 (3.1)		10.7 (3.2)	
Caregiver type ^d				0.139		0.312		0.313
Birth caregiver	68 (35)	25 (37)	43 (63)		4.6 (3.2)		8.9 (3.3)	
Non-birth caregiver	128 (65)	33 (26)	95 (74)		4.1 (3.1)		9.5 (2.7)	
Caregiver HIV status ^d				0.237		0.585		0.628
Positive	61 (31)	22 (36)	39 (64)		4.5 (3.0)		9.1 (3.2)	
Negative	135 (69)	36 (27)	99 (73)		4.1 (3.2)		9.4 (2.8)	
Caregiver ethnicity and language ^{d,e}				0.394		0.005		0.001
African American-English	101 (58)	25 (25)	76 (75)		4.2 (3.1)		8.8 (2.8)	
Latino-English	35 (20)	12 (34)	23 (66)		4.8 (3.5)		9.1 (2.8)	
Latino-Spanish	38 (22)	13 (34)	25 (66)		3.0 (2.6)		11.7 (2.8)	
Caregiver education ^d				0.305		0.008		0.012
Grade school	72 (37)	26 (36)	46 (64)		3.1 (2.7)		10.4 (2.7)	
High school	72 (37)	18 (25)	54 (75)		4.9 (3.2)		8.6 (3.0)	
College	52 (27)	14 (27)	38 (73)		4.7 (3.3)		9.1 (2.8)	
Household yearly income ^{d,f}				0.418		0.813		0.642
≤20k	72 (39)	25 (35)	47 (65)		4.5 (2.8)		9.6 (3.1)	
20k–40k	66 (36)	17 (26)	49 (74)		4.3 (3.4)		9.0 (3.1)	
>40k	47 (25)	12 (26)	35 (75)		4.0 (3.0)		9.5 (2.7)	

^aANOVA adjusting for age, except for when the demographic characteristic is youth age group.

^bT-test results for dichotomous variables, otherwise ANOVAs.

^cYouth report.

^dCaregiver report.

^e22 who did not fit any of these categories were not included in statistical analyses regarding this variable.

^f11 missing (caregiver refused).

SD, standard deviation; ANOVA, analysis of variance.

[SD] = 2.18). Sixty-five percent of youth were living with a non-birth parent and 31% with an HIV+ parent. There was substantial overlap between these characteristics, with HIV+ caregivers more likely to be the child's birth (versus non-birth) parent. Among the non-birth parents, 56% were adoptive non relatives and 44% were other relatives (e.g., grandparents, aunts, uncles). About half of the sample was African American. Among the Latino caregivers, Spanish and English were equally represented as their primary language. Almost two thirds of the caregivers had at least a high school education, but only a quarter of their households earned more than \$40,000 per year.

Demographic characteristics and disclosure

Associations between demographic characteristics and disclosure variables are presented in Table 1. According to caregiver reports, 138 (70%) of the PHIV+ youth had been told about their HIV diagnosis. Disclosed youth were more likely to be older than nondisclosed youth ($\chi^2 = 54.52$, $df = 3$, $p < 0.001$). Disclosure status was not significantly associated with any other demographic variable.

Of the 138 disclosed youth, 120 reported their age at disclosure (15 did not know their age and the caregivers of 3 refused consent for children to discuss HIV). On average, youth were told when they were 9 years old and, at the time of the baseline interview, had known for an average of 4 years.

Years since disclosure was associated with older age, therefore all analyses involving this variable were adjusted for age. Youths with Spanish-speaking Latino caregivers had known for a shorter time than youth with caregivers who were African American or English-speaking Latino ($F = 5.60$, $df = 2$, $p = 0.005$). Years since disclosure was also significantly associated with caregiver education ($F = 4.99$, $df = 2$, $p = 0.008$). Children of caregivers with low education (less than high school) knew their status for a shorter time than children whose caregivers' had at least a high school education. Years since disclosure was not associated with child's gender, caregiver type, caregiver HIV status, or household income.

Similar analyses examined the association between demographic variables and age at disclosure. Age at disclosure was associated with current age. Other findings were comparable to those for years since disclosure. Youths with Spanish-speaking Latino caregivers were told at an older age than

TABLE 2. ASSOCIATIONS BETWEEN PSYCHOLOGICAL FUNCTIONING, SOCIAL INTERACTION, AND DISCLOSURE

	Disclosure status			Timing of disclosure	
	Not disclosed (n = 58) M (SD)	Disclosed (n = 138) M (SD)	t test p	Years since disclosure (n = 120) r ^a (p)	Age at disclosure (n = 120) r (p)
Psychological functioning					
Depression ^b	7.2 (5.8)	6.4 (5.9)	0.354	−0.095 (.305)	0.085 (.358)
Anxiety ^b	35.4 (9.2)	31.9 (7.0)	0.011	−0.050 (.592)	0.042 (.649)
Internalizing behavior score ^c	46.8 (10.4)	47.3 (11.8)	0.781	0.127 (.171)	−0.100 (.280)
Externalizing behavior score ^c	47.4 (11.5)	50.9 (11.7)	0.052	0.124 (.182)	−0.107 (.248)
Social interaction ^d					
HIV-related stigma ^b	n/a	1.77 (0.4)	n/a	0.011 (0.909)	0.002 (.982)
Intentions of self-disclosure ^b	n/a	1.86 (1.1)	n/a	0.185 (0.045)	−0.132 (.153)

^aPartial correlation adjusting for age.

^bYouth report.

^cCaregiver report.

^dSocial interaction measures here are only available for the disclosed youth.
SD, standard deviation.

youth with caregivers from the other two ethnicity-language groups ($F = 7.91$, $df = 2$, $p = 0.001$). Age at disclosure was also significantly associated with caregiver education ($F = 4.64$, $df = 2$, $p = 0.012$). Children of caregivers with low education (less than high school) were told at an older age than children of high school or higher educated caregivers. Age at disclosure was not associated with child's gender, caregiver type, caregiver HIV status, or household income.

Psychological functioning and disclosure

The associations between disclosure and psychological functioning variables are shown in Table 2. Disclosed youths were significantly less anxious than non-disclosed youths ($t = 2.62$, $df = 86$, $p = 0.011$). A nonsignificant trend was observed among disclosed youths to have higher externalizing behavior problem scores ($t = -1.96$, $df = 193$, $p = 0.052$). Disclosed youths did not differ in depression or internalizing behavior problem scores from nondisclosed youths, and none of the psychological functioning variables were significantly associated with years since disclosure or age at disclosure.

Stigma and intentions to self-disclose (among disclosed youth only)

The associations between disclosure and stigma and intentions to self-disclose are shown in Table 2. On average, disclosed youth scored low on HIV-related stigma (i.e., less perceived stigma) ($M = 1.77$, $SD = 0.4$). HIV-related stigma was not significantly associated with years since disclosure or age at disclosure. The mean rating on intentions to self-disclose was 1.86, consistent with "probably" not disclosing. Greater intentions to self-disclose were associated with more years since disclosure ($r = 0.185$, $n = 120$, $p = 0.045$), meaning that those who knew their status for longer were more likely to intend to disclose to future sexual partners. Intentions to self-disclose were not associated with age at disclosure.

Multivariate logistic and linear regression

In multivariate analyses, we found that youth whose status had been disclosed to them were more likely to be older

($p = 0.000$), and less likely to have Spanish speaking Latino primary caregivers ($p = 0.01$). Similarly, age at disclosure and years since disclosure were positively associated with youth age at baseline ($p = 0.000$; $p = 0.000$, respectively) and negatively associated with having Spanish speaking Latino caregivers ($p = 0.01$; $p = 0.01$, respectively).

After adjusting for demographic variables, we found no significant associations with disclosure and anxiety or externalizing behavior problems, or between number of years since disclosure and intentions to self-disclose to a partner. No demographic variables were associated with psychological functioning or intentions to self-disclose to a partner.

Discussion

This study explored disclosure patterns and correlates among PHIV+ youth. Corresponding with a number of studies of PHIV+ youth, age was the strongest correlate of disclosure.^{6,7,15} In the present study, a high percent of youth under the age of 12 had not been formally told their HIV+ status (63% for those between the ages of 9–10, and 39% of 11–12 year olds). By age 13–14 years, 90% of youth had been told their diagnosis and 100% of 15–16 year olds knew their HIV+ status. Thus, it seems that for the most part the AAP recommendation³ to disclose to PHIV+ adolescents is being followed, although a large percentage of 9–12 year olds and 10% of 13–14 year olds were not told their diagnosis. The AAP recommendation is particularly important given that some PHIV+ youth may begin engaging in risky sexual behavior as early as 12 years of age¹⁷ and adherence to antiretroviral treatment becomes increasingly difficult for youth during adolescence.²³ Knowledge of HIV status is considered critical for interventions to promote health and reduce risk behavior.

This study also highlights caregiver characteristics associated with earlier disclosure: having a higher education level, being non-Latino or being non-Spanish speaking. Higher caregiver education has been associated with fewer sexual risk behaviors and positively correlated with better parent-child communication in studies of both infected and uninfected adolescents,^{32,33} and in overall understanding of sensitive topics encompassing HIV illness, including medical

treatment, sexual health, and increased comfort around issues related to HIV disclosure in infected youth.³⁴ Studies have also found that delayed disclosure to PHIV+ Latino youth may be explained by cultural norms within Latino families, where certain topics such as HIV/AIDS, sex, and drugs are simply not discussed with younger members of the family.^{35,36} Studies have found that acculturation in general plays a role in the timing of HIV disclosure³⁷ and it has been associated with a greater knowledge of health issues and greater likelihood in utilizing health care resources.³⁸ Similar to this study's finding, Mason et al.³⁹ found that, when compared to English-Speaking Latino men, Spanish-speaking Latino men were less likely to disclose their HIV status.

In this study, with one of the largest study samples of older PHIV+ youth in the United States, disclosure and timing of disclosure were not significantly associated with negative psychological functioning. In fact, compared to children who had not been told their diagnosis, children who had been told about their HIV+ status reported significantly less anxiety. Historically, one of the most significant barriers to disclosure reported by parents and clinicians has been the concern about increased child psychological distress.^{6,40} The current study adds to the mounting evidence suggesting that, at the very least, disclosure is not associated with worse psychological outcomes. Medical providers who encounter caregivers with fears of provoking depression, anxiety, or other behavior problems upon disclosure can inform parents and caregivers that, while every child is different, most evidence shows that youth who have been informed of their HIV+ status, even at relatively young ages, do not fare worse than those who have been told of their status at a later age.

Despite many parents' concerns about the potential for disclosed youth to experience high levels of HIV-related stigma,²³ rates of perceived HIV stigma were low among this sample; these findings contrast with those of adult populations.^{20–22} It is possible that youth in this study experienced low rates of stigma because they had not disclosed their status to friends (we did not ask about disclosure to friends). Limited experiences of stigma may also be a function of the youth's age as their constricted social experiences may have restricted opportunities for stigma experiences.²⁴ Alternatively, this younger generation, living in the United States may experience less HIV/AIDS-related stigma as they and their peers have not seen the wasting and imminent death that was experienced early in the epidemic or in countries with limited access to treatment. It is also possible that youth in this study were too young to understand/conceptualize HIV-related stigma. There is a need for future studies in this area as HIV stigma has represented a clear barrier to health behaviors such as adherence to treatment and safe sex behavior.^{22,41,42}

One of the theorized benefits of disclosure to youth is that once they know their status, they may then make informed decisions about sexual behavior and serostatus disclosure to sexual partners. In this study, the longer a child had known his/her status, the higher were his or her intentions to disclose to potential sex partners even after adjusting for age, suggesting that a longer duration between disclosure and sexual partnership may strengthen comfort and confidence in discussing HIV with partners^{43,44} or may result from fear of disease progression.⁴⁵ Note, however, that overall, intentions to disclose to partners were low in this sample. Nondisclosure to sexual partners is somewhat common among adults and

youth living with HIV,^{46,47} and disclosure does not always result in reduced HIV transmission risk.^{46,48,49}

There are several limitations to this study. Although we were able to interview 77% of participants from HIV primary care clinics who met criteria for our study, our convenience sample from NYC may not reflect all PHIV+ adolescents, particularly those not receiving care in urban centers. Selection bias may also exist in the current sample such that caregivers who voluntarily participated in the current study may represent a more motivated or less defended group than caregivers not included in the study. Moreover, the data are self-report and subject to issues of social desirability. Because it was not permissible for research staff to directly ask HIV+ youth if they knew their status, it is also possible that some of the youth in the not disclosed group actually knew their status unbeknownst to their caregivers. We did not collect data from caregivers on the disclosure process. Thus, there may be important child and/or caregiver confounders that affected the disclosure decision as well as the measures of psychological functioning and social interaction. Prior studies have identified cognitive or developmental delays in some HIV+ youth.⁵⁰ However, we did not assess cognitive or developmental delays in the current study and thus were unable to address how these delays may have impacted disclosure, timing of disclosure, and the reliability of responses on various measures used in this study. In order to address issues of literacy, all assessments were administered face-to-face by trained interviewers. Finally, these are cross sectional data, with a retrospective recall of disclosure age by the youth. They did not permit causal association between disclosure status, timing of disclosure and psychological functioning or social interaction. The study design did not enable examination of the immediate impact of disclosure, nor did it enable examination of outcomes at multiple points moving forward (e.g., 1 year, 2 years, 3 years postdisclosure) to fully assess the impact of age/development and time.

Despite these limitations, the current study has important implications for clinical practice. The majority of youth in this study had been formally told their diagnosis. However, almost one third of the sample was still unaware of their status, including 39% of 11–12 year olds and 10% of 13–14 year olds. Despite AAP recommendations and limited evidence of negative psychological outcomes of disclosure to youth, a number of preadolescent and early adolescent children remain unaware of their HIV+ status and are entering puberty without prior exposure to valuable information regarding their illness. Clinicians may improve care for this population by actively discussing with caregivers their decisions around HIV disclosure to their children over time, to ensure that developmentally appropriate messages are discussed and in an attempt to identify and assist those caregivers who are having difficulty with the process. These caregivers may need support to promote parent-child communication around disclosure, which includes addressing language needs, cultural factors, as well as fears of the consequences of disclosure. Although there is much concern regarding the ongoing process of HIV disclosure, the effects of "coming of age" should also be considered; growing up poses many experiences that can be stressful for youth and, these experiences may or may not be directly related to knowing one's HIV+ status.

Findings from the current study are also relevant for PHIV+ youth in developing countries and those hardest hit by the epidemic for which perinatal HIV infection continues

to be of considerable concern. Studies of HIV+ youth in these settings suggest that disclosure is a difficult task that caregivers often delay due to issues regarding stigma and considerable concern about the psychological impact of disclosure on their child.^{51,52} Studies also suggest that lack of training among health care providers⁵³ also contributes to this delay as caregivers must often disclose to youth without assistance or guidance.^{51,52,54} The current study found 35% of disclosures directly involved a provider, highlighting the importance of provider involvement in the disclosure process. Training for health care providers in international, low resource settings that builds provider skills in communicating with both caregiver and child around issues of HIV and disclosure, and that promotes disclosure as a collaborative process between caregiver and provider, and as an ongoing process requiring continued support and evaluation throughout the course of the illness is necessary.^{53,55}

We can expect that most PHIV+ youth will enter adolescence already knowing their HIV+ status. What remains unknown is how these HIV+ young individuals will cope within their social networks as they face the challenges that HIV imposes on maintaining good sexual, mental, and medical health. Further research around the experience of stigma in youth and ability to disclose to others—especially sex partners—is needed to inform clinical practices involving this population.

Acknowledgments

This research was supported by a grant from the National Institute of Mental Health (R01-MH069133; PI: Claude Ann Mellins, Ph.D.), and by a center grant from the National Institute of Mental Health to the HIV Center for Clinical and Behavioral Studies at the New York State Psychiatric Institute and Columbia University (P30-MH43520; Principal Investigator: Anke A. Ehrhardt, Ph.D.). Dr. Elkington was supported by a Career Development Award from the National Institute of Mental Health (K01MH089832; "A Family-based HIV-Prevention Intervention for Youth on Probation").

Author Disclosure Statement

No competing financial interests exist for any of the authors.

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