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Participation and Retention of Youth with Perinatal HIV Infection in Mental Health Research Studies: The IMPAACT P1055 Psychiatric Co-Morbidity Study

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Abstract

Background—Obtaining accurate estimates of mental health problems among youth perinatally infected with HIV (PHIV) helps clinicians develop targeted interventions, but requires enrollment and retention of representative youth into research studies.

Methods—We describe the study design for IMPAACT P1055, a US-based multisite, prospective study of psychiatric symptoms among PHIV youth and uninfected Controls aged 6–17 years old. We compared participants to non-participants by demographic characteristics and summarized reasons for study refusal. We used adjusted logistic regression models to evaluate the association of psychiatric symptoms and other factors with loss to follow-up (LTFU).

Results—Among 2281 youth screened between 2005–2006 at 29 IMPAACT research sites, 580 (25%) refused to participate, primarily due to time constraints. Among 1162 eligible youth approached, 582 (50%) enrolled (323 PHIV and 259 Control), with higher participation rates for Hispanic youth. Retention at 2 years was significantly higher for PHIV than Controls (84% vs 77%, $p=0.03$). In logistic regression models adjusting for socio-demographic characteristics and HIV status, youth with any self-assessed psychiatric condition had higher odds of LTFU compared to those with no disorder (adjusted odds ratio (aOR)=1.56, 95% confidence interval (CI): 1.00,2.43). Among PHIV youth, those with any psychiatric condition had 3-fold higher odds of LTFU (aOR=3.11, 95% CI: 1.61,6.01).

Conclusions—Enrollment and retention of PHIV youth into mental health research studies is challenging for those with psychiatric conditions, and may lead to underestimated risks for mental health problems. Creative approaches for engaging HIV-infected youth and their families are required for ensuring representative study populations.

Keywords

HIV; Psychiatric Disorders; ADHD; Antiretroviral Treatment; Retention

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Introduction

Children perinatally infected with human immunodeficiency virus (PHIV) commonly suffer from psychiatric symptoms, particularly depression and attention deficit hyperactivity disorder (ADHD).^{1–14} Obtaining accurate estimates of the prevalence of mental health problems among PHIV youth is necessary for informing clinicians, developing policies, and targeting interventions, but requires representative samples. Participation bias may occur due to recruitment from populations that differ with respect to personal and family characteristics. In addition, PHIV youth with co-morbid mental health problems (or their caregivers) may show differential desire to participate in and remain involved in research studies.

Psychiatric conditions influence rates of both initial participation and retention of adults in health research surveys and longitudinal studies.^{15–26} Depression, anxiety, and panic disorder are associated with higher risk of loss to follow-up (LTFU), particularly due to lost contact.^{15–17} In addition, comorbidity with multiple psychiatric diagnoses has been associated with higher risk of attrition than single diagnoses.¹⁶ However, in a study from the Netherlands, adults with diagnoses of depression and anxiety were more likely to be included in initial study screening, attributed to more frequent contact with primary care doctors.¹⁷ Similarly, Pfeiffer et al noted an “unhealthy volunteer” effect for studies of psychiatric outcomes, where adults with more severe depression were more likely to participate.²⁷ Whereas over-inclusion combined with higher attrition of participants with psychiatric disorders may in some cases balance to yield reasonable prevalence estimates, both forms of selection bias may impair generalizability and lead to biased inference regarding determinants of psychopathology.²⁴

Fewer studies have evaluated the association of psychiatric conditions with participation and retention in studies of youth,^{28–30} and none have specifically evaluated the relationship in PHIV youth. Most studies in youth have focused on identifying predictors of treatment dropout for psychotherapy, and have shown higher dropout among youth with depression.^{30–34} In one of the few longitudinal research studies of adolescents, no association of baseline psychopathology was observed with attrition, but a significant association was observed for incident disorders during follow-up with difficulty in contacting participants. Several studies, while not addressing psychiatric disorders, have identified socio-demographic and program-related factors associated with LTFU of PHIV youth in both developed countries³⁵ and in lower-resource settings.^{36–37} Because many of these factors (including gender, race, age, socioeconomic status, and parental education level) may in turn be associated with risk of psychiatric conditions in PHIV youth, assessment of the impact of psychiatric disorders on attrition requires adjustment for these shared risk factors.

The P1055 study was designed to evaluate the prevalence and incidence of psychiatric problems in PHIV youth and an uninfected comparison group, and was one of the first nationally-based prospective assessments of psychiatric problems in this clinical population; results of various aspects of the study have been reported.^{8–9,38–41} An uninfected comparison group was included to facilitate a better understanding of how chronic HIV disease influences mental health problems above and beyond home environment. However, during the design phase there were concerns that participating sites would tend to enroll the most compliant patients (perhaps less likely to have psychiatric problems) and that retention might be lower among youth with psychiatric conditions at study entry, limiting the ability to evaluate persistence and resolution of psychiatric symptoms over time. In this paper, we describe the procedures designed developed to enroll a representative study sample of PHIV

youth, and evaluate the influence of co-occurring psychiatric symptoms on retention adjusting for socio-demographic factors.

Methods

Participants and Study Design

The P1055 study was a prospective, multisite, 2-year observational study of psychiatric symptoms in two cohorts of youth (PHIV and uninfected Controls) conducted at 29 sites in the United States between 2005 and 2008 by the International Maternal Pediatric Adolescent AIDS Clinical Trials (IMPAACT) network. Youth were eligible if they were 6–17 years old at study entry and had lived with the same primary caregiver for at least 12 months, in order to obtain accurate caregiver assessments of youth symptoms. Youth with intellectual disability ($IQ < 70$) were excluded owing to concerns associated with an extensive battery of self-assessment measures. Controls were uninfected youth meeting these same criteria and were either perinatally HIV-exposed or living in a household with at least one HIV-infected member.

In order to enroll a representative study population, some studies have approved participant registration requests with a certain probability, sometimes within study-defined strata.^{42–43} However, this approach can be biased by neglecting hard to reach patients who rarely present at the clinic. In addition, clinical research sites find such designs difficult to implement because willing candidates may be prevented from enrollment. Instead, we developed a design based on random ordering of all potentially eligible participants.

Sites submitted a screening form for each potential participant reporting the age, gender, and race/ethnicity. This information was deemed by both the funding agency and individual site IRBs to be sufficiently limited that it did not require signed informed consent. Using these screening forms, the PHIV screened youth were randomly ordered into blocks of 8 within each site, balanced by gender and age (<12 , 12 years). The recruitment blocks allowed sites to contact and enroll multiple participants within a given time period, and sites were allowed to enroll as many youth as they could manage provided they completed blocks in the pre-specified order. Thus, all screened youth within a block either had to be enrolled, identified as ineligible, or confirmed as unwilling to enroll before the site could proceed to the next block. For screenees who agreed to enroll, both the screening ID and standard patient ID numbers were entered, allowing the study team to link information at the individual level. A similar process was implemented for the Control group. Use of randomly ordered recruitment blocks provides a representative sample regardless of how many blocks a site completed, in contrast to simply allowing sites to choose which participants they wanted to enroll.

Similarity between age and gender distributions between the PHIV and Control cohorts was designed by setting target accrual of 100 participants for each of the four age-gender groups within each cohort, such that balance would be achieved if the study fully accrued its target sample size (400 within each of the PHIV and Control cohorts).

Study Assessments

Participants were assessed at study enrollment and at 1 and 2 years after entry, with each visit taking 2–3 hours. Instruments were available in both English and Spanish. Caregivers reported their education level, household income, and biological relationship to the study participant. Information about family environment and the youth's neuropsychological, school and social functioning was collected via questionnaires. For PHIV youth, antiretroviral (ARV) medication histories and HIV disease severity measures were obtained through chart reviews and face-to-face clinical interviews.

At each study visit, participating youth and their primary caregivers completed behavior rating scales (Youth Inventory-4 and Child and Adolescent Symptom Inventory-4R, respectively) based on the Diagnostic and Statistical Manual of Mental Disorders IV (DSM-IV).⁴⁴⁻⁴⁵ These rating scales include symptoms of common childhood psychiatric conditions, which we grouped into four categories of targeted disorders: ADHD (inattentive, hyperactive, or combined type), anxiety (generalized anxiety and separation anxiety disorders), disruptive behavior (conduct and oppositional defiant disorders), and depression (major depression and dysthymia). These previously validated rating scales do not require administration by licensed and/or trained psychologists, reducing their cost and increasing the ease of assessment, and have demonstrated high reliability and internal consistency for evaluation of child and adolescent psychiatric symptoms.⁴⁶⁻⁴⁷ Youth reported on their symptoms and caregivers rated both their child's symptoms as well as their own, as detailed previously.⁸⁻⁹ The presence of psychological conditions was determined by predefined cutoff scores (as defined by DSM-IV threshold criteria) for each condition. Severity scores also were computed for each condition. In addition, we constructed a composite category of "any disorder", reflecting whether a participant met or exceeded threshold criteria for any of these targeted conditions or for a limited number of additional disorders (somatization, bipolar disorder, post-traumatic stress disorder, or social phobia).^{8,9,38-41} Younger children (<12 years of age) did not self-report ADHD or disruptive behavior symptoms owing to concerns about the validity of self-assessment of these symptoms by young children.⁴⁶⁻⁴⁷

This study was approved by an Institutional Review Board (IRB) at each participating clinical site. Written informed consent was obtained from primary caregivers of all participants and assents were obtained from youth as allowed by local IRBs. Each participating site submitted an implementation plan for managing psychiatric referrals and unintended HIV disclosure, recruitment and retention, incentives and quality control. Incentives varied by site owing to differences in local IRB requirements, and included cash or vouchers to cover the cost of attending the study visit (eg., meals or parking), as well as small cash amounts, gift cards, or vouchers.

Statistical Analyses

Participation rates were summarized overall, by age/gender strata and HIV status, and compared between cohorts using Fisher's exact test. Reasons for ineligibility and refusal to participate were compared using Chi-square tests. Logistic regression models were used to evaluate socio-demographic risk factors for LTFU, which we defined as missing the 2-year study visit. Models were fit including all enrolled participants with a completed baseline visit, and were separately fit to the subset of PHIV participants to evaluate the added contribution of HIV disease severity. Individual covariates with $p < 0.15$ were considered for inclusion in a multivariable model, which was reduced to those covariates with $p < 0.15$. This resulted in two separate core models, one for all participants and one among PHIV participants. We fit logistic regression models to evaluate both youth self-assessed and caregiver-assessed psychiatric conditions at baseline as risk factors for LTFU, both unadjusted and adjusted for the aforementioned core covariates. Primary emphasis was given to presence of psychiatric conditions based on DSM-IV symptom cutoffs, but we also evaluated the continuous severity scores of each psychiatric condition. In addition, we evaluated potential interactions of HIV status with both demographic and psychiatric conditions on risk for LTFU via inclusion of interaction terms in the logistic regression models. Sensitivity analyses were conducted to account for correlation of youth within both families and within clinical sites, via Generalized Estimating Equations with an equicorrelation assumption.

Results

Characteristics of Screened Candidate Participants

A total of 1328 PHIV and 986 Control youth were screened by participating sites (Table 1 and Figure 1), of which 1319 and 962, respectively, were randomly ordered into blocks of 8 youth within each site. Not included were individuals who did not meet the age requirements or were screened after the announced deadline. Four screenees under age 6 were included with the stipulation that study visits occur after age 6. Among those included in the randomly ordered site lists, 863 screenees (485 PHIV, 378 Controls) were never contacted due to study closure. Of the remaining 1418 screenees, 256 were determined to be ineligible (174 PHIV, 82 Controls). The primary reason for ineligibility was that the youth had not lived with their caregiver for the last 12 months (101 screenees, or 39% of ineligible). Ineligibility was more often the result of intellectual disability in PHIV youth than in Controls (26% vs 9%), consistent with higher cognitive impairment observed in PHIV youth,⁴⁸ and also was more often attributable to death or relocation (16% vs 0%, respectively), whereas caregiver issues accounted for a similar percentage of ineligible PHIV and Control youth (40% and 38%, respectively).

Participation Rates and Reasons for Refusal

Of the 1162 eligible youth who were approached, 582 participated (323 PHIV and 259 Controls, 49% and 52% of eligible, respectively) (see Figure 1). Over half of the sites (16/29, 55%) enrolled more than half of their eligible contacted youth, with 5 sites enrolling over 90% of their eligible candidates. Among the 580 youth who refused to participate, the primary reasons included difficulties with the time commitment or travel to the site ($n=205$, 35%), caregiver concerns about privacy or disclosure of HIV status ($n=123$, 21%), active illness preventing participation ($n=10$, 2%), and general unwillingness to participate ($n=242$, 42%), with no overall difference in the distribution of reasons for refusal between PHIV and Controls.

Participation rates by youth and caregiver characteristics at screening are summarized in Table 2. Participation rates did not differ significantly by gender or by HIV status. Participants were slightly older on average than non-participants and participation rates were higher among Black non-Hispanic and Hispanic youth than among White non-Hispanic youth ($p=0.01$). The older age of participants versus non-participants was primarily observed among the PHIV screenees (median 13.1 vs 12.0 yrs, $p<0.001$), whereas there was no age difference for Controls (median 11.2 vs 11.0 yrs, $p=0.40$).

PHIV youth and Controls who enrolled were comparable by gender, race and ethnicity, as reported previously.⁹ However, PHIV youth were older on average than Controls, less likely to live with biological parents and more likely living in households with higher household income and caregiver education. At study entry, 83% of the PHIV youth were taking highly active ART (HAART). At the baseline visit, both groups had a similar prevalence of psychiatric symptoms based either on youth self-report or caregiver assessment (61% with at least one condition), although PHIV youth had slightly higher rates of conduct disorder.⁸⁻⁹

Retention in Study at 2-year Follow-up Visit

Among the 575 enrolled participants who completed a baseline visit, 506 (88%) attended the 1-year follow-up visit and 465 (81%) attended the 2-year follow-up visit, including 22 youth who missed the Year 1 visit but returned at Year 2 (Figure 1). The retention rates over the 2-year study were significantly higher for PHIV participants than for Controls (84% vs 77%, $p=0.03$). In adjusted logistic regression models for LTFU (see Table 3), PHIV participants and those whose primary caregiver was their biological mother had reduced odds of LTFU

(adjusted odds ratios (aORs)=0.45, $p=0.002$; aOR=0.61, $p=0.06$, respectively). In contrast, increased odds of LTFU were observed for youth whose caregivers had at least a high school education (aOR=2.40, $p=0.003$) or higher annual income (aOR=1.61, $p=0.07$). Although Hispanic youth had reduced odds of LTFU in unadjusted models, this finding did not persist after adjustment for other socio-demographic factors. We observed no association of age with LTFU after adjustment for HIV status, and no interaction between HIV status and any demographic risk factor.

Our study included 457 families, of which 91 (20%) enrolled two or more children and 45 (10%) included at least one PHIV and one Control youth. However, even after adjusting for within family correlation in LTFU, there remained a significant decrease in LTFU for PHIV as compared to Control youth (aOR=0.49, 95%CI: 0.32, 0.75, $p=0.001$). Effects of other socio-demographic predictors shown in Table 3 remained similar. Sensitivity analyses accounting for clustering of youth within research sites also yielded very similar estimated associations.

In models adjusting for socio-demographic covariates, youth with at least one self-assessed psychiatric condition compared to those without had a 56% increased odds of LTFU ($p=0.05$, Table 3). The rate of LTFU for Controls was fairly similar for those with and without a psychiatric condition (20.9% vs 24.1%) whereas the percent LTFU was twice as high for PHIV youth with versus without psychiatric conditions (23.9% vs 10.9%, p -value for interaction test=0.011). Although no individual condition was a significant predictor of LTFU, estimated odds ratios were consistently above 1. No association with LTFU was observed for any psychiatric condition by caregiver assessment (Table 3). Additional analyses evaluating associations with symptom severity scores indicated greater odds of LTFU for youth with higher self-assessed severity of ADHD or disruptive behavior symptoms (Supplemental Table I).

Within the subset of PHIV youth, associations of demographic measures with LTFU were similar to those for the overall study population (Table 4). In addition, PHIV youth with higher viral load at entry had almost twice the odds of LTFU (aOR=1.90, $p=0.08$), whereas those receiving HAART at entry had reduced odds (aOR=0.53, $p=0.08$). After adjustment for socio-demographic and HIV disease severity measures, youth with any self-assessed psychiatric condition had over three-fold higher odds of LTFU (aOR=3.11, $p=0.001$). The psychiatric condition associated with the highest odds of LTFU was anxiety disorder (aOR=2.77, $p=0.003$). However, in analyses based on severity scores, youth with higher self-assessed symptom severity had significantly higher odds of LTFU for each of the four targeted conditions (Supplemental Table II). In evaluating the association of caregiver-assessed psychiatric conditions with LTFU, we observed marginally increased odds of LTFU for youth with at least one condition (aOR=1.90, $p=0.07$), and for all other specific conditions except anxiety (Table 4). Higher caregiver-assessed severity scores for disruptive behavior were also associated with LTFU (Supplemental Table II).

Discussion

As PHIV youth are living longer owing to advances in treatment and clinical management, improving our understanding of psychiatric and neurocognitive outcomes and their treatment options has developed into a top research priority. However, observational studies and clinical trials face challenges in enrolling representative samples of participants with HIV as well as those living in families affected by HIV. These difficulties are exacerbated by both declining participation in health research in the U.S. owing in part to decreases in volunteerism and a lack of trust in scientific research, particularly in pediatric and underserved populations.^{49–54}

In our study, 50% of eligible youth agreed to participate. This rate is slightly higher than the 42% enrollment rate observed among the HIV-infected pregnant women enrolling into the US-based IMPAACT P1025 perinatal cohort study,⁴² but is slightly lower than a single-visit study of metabolic abnormalities in youth with HIV, in which 60% of screened eligible youth participated.⁴³ We observed similar rates of participation by HIV status, in contrast to the PACTS-HOPE study which reported a much higher enrollment rate in HIV-infected youth than in HIV-exposed uninfected controls (89% vs 22%).⁴⁹ Pediatric health research studies in non-HIV settings have reported higher response rates for completion of questionnaires, but lower response rates for studies that involve a clinical examination or collection of biological samples.⁵¹ Our study required no physical examination or collection of biological samples, but required completion of an extensive battery of psychiatric questionnaires at the clinical sites, which may have led to decreased participation rates.

After exclusion of ineligible and non-approached candidates, we observed the highest participation rates among Hispanic families, similar to findings of Freedman et al.⁴⁹ The P1025 study of HIV-infected pregnant women also observed a higher enrollment rate among Hispanics than non-Hispanic whites (28% vs 20%) and an even lower rate among non-Hispanic Blacks (17%).⁴² In our study, Hispanic participants also had lower odds of LTFU, but this finding did not persist in adjusted models, possibly due to the correlation of Hispanic ethnicity with other demographic measures.

The P1055 study successfully retained over 80% of enrolled participants over the 2-year study follow-up period, which compares favorably with other studies of youth with HIV infection.^{35–37} High retention was achieved in part by requiring sites to develop a retention approach as part of their site implementation plan. Most sites attempted to maintain engagement with participants through frequent contact between study visits (e.g., telephone, mailings) along with financial incentives or vouchers for meals and transportation costs. However, the retention rate for Controls was lower, which may be partially attributable to their avoidance of the potential stigma associated with being seen at an HIV clinic,⁵⁵ and by the fact that most did not receive routine care at the clinical sites.³⁵

Although retention rates were high overall, youth with a self-assessed psychiatric condition were less likely to remain on study for the 2-year follow-up. This difference in retention rates was more evident in the PHIV youth than in the Controls, and among PHIV youth there were also similar associations of youth- and caregiver-assessed psychiatric conditions with LTFU. Studies of drug and alcohol treatment programs among adolescents also have observed lower retention rates for those with ADHD, whereas inconsistent patterns of retention have been reported among those with conduct disorder.^{56,57} The observed association of lower retention among PHIV youth with psychiatric conditions at entry is consistent with findings in adults^{15–17} and has several implications. First, it may lead to underestimates in the prevalence of psychiatric conditions at later ages, and may similarly bias estimates of persistent or resolving psychiatric diagnoses over time. Secondly, it may introduce bias into analyses of the determinants of psychopathology in PHIV youth, particularly for risk factors which influence both psychiatric status and attrition. Approaches to adjust for selective attrition such as use of inverse-probability-weighting methods, imputation of missing psychiatric status outcomes based on measured covariates, and sensitivity analyses under various assumptions regarding differences in associations between dropouts versus retained youth may be desirable if the rates of attrition are high.^{22,24,29}

Other characteristics associated with lower retention in this study included higher socioeconomic status, in contrast to prior studies which have generally observed both lower participation rates and lower retention rates for those of lower socioeconomic status.^{35–37,50,53} Within the limited range of our study, we observed no differences by age in

LTFU after adjustment for HIV infection status, whereas prior studies have found higher rates of LTFU among older adolescents.^{35,51} We observed higher retention among females, consistent with other epidemiologic research studies.⁵⁰ Among PHIV youth, we observed marginally higher rates of LTFU among those with greater HIV disease severity and lower LTFU among those receiving HAART therapy, as noted in other studies.³⁵ These findings suggest that youth who return regularly to clinics to obtain ART medications may find study participation more convenient or perceive more personal benefit for attending research visits. Alternatively, clinicians may be more willing to initiate HAART in PHIV youth perceived to have good compliance with both treatment and scheduled clinic visits.

Our study design neglected to take into account household structure, and thus siblings were occasionally in separate blocks and could not be enrolled at the same date. Future studies should consider random ordering in clusters by household, to enhance enrollment of multiple family members. Our study strengths included being able to evaluate participation based on characteristics of individual participants. Finally, our study demonstrated the feasibility of maintaining relatively high retention rates over the 2-year follow-up period. Future studies may require creative approaches for engaging the HIV-affected community in research efforts and in promoting retention efforts, particularly for youth with psychiatric conditions.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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Appendix

The following institutions and individuals participated in IMPAACT P1055:

Children's Hospital Boston: Sandra Burchett; **UCLA-Los Angeles AIDS Consortium:** Karin Nielsen, Nicole Falgout, Joseph Geffen, Jaime Deville; **Long Beach Memorial Medical Center:** Audra Deveikis; **UCLA Medical Center:** Margaret Keller; **University of Maryland Medical Center:** Vicki Tepper; **Chicago Children's CRS:** Ram Yogev; **UCSF Pediatric AIDS CRS:** Diane Wara; **UCSD Maternal Child and Adolescent HIV CRS:** Stephen Spector, Lisa Stangl, Mary Caffery, Rolando Viani; **Duke University Medical Center:** Kreema Whitfield, Sunita Patil, Joan Wilson, Mary Jo Hassett, **New York University School of Medicine:** Sandra Deygoo, William Borkowsky, Sulachni Chandwani, Mona Rigaud; **Jacobi Medical Center:** Andrew Wiznia; **Univ. of Washington Children's Hosp. Seattle:** Lisa Frenkel; **USF Tampa:** Patricia Emmanuel, Jorge Lujan Zilberman, Carina Rodriguez, Carolyn Graisber; **Mt Sinai School of Medicine:** Roberto Posada, Mary Dolan; **San Juan City Hospital:** Midnela Acevedo-Flores, Lourdes Angeli,

Milagros Gonzalez, Dalila Guzman; **Yale University School of Medicine**: Warren Andiman, Leslie Hurst, Anne Murphy; **SUNY Upstate Medical University**: Leonard Weiner; **SUNY Stony Brook**: Denise Ferraro, Michele Kelly, Lorraine Rubino; **Howard University**: Sohail Rana; **University of Southern California**: Suad Kapetanovic; **University of Florida Jacksonville**: Mobeen Rathore, Ayesha Mirza, Kathleen Thoma, Chas Griggs; **University of Colorado**: Robin McEvoy, Emily Barr, Suzanne Paul, Patricia Michalek; **South Florida Center for Diagnostic Care**: Ana Puga; **St Jude**: Patricia Garvie; **Children's Hospital of Philadelphia**: Richard Rutstein; **St Christopher's Hospital for Children**: Roberta LaGuerre; **Bronx-Lebanon Hospital**: Murli Purswani; Metropolitan Hospital Center: Mahrukh Bamji; **WNE Maternal Pediatric Adolescent AIDS**: Katherine Luzuriaga.

Figure 1.
P1055 Study Design Flowchart

Table 1
Number of Candidate Participants Screened, Randomly Ordered, and Enrolled by HIV infection Status and Age and Gender Strata.

Age and Gender Stratum	HIV-Infected				HIV-Uninfected Controls			
	Screened	Randomly Ordered	Enrolled	N (% of total)	Screened	Randomly Ordered	Enrolled	N (% of total)
6–11, Female	292	290	65	(22%)	284	276	81	(31%)
6–11, Male	262	261	71	(20%)	277	269	75	(29%)
12–17, Female	390	389	94	(30%)	205	202	55	(21%)
12–17, Male	380	378	92	(29%)	215	212	48	(19%)
Other	4	1	1	(<1%)	5	3	0	(0%)
TOTAL	1328	1319	323	---	986	962	259	---

Table 2

Comparison of Participation Rates by Screening Characteristics, among 1162 Eligible Contacted Candidate Participants

Characteristic	Total Contacted and Eligible (N=1162)	Enrollment Status	
		Participated (N=582)	Refused to participate (N=580)
HIV Status			
Control	502	259 (52%)	243 (48%)
HIV infected	660	323 (49%)	337 (51%)
Age at Entry in years			
Median (IQR)	12.0 (9.2, 14.7)	12.4 (9.5, 14.9)	12.0 (9.0, 14.0)
6 – <9 yrs	222	114 (51%)	108 (49%)
9 – <11 yrs	204	100 (49%)	104 (51%)
11 – <13 yrs	229	110 (48%)	119 (52%)
13 – <15 yrs	237	120 (51%)	117 (49%)
15+ yrs	270	138 (51%)	132 (49%)
Gender			
Male	556	286 (51%)	270 (49%)
Female	606	296 (49%)	310 (51%)
Race/Ethnicity			
White, non-Hispanic	179	76 (42%)	103 (58%)
Black, non-Hispanic	609	295 (48%)	314 (52%)
Hispanic	361	205 (57%)	156 (43%)
Other/Unknown	13	6 (46%)	7 (54%)

Predictors of Loss to Follow-up (LTFU) at 2 Years based on Logistic Regression Models, including 575 Eligible Youth with Completed Baseline Visit

Table 3

Predictor	% Lost to Follow Up		Unadjusted Model for LTFU		Adjusted Model for LTFU ^a		
	% in category	In category	Not in category	OR (95% CI)	p-value	aOR (95% CI)	p-value
Demographic Characteristics ^b							
Male	50%	22%	17%	1.40 (0.92, 2.13)	0.11	1.44 (0.91, 2.27)	0.12
Hispanic	35%	14%	22%	0.56 (0.35, 0.90)	0.02	---	---
HIV-infected	55%	16%	23%	0.64 (0.42, 0.96)	0.03	0.45 (0.27, 0.75)	0.002
Caregiver is biological mother	51%	15%	23%	0.59 (0.38, 0.90)	0.01	0.61 (0.36, 1.03)	0.06
Caregiver has HS education	65%	24%	10%	2.89 (1.70, 4.90)	0.001	2.40 (1.34, 4.29)	0.003
Annual income >\$20K/year	44%	26%	14%	2.12 (1.36, 3.31)	0.001	1.61 (0.96, 2.70)	0.07
Child-assessed psychiatric conditions based on symptom cutoff criteria							
ADHD ^c	11%	30%	18%	1.97 (0.88, 4.40)	0.10	1.80 (0.78, 4.17)	0.17
Disruptive behavior ^c	14%	23%	19%	1.27 (0.59, 2.74)	0.55	1.24 (0.55, 2.79)	0.61
Anxiety	32%	23%	17%	1.44 (0.93, 2.23)	0.10	1.57 (0.99, 2.50)	0.06
Depression or Dysthymia	16%	22%	19%	1.24 (0.71, 2.14)	0.45	1.26 (0.71, 2.24)	0.43
Any Disorder ^d	43%	23%	17%	1.46 (0.96, 2.23)	0.08	1.56 (1.00, 2.43)	0.05
Caregiver-assessed psychiatric conditions based on symptom cutoff criteria							
ADHD	13%	24%	18%	1.47 (0.82, 2.62)	0.19	1.31 (0.71, 2.42)	0.38
Disruptive behavior	9%	24%	18%	1.41 (0.71, 2.80)	0.33	1.14 (0.55, 2.35)	0.72
Anxiety	12%	14%	19%	0.69 (0.34, 1.40)	0.30	0.84 (0.40, 1.74)	0.63
Depression or Dysthymia	2%	30%	19%	1.87 (0.48 (7.36)	0.37	1.76 (0.41, 7.60)	0.45
Any Disorder ^d	39%	20%	18%	1.19 (0.77, 1.84)	0.43	1.17 (0.75, 1.83)	0.49

LTFU=lost to follow-up, OR=odds ratio, aOR=adjusted OR, CI=confidence interval, ADHD=attention-deficit hyperactivity disorder.

^aEach psychiatric condition was evaluated separately, adjusted for demographic covariates with p<0.15, including male gender, HIV infection status, type of caregiver (biological mother or not), caregiver education level, and household income level, as shown under adjusted model. Predictors without an entry in this column did not meet criteria for inclusion in the final adjusted model.

^bMissing data for demographic characteristics included 4 participants with unknown relationship of caregiver, 7 with unknown caregiver education level, and 56 who did not wish to report income level. Percentages are calculated among those with non-missing information.

^c ADHD and disruptive behavior self-assessed only for youth 12 years or older (N=304).

^d "Any disorder" includes conditions in table as well as somatization, bipolar disorder, post-traumatic stress disorder, and social phobia.

Table 4

Predictors of Loss to Follow-up (LTFU) at 2 Years based on Logistic Regression Models Among 319 Perinatally HIV-infected Youth

Predictor	% Lost to Follow Up		Unadjusted Model for LTFU		Adjusted Model for LTFU ^a	
	In Category	Not in Category	OR (95% CI)	p-value	aOR (95% CI)	p-value
<i>Demographic Characteristics^b</i>						
Male	51%	19%	1.60 (0.87, 2.94)	0.13	1.66 (0.88, 3.14)	0.12
Hispanic	31%	14%	0.81 (0.42, 1.59)	0.55	---	---
Caregiver is biological mother	35%	9%	0.42 (0.20, 0.87)	0.02	0.40 (0.19, 0.84)	0.02
Caregiver has HS education	70%	19%	2.16 (1.01, 4.65)	0.05	2.14 (0.98, 4.70)	0.06
Annual income >\$20K/year	52%	21%	2.09 (1.07, 4.08)	0.03	---	---
<i>HIV Disease Severity Characteristics</i>						
Viral load >10,000 cp/mL	20%	23%	1.82 (0.92, 3.57)	0.08	1.90 (0.93, 3.89)	0.08
CD4% < 15%	7%	27%	2.10 (0.78, 5.65)	0.14	---	---
CDC Class C Diagnosis	23%	18%	1.19 (0.59, 2.37)	0.63	---	---
On HAART at Entry	83%	14%	0.48 (0.24, 0.96)	0.04	0.53 (0.25, 1.09)	0.08
Not on ARV at Entry	8%	28%	2.21 (0.87, 5.60)	0.10	---	---
<i>Child-assessed psychiatric conditions based on symptom cutoff criteria</i>						
ADHD ^c	10%	32%	2.31 (0.81, 6.55)	0.12	1.84 (0.62, 5.50)	0.28
Disruptive behavior ^c	12%	17%	0.89 (0.29, 2.79)	0.85	1.08 (0.32, 3.58)	0.90
Anxiety	29%	24%	2.12 (1.14, 3.94)	0.02	2.77 (1.42, 5.40)	0.003
Depression or Dysthymia	14%	22%	1.58 (0.73, 3.44)	0.25	1.85 (0.82, 4.18)	0.14
Any Disorder ^d	42%	24%	2.55 (1.38, 4.72)	0.003	3.11 (1.61, 6.01)	0.001
<i>Caregiver-assessed psychiatric conditions based on symptom cutoff criteria</i>						
ADHD	14%	27%	2.36 (1.12, 4.99)	0.02	2.06 (0.93, 4.57)	0.08
Disruptive behavior	7%	30%	2.53 (0.98, 5.42)	0.05	2.54 (0.94, 6.90)	0.07
Anxiety	13%	7%	0.37 (0.11, 1.25)	0.11	0.42 (0.12, 1.44)	0.17
Depression or Dysthymia	1%	50%	5.48 (0.75, 39.9)	0.09	6.72 (0.87, 52.1)	0.07
Any Disorder ^d	41%	19%	1.41 (0.77, 2.58)	0.27	1.90 (0.94, 3.84)	0.07

LTU=loss to follow-up, OR=odds ratio, aOR=adjusted OR, CI=confidence interval, HS=high school, ADHD=attention-deficit hyperactivity disorder, CDC=Centers for Disease Control and Prevention, HAART=highly active antiretroviral therapy, ARV=antiretroviral

^aEach psychiatric condition was evaluated separately, adjusted for demographic and HIV disease severity covariates including male gender, type of caregiver (biological mother or not), caregiver education level, HIV-1 viral load >10,000 copies/mL at study entry, and current HAART use at study entry, as shown under adjusted model. Predictors without an entry in this column did not meet criteria for inclusion in the final adjusted model.

^bMissing data for demographic characteristics included 2 participants with unknown relationship of caregiver, 5 with unknown caregiver education level, and 39 who did not wish to report income level. Percentages are calculated among those with non-missing information.

^cADHD and disruptive behavior self-assessed only for youth 12 years or older (N=199).

^d“Any disorder” includes conditions in table as well as somatization, bipolar disorder, post-traumatic stress disorder, and social phobia.