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Brief Report: Language Ability and School Functioning of Youth Perinatally Infected with HIV

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Abstract

Introduction—The purpose of this paper is to describe the language ability and school functioning of early adolescents with perinatal HIV/AIDS.

Method—Participants included 43 youths, 9–15 years, and their primary caregivers. Youths completed the Peabody Picture Vocabulary Test (PPVT) and the Reading Subtest of the Wide Range Achievement Test (WRAT3), and were interviewed regarding their future educational aspirations and parental supervision and involvement with homework. Caregivers were interviewed regarding the child’s school achievement, parental supervision and monitoring, and educational aspirations for their child.

Results—Fifty-four percent of youths scored below average (<25th percentile) on the PPVT, and 29% scored <10th percentile; 40% scored below average (<25th percentile) on the WRAT3, and 24% scored <10th percentile. Scores were associated with parental monitoring and educational aspirations.

Discussion—Youths performed poorly on tests of verbal and reading ability, although not dissimilar to other samples of inner-city youths. Future research should attempt to isolate the impact of HIV disease on intellectual and school functioning of HIV+ youths.

Keywords

perinatal HIV infection; verbal ability; reading ability

With the advent of antiretroviral treatment (ART), children living with perinatal HIV/AIDS are reaching adolescence in large numbers. By 2006, in New York City (NYC), over 60% of children living with perinatal HIV/AIDS were over the age of 13 years (NYC DOHMH, 2006). They are primarily poor ethnic minorities living in impoverished, inner-city communities with a large number of risk factors for poor cognitive functioning (e.g., exposure to substances in utero, attendance at schools in “poor performance districts”, co-morbid behavioral problems, inconsistent school attendance due to poor health or health care appointments). Clinical reports indicate that older school age perinatally infected children present with significant learning problems affecting their ability to perform in school, achieve developmental milestones, and function independently (Martin, 2006). Poor educational

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achievement, including poor development of reading and verbal skills, might place this cohort at risk for difficulty understanding their illness and its treatment, adhering to potentially complex medication regimens, and making decisions about sexual and/or drug risk behaviors as has been found in HIV-positive (HIV+) adults and other populations of adolescents (Halpern, Joyner, Udry, & Suchindran, 2000; Hinkin et al., 2002; Wagner, 2002).

From the beginning of the epidemic, there have been consistent findings of significant neurological, developmental, cognitive and language deficits in HIV-infected infants and younger children (Belman et al., 1996; Coplan et al., 1998; Epstein et al., 1988; Mellins et al., 1994). Unfortunately, less is known about these children as they age. In general, the severity of neurologic and neuropsychologic compromise increases with the severity of HIV-related illness (Pulsifer & Aylward, 2000; Jeremy et al., 2005). Prior to the advent of ART, two relatively distinct neurodevelopmental patterns were described in largely untreated HIV-infected infants and children: progressive encephalopathy, characterized by the loss of developmental milestones, declining IQ scores, increasing difficulties with language, attention, concentration, and memory, and static encephalopathy, characterized by non-progressive deficits in cognitive, motor and/or language function, likely attributable to prenatal drug exposure, prematurity, low birth weight and heritable or environmentally mediated impairment rather than the disease itself (Epstein et al., 1988; Brouwers et al., 1991; Mellins et al., 1994). Before the development of ART, HIV-related encephalopathy was a common sequela of HIV infection in children, reported in 35–50% of children with pediatric AIDS (Lobato et al., 1995; Rigardetto et al., 1999; Cooper et al., 1998). Since the advent of ART, the rate of HIV encephalopathy has declined markedly, yet with some residual neurological, cognitive and academic difficulties (Chiriboga et al., 2005; Jeremy, 2005; Manisha et al., 2005).

To date, few if any research studies of perinatally infected older children and adolescents have documented their level of cognitive functioning and/or educational attainment as they approach adolescence or factors that might be associated with that functioning. One study by Martin and colleagues (2006) found that children and adolescents (6–16 years, mean = 11 years) with HIV infection being treated with ART typically score at the low end of the Average range on a composite measure of cognitive functioning, and children with CT scan abnormalities are at risk for poorer cognitive functioning than those without scan abnormalities. One recent dissertation that looked at overall cognitive functioning of HIV+ and negative youth (mean age = 10.2 years) found that HIV+ youths who were healthier performed similarly to HIV-negative youth, but that lower CD4 percentages were associated with lower overall cognitive functioning (Shaw, 2007). Information about cognitive functioning of these youths would be useful to both clinical providers as well as for educational and vocational planning.

Given that perinatally HIV-infected youths were not expected to live to adolescence, parental expectations as well as their own expectations regarding school achievement may be low. Although adolescence marks the time when children become more independent from parents and rely more on peer groups, they continue to rely on their parents for guidance. Parental involvement and supervision are critical for children's academic functioning and have been associated with positive school adjustment and better grades for children, particularly in language achievement (e.g., Klein & Forehand, 2000; Gutman, Sameroff, & Eccles, 2002). Among a sample of perinatally HIV-infected youths ages 9–15 years, the goals of this brief report are to 1) describe levels of verbal ability, reading ability, and school achievement, and 2) examine child and family factors (e.g., health status, parental supervision and monitoring) that might predict those skills. We hypothesize that a) these youths will score poorly when compared to the general population, b) youths with greater disease progression will have lower scores, and c) family factors, such as parental involvement and interest in school functioning will be associated with better scores.

Methods

Participants and Procedures

In a pilot study for a larger, longitudinal project examining a range of psychosocial and behavioral functioning variables (Mellins, Brackis-Cott, Dolezal, & Abrams, 2006), 43 early adolescents perinatally infected with HIV/AIDS and their primary caregivers were recruited in 2004 from a comprehensive pediatric HIV care and research program in NYC. Inclusion criteria for youth were 1) perinatal infection with HIV, 2) ages 9–16 years, 3) English speaking, and 4) having a legal guardian who could provide informed consent. Caregivers had to be English or Spanish speaking. Both youths who had and had not been formally told of their HIV status were included.

To determine eligibility, a list of all eligible families was created by the medical director (n=63). Each caregiver was approached by a medical provider during the child's monthly medical appointment. The project was presented and verbal consent to be contacted by the research team was requested. A member of the research team then contacted the family to further explain the study and confirm eligibility and interest. Of the 63 eligible dyads, 48 were enrolled; 13 refused to participate due to time constraints, family stressors, or lack of interest; two dyads agreed to participate but were never available to be interviewed. New York State HIV confidentiality laws preclude any data collection on families who refused participation.

Caregivers and children signed consent/assent forms and were interviewed simultaneously and separately at two time points, one-to-three months apart (to reduce interview burden). Each interview lasted from one to two hours and was conducted at the youth's medical clinic (79%), research offices (15%), or the families' homes (5%) depending on participant preference. Participants were compensated \$25 for each interview, and reimbursed for travel expenses. This study received Institutional Review Board approval and was compliant with the Health Insurance Portability and Accountability Act of 1996. Among the 48 dyads enrolled who received the first interview, 4 were not able to complete the two study interviews within the three month time period, and one (2%) child was too distressed to complete the interview. Thus, the final sample size was 43.

Assessments

Child verbal ability and reading skills

The Peabody Picture Vocabulary Test, is a widely used test of verbal ability (PPVT-III, Dunn & Dunn, 1997). The examiner reads each word aloud; the child chooses which of four pictures best illustrates the word. The Wide Range Achievement Test (WRAT3; Wilkinson, 1993) Reading Subtest is a widely used measure of reading skills, focusing on recognizing and naming letters and pronouncing printed words. Excellent psychometric properties have been established including reliability and validity for both measures (Dunn & Dunn, 1997; Wilkinson, 1993).

Maternal-child supervision and involvement

The Supervision and Involvement Scale (S&I Scale) from the Pittsburgh Youth Study (Loeber, Stouthamer-Loeber, Van Kammen, & Farrington, 1991) was administered to caregivers and youths and consists of 37 items assessing the caregiver's knowledge of where the child is at all points in the day, family routines, caregiver's knowledge of child's friends, amount of time caregiver and youth spend together, etc. The Pittsburgh Youth Study is a longitudinal study of a community sample of inner-city boys documenting the development of antisocial and delinquent behavior from childhood to early adulthood. The scale is based on a literature review of family factors related to delinquency (Loeber & Stouthamer-Loeber, 1986), on Moos'

Family Environment Scale (Moos & Moos, 1975), and Skinner, Steinhauer, and Santa-Barbara's (1983) Family Assessment Measure. Descriptions of the psychometrics have been published elsewhere supporting the use of this measure (Loeber, Drinkwater, Yin, Anderson, Schmidt & Crawford, 2000). Caregiver and youth versions of this measure are not comparable. We used the communication, supervision, and monitoring scales from the caregiver responses only for this paper.

Future goals and school motivation

Questions from the Monitoring the Future survey (Johnstone, Bachman, O'Malley, 1993) were used to assess the youths' future goals in the areas of school and vocational aspirations as well as the caregivers' goals for their children. In addition, caregivers and youths were asked to report on level of parental supervision over homework and amount of communication about homework. Monitoring the Future is an ongoing study of the behaviors, attitudes, and values of American secondary school students, college students, and young adults and has been administered annually since 1975. Adequate psychometric properties have been established for this measure (Johnston, O'Malley, Bachman, & Schulenberg, 2007).

Demographics

Items included child age, gender, ethnic identity, child relationship to caregiver (biological vs. adoptive), household income, education and work status of caregiver, single-parent status of caregiver. Caregivers also reported on whether the child was in special or regular education classes, whether the child had ever skipped a grade, been held back, suspended, expelled.

Child health status

CD-4+ number (cells/m³), HIV RNA viral load (copies/ml) values and CDC classification for the closest date to the research interview were obtained through medical record abstraction. The mean interval between the date chart abstractions were obtained and the research interview was completed was 67 days (range=12–184 days).

Data Analyses

Post hoc, secondary analyses were conducted on youths' verbal ability, reading ability, and school achievement. SPSS was used to generate descriptive statistics. Regression analyses were used to assess the associations between WRAT3/PPVT scores and various predictor variables. Individual models were tested for each predictor variable separately. We also ran these analyses on dichotomized outcome variables (WRAT3 <25th percentile vs. > 25th percentile, PPVT <25th percentile vs. > 25th percentile). The pattern of significant associations was comparable to analyses using continuous scores (data not shown). Some variables from the Monitoring the Future survey had little to no variability and thus were deemed inappropriate for inclusion in statistical analyses and only used for descriptive purposes.

Results

Table 1 describes the demographic characteristics of the youths and their caregivers. Table 2 describes school-related difficulties for these youths.

Verbal and reading ability

The mean PPVT score was 84.65 (SD=16.66). Scores ranged from 1st–87th percentile (mean=24th percentile); 54% scored below average (<25th percentile) and 29% scored <10th percentile. The mean WRAT3 score was 91.72 (SD=18.25). Scores ranged from <1st–95th percentile (mean=38th percentile); 40% of the sample scored below average (<25th percentile) and 24% scored <10th percentile.

Caregiver-child educational involvement

The majority of caregivers reported that it was very important that their child graduate high school (95%), attend college (84%), graduate college (88%), and get a job (93%). Similarly, the majority of youths felt they definitely would graduate high school (74%), go to college (74%), graduate college (74%), and get a job (61%). Both caregivers and youths reported high levels of parental supervision over homework. All of the caregivers reported that they either ask if homework is done or ask to review it; 86% of youths said that their caregivers ask if homework is done and 70% ask to review it. Both caregivers and youths reported good communication about school. All of the caregivers reported talking with their children about school in the past month; 65% of the youths reported talking with their caregivers about school in the past month.

Associations with verbal and reading ability

Increased parental monitoring of the child (the parental monitoring subscale of the S&I scale) was associated with better PPVT scores ($b=14.3$, $se=5.8$, $p=.018$) and better WRAT3 reading subscores ($b=24.4$, $se=8.6$, $p=.007$). Better WRAT3 reading subscores were also associated with the greater level of importance parents placed on going to college ($b=16.3$, $se=7.3$, $p=.032$). Neither the PPVT or WRAT3 subscores were related to CD4+ number, viral load, CDC classification, child relationship to caregiver, whether caregiver was single parent, caregiver employment, caregiver education, income, or child or caregiver ethnic identity.

Discussion

Although caregivers and youths reported high educational aspirations and levels of parental supervision over homework, our sample of perinatally HIV-infected youths scored poorly on measures of language functioning: 29% scored <10th percentile on the PPVT and 24% scored <10th percentile on the WRAT3. Large numbers of youths were academically retained and placed in special education classes.

As hypothesized, performance by this cohort of early adolescents was below age expectations. However, performance was similar to previous studies of urban African-American uninfected children (Luster & McAdoo, 1994), prenatally drug exposed children (Goldschmidt, Richardson, Corneliuss, & Day, 2004), and impoverished inner-city chronically ill adolescents (Silver, Bauman, Coupey, Doctors, & Boeck, 1990), suggesting that poor language functioning may not necessarily be attributed to HIV infection. Rather, the etiology may likely be multifactorial, including the realities of living in impoverished neighborhoods with under-resourced schools, and the immediate stressors of daily living.

Despite comparable achievement profiles between our sample and youths of similar demographic backgrounds, the implications of being placed in a remedial educational setting or being functionally illiterate becomes an additional stigmatizing attribute for youths with HIV. The stressors of living with a chronic stigmatized illness coupled with a sense of educational failure place youths with HIV at further risk for behavioral and health problems. For example, poor language skills may limit youths' ability to understand their illness and compromise their ability to adhere to challenging medication regimens (Hinkin et al., 2002; Wagner, 2002). Furthermore, better skills may operate as a protective factor against early sexual activity during adolescence, and lower intelligence may be a risk factor (Halpern, Joyner, Udry, & Suchindran, 2000).

Contrary to our second hypothesis, language delays were not associated with disease severity. Martin and colleagues' (2006) also found viral load to be unrelated to cognitive test scores, although they found that CD4+ counts ≤ 500 was associated with lower scores on subtests

measuring processing speed. The authors speculate that the lack of association with viral load might be due to the fact that viral load values can be more variable and fluctuate with changes in adherence (Haubrick et al., 1999; Van Dyke et al., 2002). Further research should continue to examine the relationship between markers of disease severity and cognitive functioning.

Although many clinics providing medical care to perinatally HIV-infected youths grapple with these issues, it has been unclear how best to facilitate interventions to increase opportunities for these youths to acquire requisite skills for adult independent living, in part due to limited research. As this population ages, studies examining the association of cognitive and language skills and risk vs. health promoting behaviors will be needed. Interventions to address the learning gap among perinatally infected youths may need to consider multiple risk factors at the individual, familial, and environmental level. Psychosocial interventions for HIV+ children and adolescents commonly focus on behavioral and adjustment difficulties that compromise their medical treatment. However, it may be important to broaden the scope of these psychosocial services to include specialized evaluations and interventions that help youths and their parents identify effective learning strategies or navigate educational systems. Given that high levels of parental supervision and monitoring was associated with better language functioning, strategic family based interventions that promote structured, stimulating home environments, and facilitate caregiver-child interactions may also be helpful in HIV specialized programs for youths. In Coscia and colleagues' (2001) study of impoverished HIV-infected children, for example, stimulating and supportive home settings buffered the negative effects of poverty on cognitive functioning.

In conclusion, although our sample of youths with perinatal HIV infection performed poorly on tests of verbal and reading ability, they were not dissimilar to other samples of inner-city youths. The findings are however limited to a small convenience sample of HIV+ early adolescents receiving medical care from an urban medical center. The cross-sectional study design and small sampling does not allow us to determine the temporal sequence of events. Longitudinal follow-up studies with this cohort are needed to clarify whether family management practices continue to influence children's cognitive and achievement functioning over time. Future research should focus on isolating the impact of HIV disease on intellectual and school functioning of HIV-infected youths by including a comparison group with similar socioeconomic status and other risk factors. Because of the high risk backgrounds of HIV-exposed children, both in the U.S. and internationally, the effects of HIV-infection on cognitive functioning, in the absence of disease progression, are often difficult to disentangle from other background characteristics that are also known to affect neuropsychological outcomes. Notwithstanding these limitations, this study highlights poor verbal and reading ability among youths with perinatal HIV, and highlights the importance of educational and family based interventions that address this emerging need, regardless of its etiology.

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Table 1
 Characteristics of 43 HIV Infected Youth and Their Primary Caregivers*.

Child Variables	n (%)
Race	
African American	35 (81)
Hispanic or Other	8 (19)
Age (in years)	
9–10	12 (28)
11–12	15 (35)
13–14	10 (23)
15	6 (14)
Female Gender	20 (46)
Education (current grade)	
3 rd –4 th	9 (21)
5 th –6 th	15 (35)
7 th –8 th	11 (25)
9 th –10 th	8 (19)
Caregiver Variables	n (%)
Relationship to child	
Biological parent	10 (24)
Adoptive parent	32 (76)
HIV Infected	10(23)
Race	
African American	35 (81)
Hispanic	6 (14)
Age (in years)	22–74 (mean=52)
Female Gender	39 (91)
Education	
< high school	4 (10)
10 th –12 th grade	25 (61)
> high school	12 (29)
Currently unemployed	34 (79)
Single parent	34 (81)

* Note. Numbers do not always sum to 43 due to missing data.

Table 2
School-Related Characteristics for 43 HIV Infected Youth

School-related Characteristics	n (%)
Currently in school (yes)	42 (98)
Ever held back in school (yes)	15 (35)
Ever suspended from school (yes)	10 (23)
Type of class child currently attends	
Regular education	29 (67)
Special education	9 (21)
Resource room or transitional class	5 (12)
Ever attended special education class (yes)	21 (49)
Reason for special education placement (n=21)	
Reading problems	12 (57)
Math problems	8 (38)
Attention problems	7 (33)
Discipline problems	7 (33)