

# Psychological Adjustment in Children and Families Living with HIV

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**Objective** To assess psychological adjustment in children living with human immunodeficiency virus (HIV) and their primary caregivers. **Methods** The study protocol included use of standardized questionnaires to assess emotional and behavioral health of 57 children and 54 caregivers (Phase 1). Positive screening led to standardized interviews to assess current psychiatric diagnoses (Phase 2). **Results** Of the 16 children who entered Phase 2, 6 (38%) met the criteria for a psychiatric diagnosis. Of the 15 adults who met the screening criteria, 13 completed a computerized psychiatric interview and all 13 (100%) met the criteria for a psychiatric diagnosis. **Conclusions** While important mental health needs were identified in families with HIV, the majority of families did not exhibit mental health disorders. These results might reflect the substantial psychosocial resilience of these families. Further study is needed to determine to what extent the mental health needs of children and their caregivers are being met. In addition, identification of protective factors in resilience and coping in families living with a chronic illness is warranted.

**Key words** children and families; HIV; psychological adjustment.

Significant advances in the treatment of human immunodeficiency virus (HIV) have led to dramatic improvements in health outcomes for children born with HIV (Gortmaker et al., 2001; McConnell et al., 2005). Given the complex physiology of the disease, the difficulty of its treatment, and its potential to affect multiple family members, children who live with HIV disease are at risk of a multitude of medical, neurological, and psychosocial problems (Brouwers, Wolters, & Civitello, 1998; Brown, Lourie, & Pao, 2000; Donenberg & Pao, 2005).

Children with a chronic illness have significantly more mental health problems than those who are healthy. For example, children with sickle cell disease were perceived by their caregivers as having more behavioral and emotional problems than their healthy peers (Trzepacz, Vannatta, Gerhardt, Ramey, & Noll, 2004). Children with epilepsy are at greater risk of mental health disorders (i.e., internalizing and externalizing disorders) than are children from the general population (Rodenburg, Stams, Meijer, Aldenkamp, & Dckovic, 2005). Despite the potential psychosocial risks associated

with having a chronic illness, a limited number of empirical studies have examined the prevalence of mental health problems in children living with HIV and their primary caregivers.

Neurological and neuropsychological deficits caused by HIV infection are well documented. Children with HIV are likely to present with learning problems and attentional disorders (Brouwers et al., 1998; Fundaro et al., 1998), behavioral problems (Bose, Moss, Brouwers, Pizzo, & Lorion, 1994; Havens, Mellins, & Pilowsky, 1996; Havens, Whitaker, Feldman, & Ehrhardt, 1994), and cognitive deficits (Armstrong, Seidel, & Swales, 1993; Donenberg & Pao, 2005). However, studies examining the relationship between IQ scores and psychopathology in chronically ill pediatric populations have obtained mixed results. In children with congenital heart disease, IQ was found to be negatively correlated with Child Behavior Checklist (CBCL) (Achenbach, 1991) total problems scores (Utens et al., 1993). In contrast, no relationship was found between IQ and CBCL scores in a population of children and

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adolescents with spinal muscular atrophy (Lauferweiler-Plass et al., 2003). To our knowledge, no studies have examined the relationship between these variables in children with HIV. Furthermore, research examining rates of mental health problems, *per se*, has been limited (Mellins et al., 2003).

Examination of mental health needs in this population is important because emotional and behavioral problems may affect disease status and illness adjustment (Forehand et al., 2002; Jones, Beach, Forehand, & Family Health Project Group, 2001). Early identification of such problems may provide opportunities for prevention and intervention that could improve quality of life (Jones et al., 2001). Recent data from the Pediatric Acquired Immunodeficiency Syndrome (AIDS) Clinical Trials Group (PACTG) found that children with HIV are at increased risk of psychiatric hospitalizations compared with the general pediatric population (Gaughan et al., 2004). They reported that it is possible that acute and chronic effects of HIV infection throughout neurodevelopment may predispose perinatally infected children to specific mental disorders. They conclude that as children with HIV live longer, the incidence of psychiatric illness may increase, and screening should be provided within the context of primary care.

Several factors are thought to influence the psychosocial adjustment of children born with HIV infection, including (a) the presence of HIV in the central nervous system during fetal development and throughout childhood; (b) co-occurring medical conditions and complications of HIV disease, including body image issues; (c) teratogenic effects of drug and alcohol during the prenatal period; (d) cognitive and neurological deficits; (e) other psychosocial factors (maternal illness, multiple separations, transitions, and losses); (f) whether the child knows his or her HIV status; and (g) environmental factors (Brown et al., 2000; Donenberg & Pao, 2005; Gaughan et al., 2004; Havens et al., 1994; Lwin & Melvin, 2001; Mellins et al., 2003). Environmental factors affecting families living with HIV include poverty, violence, racism, overcrowding, and single-parent households (Armistead & Forehand, 1995). Such factors would likely increase the risk of psychological difficulties. Clinical rates of depression have been reported in both men and women with HIV (Bing et al., 2001). Furthermore, recent studies have begun to examine the impact of maternal HIV on children's emotional and behavioral functioning. For example, children whose mothers are HIV positive demonstrate more externalizing and internalizing problems compared to children in the general population (Armistead & Forehand, 1995;

Forehand et al., 2002; Levine, 1995). Despite these proposed risks, there have not been extensive studies that adequately characterize the nature of psychological difficulties these children and their caregivers face.

Previous work has suggested that children living with HIV may be at higher risk of social and psychological problems, but available data have been limited and subject to methodological problems. For example, small samples and the use of unstandardized measures have been frequent limitations. Also, although there is a separate body of information available about adults living with HIV, little is known about caregiver mental health in families living with HIV. More information is needed to develop appropriate services for children with this unique chronic disease and for their families. Only a few studies have examined the prevalence of mental health difficulties in children infected with HIV. The primary objective of this study, then, was to examine psychosocial adjustment in children living with HIV and their primary caregivers. It was anticipated that children infected with HIV would present with significantly more mental health problems (e.g., based on DSM-IV criteria) than children in the general population (Armistead & Forehand, 1995; Forehand et al., 1998; Penzak, Reddy, & Grimsley, 2000). Furthermore, because the impact of caregiver mental health on child mental health is clearly established, it was anticipated that the caregivers of these children would also present with significant mental health problems.

## Methods

### *Participants and Procedures*

Following approval by the Institutional Review Board at Children's National Medical Center in Washington, DC, children with a diagnosis of HIV infection who were receiving treatment at the hospital were recruited into the study. Inclusion criteria for children were the following: (a) a diagnosis of HIV infection and (b) age between 6 and 12 years. Fifty-nine families were approached over a 4-month period to participate. Of the 59 eligible families approached, 54 participated (one refused and four deferred their decision but were not able to be contacted in time to enroll them).

The initial phase (Phase 1) of the study involved an assessment of the child and his/her primary caregiver's mental health using questionnaires designed to screen for mental health problems (completed by the caregivers). Subsequently, children and caregivers who met the criteria for "caseness" on the basis of the Phase 1 screen were eligible for the next phase of the study. Phase 2

involved the completion of standardized psychiatric interviews [Computerized Diagnostic Interview Schedule for Children—Version 4 (C-DISC 4) and Structured Clinical Interview for the DSM-IV (SCID) Screen Patient Questionnaire (SSPQ)]. The participants were 54 caregivers and their 57 children who were HIV positive. The study was conducted at a large urban children's hospital, and where possible, interviews were conducted when families were visiting for other medical appointments.

Two mothers did not complete Phase 2 of the study, despite meeting the criteria for Phase 2 by virtue of the screening instruments used in Phase 1. One mother was hospitalized, became seriously ill, and subsequently died, and another mother declined to take part in the second phase of the study (she did not provide a reason).

## Measures

### Demographic Questionnaire

A data form was developed for the study to assess basic background characteristics of the respondents. Demographic variables included child's and caregiver's gender, age, and ethnicity, caregiver relationship to the child, and caregiver HIV status. Also available from the child's medical charts was the child's immunologic status (CD4+ cell count and percent, RNA viral load, and CDC AIDS category), as well as data on cognitive functioning and academic achievement based on standardized testing. The child's disclosure status also was determined based on caregiver report as to whether their child knew his/her own HIV diagnosis.

### CBCL

The CBCL (Achenbach, 1991; Achenbach & Edelbrock, 1983) is a well-standardized and widely used 113-item caregiver-report measure of emotional and behavioral problems in children. The CBCL yields dimensional scores on three scales (total, externalizing, and internalizing problems). The CBCL was selected because it has been used as a screening tool in several studies examining mental health symptoms in chronically ill children (Hudziak, Copeland, Stanger, & Wadsworth, 2004). A T score above 63 (90th percentile) on either of these scales is considered to be indicative of clinically significant behavior problems. A T score between 60 and 63 is considered in the borderline clinical range. One-week test-retest reliability has been reported as 0.89, whereas the intraclass correlation coefficient was 0.95 (Achenbach, 1991). Furthermore, criterion-related validity is supported by the CBCL's ability to discriminate between referred and nonreferred children with its clinical cut-points (Achenbach, 1991).

### C-DISC 4

Children who met the criteria for clinically significant problems as measured by the CBCL were requested to complete the C-DISC 4. The C-DISC 4 is a structured diagnostic interview designed to assess psychiatric disorders using the DSM-IV criteria (APA, 1994). The C-DISC 4 was designed to be completed by the children themselves if aged  $\geq 9$  years or by their parent or caregiver if the children are aged  $< 9$  years. The psychometric properties of the DISC 4 (upon which the C-DISC 4 is based) are well established, and this interview survey is one of the most widely used standardized diagnostic instruments for use with children (Shaffer, Fisher, Lucas, Dulcan, & Schwab-Stone, 2000). Overall, the DISC 4 showed good-to-moderate diagnostic reliability in a clinical sample for both parent and child versions (Shaffer et al., 2000), as well as good sensitivity (Fisher et al., 1993).

### Brief Symptom Inventory

The Brief Symptom Inventory (BSI) (Derogatis, 1993) is a 52-item self-report measure adapted from the Symptom Checklist-90-R (SCL-90-R). Items measure current psychological symptoms on a 5-point scale, ranging from "not at all" to "extremely." The measure yields nine primary symptom dimensions (somatization, obsessive-compulsive behavior, interpersonal sensitivity, depression, anxiety, hostility, phobic anxiety, paranoid ideation, and psychoticism) and three global indices [Global Severity Index (GSI), Positive Symptom Distress Index (PSDI), and Positive Symptom Total (PST)] (Derogatis, 1993). The BSI measures the experience of symptoms in the past 7 days, including the day the BSI was completed. The BSI yields raw scores for individual scales and subscales that are converted to T scores (standard scores with  $M = 50$ ;  $SD = 10$ ) using age and gender appropriate nonpatient norms. T scores of 63 or above on two of the six clinical subscales meet the criteria for a clinical "case" (Derogatis, 1993). Caregivers who met the criteria for "caseness" based on BSI scores were asked to complete Phase 2 of the study. The BSI has high scale-by-scale correlations with the SCL-90-R. The BSI also has high internal consistency (Cronbach's alpha: 0.71–0.85), test-retest reliability, and convergent, discriminant, and construct validity (Derogatis & Melisaratos, 1983). Previous studies administering the BSI to adult patients with HIV indicated higher distress levels in HIV-positive men (Williams, Rabkin, Remien, Gorman, & Ehrhardt, 1991).

### SSPQ

The SSPQ is an abbreviated computer-administered version of the SCID for use with adult populations. The

SSPQ program probes DSM-IV Axis I symptoms at a 7th-grade reading level. Though there are 76 questions, the branching feature of the program skips questions if a respondent reports not having certain symptoms (First, Gibbon, Williams, & Spitzer, 2001). Initial research on the SCID (upon which the SSPQ is based) supports its concurrent, discriminant, and predictive validity in a sample of substance-abuse patients (Basco et al., 1993), as well as its test-retest reliability (First et al., 2001; Williams et al., 1992) and interrater reliability (Segal, Hersen, Van Hasselt, Kabacoff, & Roth, 1993).

### Wechsler Intelligence Scale for Children—Third Edition

The Wechsler Intelligence Scale for Children—Third Edition (WISC-III) (Wechsler, 1991) is an individual intelligence test that does not require reading or writing. After 2002, the WISC-III was replaced by the WISC-IV. The WISC-III was used as data were collected prior to the new test being published. It consists of verbal and nonverbal subtests. The verbal subtests comprise the Verbal Intelligence Quotient (VIQ), and the nonverbal subtests comprise the Performance Intelligence Quotient (PIQ). The Verbal and Performance Scales together comprise the Full Scale IQ (FSIQ). Subtest scores and IQ scores are based on the scores of the 2,200 children originally tested in a very carefully designed, nationwide sample (Wechsler, 1991). Average reliability coefficients for the VIQ, PIQ, and FSIQ are 0.95, 0.91, and 0.96, respectively. Studies comparing the WISC-III with older versions of the WISC (i.e., WISC-Revised) and other major intelligence tests address the construct and criterion-related validity of the WISC-III (Wechsler, 1991).

Results of the WISC-III were included in this report because (a) these data were available as part of the children's clinical record and (b) the authors were interested in evaluating whether there was a relationship between IQ and adjustment or behavioral problems in this population.

### Data Analysis

Given the complexity of the data set and the multiple questions being investigated, several data analytic strategies were used. Descriptive statistics (means and standard deviations) were used to characterize the demographic variables for both caregivers and children and to evaluate the results of the BSI and CBCL. Correlational analyses were used to compare the results of BSI and CBCL as ways of determining the extent to which caregiver distress/symptom reporting was associated with the identification of externalizing and internalizing problems in the infected children. Correlational analyses also were used to compare caregiver demographics and child characteristics to

BSI and CBCL scores and FSIQs to CBCL scores. Because data did not meet the criteria for parametric tests, age differences in diagnosis' disclosure status were analyzed with Kruskal-Wallis nonparametric tests. Multivariate analysis of variance (ANOVA) was used to evaluate the effects of diagnosis' disclosure on CBCL scores. Finally, paired sample *t* tests were used to compare VIQ to PIQ as measured by the WISC-III. Only those analyses that reached statistical significance at  $p < .05$  are reported.

## Results

### Child Characteristics

Table I describes the demographics on the total sample of 57 children. About half of the sample was male (51%). All 57 of the children interviewed contracted HIV through vertical (mother-child) transmission. The mean age of the children was 9.9 years ( $SD = 1.8$ ; range 6.2–12.7). Seventy-four percent of the children interviewed were from single caregiver families. Twenty-five children (44%) knew their HIV status, according to caregiver report. Older (age 10–12 years) children were more likely to know their HIV status than younger (age 6–9 years) children ( $\chi^2 = 3.87, p = .049$ ).

### Immune Status

Of the 57 children interviewed, 51% ( $n = 29$ ) met the CDC criteria for an AIDS diagnosis. The mean CD4 percent for these children was 28% ( $SD = 11\%$ ; range 2–58%). The median viral load was 1,538 copies/mL of plasma (range  $\leq 400$ –36 million copies).

### Academic and Intellectual Functioning

Each child who participated in this study had previously been evaluated with the WISC-III to determine current intellectual functioning (see Table II). Most of the children (67%) achieved FSIQ scores that placed them in

**Table I.** Sample Description of Children with HIV ( $n = 57$ )

	<i>n</i>
Female	28
Mean age ( <i>SD</i> ; range)	9.9 (1.8; 6.2–12.7)
Ethnicity	
African American	53
Caucasian	3
Mixed ethnicity	1
AIDS diagnosis	29
Median CD4+ cell count ( <i>SD</i> ; range)	731 (523; 3–2,910)
Mean CD4 percentage ( <i>SD</i> ; range)	28 (11; 2–58)
Median viral load ( <i>SD</i> ; range)	1,538 (4.7 m; $\leq 400$ –36 m)
Child knows HIV+ status	25

**Table II.** Sample Description of Cognitive factors in Children with HIV

	X (SD; range)
Full Scale IQ	x = 85.9 (17.09; 52–122)
Verbal IQ	x = 87.55 (16.02; 55–125)
Performance IQ	x = 87.24 (17.27; 57–123)

the borderline–average range of intellectual functioning ( $M = 86$ ;  $SD = 17$ ; range = 52–122). Twenty-five percent of the children had FSIQ <69, placing them in the significantly delayed or mental retardation range. Five percent of the children had FSIQ >109, placing them in the high average or above range. There was no significant difference between the mean PIQ and the mean VIQ of children surveyed. The majority of children who participated in this study were currently enrolled in a regular education classroom (68%). While only 32% of these children receive special education services, the fact that 51% obtained FSIQs in the low average or below average range (89% or below) suggests that they may be at risk of learning difficulties.

### Caregiver Characteristics

The majority of the sample of caregivers were female (91%); 89% were African American (see Table III). Thirty-seven percent of the caregivers ( $n = 20$ ) were HIV+. The mean age of the caregivers was 46.6 years ( $SD = 13.2$ ; range 27.3–89.2). Forty percent of the caregivers reported they were single. Twenty percent of the caregivers were employed part- or full-time. Approximately one-third of the caregivers (37%) were the child's biological mothers, 29% were the child's grandparents, 23% were adoptive parents, and 2% were foster parents. The remaining 9% of the caregivers consisted of relatives of the child (e.g., aunts and uncles).

**Table III.** Sample Description of Caregivers ( $n = 54$ )

	<i>n</i>
Female	49
Mean age (SD; range)	46.6(13.2; 27.3–89.2)
Ethnicity	
African American	48
Caucasian	5
Mean education ( <i>n</i> ; range)	12.1 years (2.3; 4–16.5)
Employed (full or part time)	20
Single	40
Caregiver HIV+	20
Relationship to child	
Birth parents	20
Foster/Adoptive parents	13
Grandparents	13
Other relatives	8

### Child Mental Health History

Information about the child's mental health history was obtained via parent report and medical records (i.e., these data are based on previous diagnoses or collateral reports, not from data obtained during this study). Of the children surveyed, 14% had a previous or current diagnosis of Attention Deficit Hyperactivity Disorder (ADHD), 12% had a diagnosis of a mood disorder, and 5% met the criteria for both. Another 2% met the criteria for another mental health disorder (e.g., enuresis and anxiety disorder). Approximately 21% of the children were currently taking psychotropic medications.

### CBCL and C-DISC 4

All caregivers completed the CBCL to provide information on children's social–emotional functioning. Results of the CBCL revealed that approximately 20% of them endorsed their child as having either internalizing (clinical range: 14%; borderline range: 9%) or externalizing problems (clinical range: 14%; borderline range: 7%). On the basis of these results, a total of 6 caregivers and 10 children completed the C-DISC 4 as part of Phase 2 of the study. Of these, 38% ( $n = 6$ ) met the criteria for a DSM-IV diagnosis. Specifically, according to the C-DISC 4, three children met the criteria for specific phobia (one child with comorbid ADHD), two children met the criteria for enuresis (nocturnal only), and one child met the criteria for dysthymic disorder. CBCL scores were not significantly correlated with child age or gender. Higher CBCL scores, however, were associated with higher symptoms reporting on the BSI.

Previous studies have suggested that one's awareness of HIV status may contribute to mental health problems. A recent report from the PACTG indicated that diagnosis' awareness was positively correlated with psychiatric hospitalization (Gaughan et al., 2004). Results from the current study appear to partially confirm these findings. Children who were aware of their HIV status were more likely to present with internalizing problems [ $F(1, 55) = 8.75, p = .005$ ] as measured by the CBCL. The effects of diagnosis disclosure on externalizing problems existed only as a trend [ $F(1, 55) = 3.41, p = .07$ ]. Because older children (10–12 years) are more likely to be aware of their diagnosis than are younger children (6–9 years), this analysis also was run using age as a covariate. Indeed, further analyses revealed a significant effect of disclosure status on both internalizing [ $F(1, 54) = 4.44, p < .05$ ] and externalizing [ $F(1, 54) = 5.51, p < .05$ ] problems.

The authors also included data from the WISC-III to determine whether there was any relationship between a

**Table IV.** Correlations between Brief Symptom Inventory (BSI) Scores and Child Behavior Checklist (CBCL) Scores

	CBCL internalizing	CBCL externalizing
BSI Global Severity Index	.628*	.700*
BSI Positive Distress Index	.420*	.406*
BSI Positive Symptom Index	.628*	.518*

\*Correlation is significant at the  $p < .01$  level (two-tailed).

child's intellectual functioning and reported emotional and behavioral problems. FSIQ was not significantly correlated with CBCL scores in this population.

### Caregiver Psychiatric History and BSI

Of the 54 adults who completed the BSI, 15 obtained scores that reached clinical significance. Thirteen caregivers went on to complete the SSPQ as part of Phase 2 of the study. All of those who completed the SSPQ met the diagnostic criteria for a mental health disorder. Scores on the BSI were significantly correlated with scores on the CBCL (see Table IV), such that caregivers with higher scores on the BSI likely rate more symptoms on the CBCL. BSI scores were not related to age, marital status, employment status, caregiver HIV+ status, or the relationship of the caregiver to the child (e.g., biological mother, grandparent, etc).

### Discussion

This qualitative study is an early step in systematically reviewing the mental health problems facing families living with HIV. If we consider only those children who meet the DSM-IV criteria for mental health disorders, then the results of this study indicate that only a small proportion of children and caregivers living with HIV experience mental health problems. In fact, the percentage of children in our sample who had identifiable mental health problems was consistent with the rates of mental health problems among the general population (USDHHS, 2005). These findings are surprising and contrary to what was expected and might suggest that children with HIV and their caregivers are remarkably resilient in the face of a multitude of challenges to their own and to their child's physical and mental health.

What makes these findings even more striking is the fact that the children who participated in this study come from traditionally high-risk backgrounds where social support and access to resources may be limited, and low economic status and frequent caregiver transitions because of illness and death are common. These psychosocial stressors undoubtedly add to the burden of care for these children and their families. Given these

risk factors, one might expect that the rates of mental illness in these children and their caregivers would be higher than those we found in this study.

However, several factors are important to consider when interpreting these results. Twenty percent of children with HIV manifested symptoms that reached clinical significance for externalizing or internalizing disorders as measured by the CBCL. Twenty-one percent of the children were on psychotropic medication. Furthermore, 30% of caregivers endorsed symptoms that reached clinical significance on the BSI for their own symptoms of distress. Therefore, although some signs are present, the behavioral and emotional symptoms do not meet the DSM-IV criteria for a mental health disorder. These results are relevant in two important ways: (a) the rates of mental illness identified in this population are comparable to rates in the general population (USDHHS, 2005) and (b) findings from all measures suggest that less than half of the families surveyed reported experiencing significant emotional distress.

An optimistic interpretation of these findings is that the families are remarkably resilient and have effectively managed the negative aspects of their child's HIV diagnosis and treatment. However, several factors must be considered before any conclusions can be drawn. First, we relied heavily on caregiver report. Some caregivers may underestimate or overestimate symptoms. A tendency to underreport may explain the discrepancy between caregiver-reported distress, previous diagnoses of children based on collateral records, and the prevalence of DSM-IV diagnoses in this population. We also found that there was a significant association between the caregiver's rating of their own distress (BSI) and elevated symptoms on their child's CBCL. It is possible that adults with depression view the world, and therefore their child's behavior, more negatively, and it is also known that adults who are depressed are more likely to have children with emotional and behavioral problems (Downey & Coyne, 1990).

Another issue to be addressed in future studies is the utility of the C-DISC 4 to children with learning difficulties. A significant number (25%) of the current sample of children had a measured IQ in the mental retardation range (<69). It is likely that this would impede their ability to self-reflect and understand questions in the C-DISC 4; however, further studies are needed to determine to what extent this is true. The addition of collateral reports from teachers, mentors, or peers may add to our knowledge of how children are functioning at school and in social environments.

It is also possible that the measures used lack sensitivity or specificity in identifying adjustment difficulties or illness-specific factors experienced by children living with chronic illness (Abidin, 1990; McCubbin et al., 1983). A few studies have indicated that while the CBCL has high specificity, it is likely to under-identify medically ill children with comorbid psychiatric disorders (low sensitivity) (Canning & Kelleher, 1994; Harris, Canning, & Kelleher, 1996). Additional studies should incorporate a wider variety of measures to determine whether other psychological factors such as caregiver stress might affect coping in this population. Furthermore, future studies are needed to compare children with HIV to children with other chronic diseases such as juvenile rheumatoid arthritis, sickle cell anemia, diabetes, and cancer to determine if their needs are specific to HIV or consistent with a broader pediatric illness spectrum.

Overall, the current study yielded interesting preliminary findings about the prevalence of mental health problems in a sample of children with HIV and the levels of emotional distress in their caregivers. These findings, however, must be considered within the limitations of the study. First, the current study was conducted on a select sample in a large metropolitan area and may not fully represent the population of children with HIV in the United States. Second, only two measures were used to index the level of emotional distress experienced by the caregivers. Furthermore, the children did not complete any measures in the first phase of the study. It is possible that these measures were not sensitive enough to detect the mental health needs of these individuals. Future studies might also consider adding a measure of parenting stress to determine the level of stress experienced by caregivers caring for children with HIV. Also, it might be valuable to include a self-report measure for children to examine the level of distress that they personally experience (e.g., a self-report measure to determine whether children who are aware of their diagnosis similarly endorse more problems with adjustment than do children who are not aware). A final limitation of the study was that it was qualitative in nature. It would be interesting to examine the extent to whether factors such as immune function, caregiver age, caregiver perceived support, or caregiver health status predict mental health outcomes in this population and which factors may be protective in nature.

In summary, while the overall findings might suggest that there are lower than expected rates of emotional distress among this population, the fact that a proportion of these families do experience significant distress cannot be ignored. HIV is truly a family illness.

Screening, ongoing support, and family-friendly, culturally sensitive mental health services should be an integral part of whole childcare for families living with HIV.

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