Objective To assess differences in caregiver report of youth and family psychosocial adjustment associated with HIV infection and greater immune compromise in youths with hemophilia. METHODS Caregivers of 162 boys with hemophilia 8 to 20 years old completed three youth and family questionnaires (Personality Inventory for Children, Revised [PIC-R]; Questionnaire on Resources and Stress [QRS]; Family Environment Scale). Results Caregivers of HIV positive (HIV+) youths reported greater health concerns, social withdrawal (PIC-R), physical and adaptive limitations associated with illness (QRS) in their sons, and more pessimism about their sons' future and negative attitudes about parenting (QRS). Caregivers of HIV+ youths with greater immune compromise reported greater concerns about their sons' health and greater pessimism about their futures, as well as lower levels of family integration and more limited family opportunities. Conclusions Results suggest caregivers perceive psychosocial problems in HIV+ youths with hemophilia and their families; some problems are specifically associated with greater immune compromise.

Key words hemophilia; HIV; psychosocial; youth; family stress; immune compromise.

Youths with hemophilia and HIV infection form a unique cohort for studying the long-term developmental effects of HIV infection. Most were infected past infancy, and most lack the risk factors associated with vertical transmission, including lower socioeconomic status (SES) and maternal HIV infection. The Hemophilia Growth and Development Study (HGDS), a multicenter, multidisciplinary longitudinal study, was formed to follow the growth and development of these young people (Loveland et al., 1994, 2000; Nichols et al., 2000; Stehbens et al., 1997). In this article we report results from the Family Stress and Coping Study (FSCS), an HGDS adjunct study on caregiver report of the psychosocial adjustment and family functioning of 162 male youths with hemophilia ages 8 to 20 with and without HIV infection.

The psychosocial adjustment of youths with HIV infection and their families may be affected by the cognitive effects, social stigma, and life-threatening nature of HIV infection (Kazak, 1997; Lewis, 2001; Moss, Bose, Wolters, & Brouwers, 1998). Some studies suggest that youths with HIV exhibit more anxiety disorders (Bussing & Burket, 1993) and depression (Burton, Sarkis, Hill, Kemph, & Mehta, 1991). A longitudinal study examining youth and parent report of adjustment in children and adolescents with HIV (both vertical transmission and transfusion associated) found that youths self-reported...
elevated depression and anxiety (Bose, Moss, Brouwers, Pizzo, & Lorlon, 1994; Moss et al., 1998). Parents reported that their sons had problems with social functioning, anxiety, and conduct that persisted at a 2-year follow up. Bachanas, Kullgren, Schwartz, Lanier, et al. (2001) found that parents reported greater emotional and behavioral problems for youths with vertically transmitted HIV infection than expected for their ages but no more adjustment problems than a healthy comparison group of similar SES. This result could reflect availability of psychosocial services for the group with HIV, or underreporting of problems by parents. Similarly, Nichols et al. (2000) reported that HGDS youths with HIV and hemophilia had fewer externalizing behavior problems over time, suggesting a decrease due to advancing illness, or a shift in parents’ focus from their son’s behavior to his health problems. However, other findings from the HGDS (Loveland et al., 2000; Nichols et al.) indicate that significant declines in immune functioning in youths with hemophilia and HIV are associated with declines in cognitive and adaptive functioning, which may in turn affect emotional and behavioral functioning. A large study of youths with hemophilia (Drotar, Agle, Eckl, & Thompson, 1997) found no differences in psychosocial adjustment between those with and without HIV, although it excluded youths with HIV-related immune compromise and dementia, a subgroup likely to be more at risk. These findings suggest that effects of chronic HIV on youth adjustment may differ by associated risk factors, illness course, and availability of services.

The effects of HIV disease on youths should also be considered within the context of family adjustment (Drotar, 1997). In addition to potential stressors associated with chronic illness, such as increased financial burden, medical procedures, disruption of normal activities, and less equitable relations with healthy siblings (Hamlett, Pellegrini, & Katz, 1992; Holden, Chmielewski, Nelson, Kager, & Foltz, 1997; Kazak, 1989; Lewis, Haiken, & Hoyt, 1994), HIV disease can be associated with fear of ostracism, severe debilitation, premature death, and even deaths across generations (Bose et al., 1994; Kazak, 1997; Mellins & Ehrhardt, 1994; Sherwen & Boland, 1994; Wiener, Vasquez, & Battles, 2001). Drotar et al. (1997) found that compared to mothers of uninfected youths with hemophilia, mothers of youths with both hemophilia and HIV reported a greater impact of negative life events on mothers’ psychological distress, suggesting that HIV disease may increase the family’s vulnerability to stress. Although Bachanas, Kullgren, Schwartz, McDaniel, et al. (2001) found that caregivers of vertically infected youths did not differ in distress and adjustment problems from caregivers of youths without HIV, this finding could reflect the presence of additional risk factors (e.g., lower SES) whose effects might outweigh effects of HIV.

The illness course of HIV, together with both stressors and resources for coping, can affect both youth adjustment and family functioning. Chronic HIV disease in young men with hemophilia may have a prolonged asymptomatic phase that may be less stressful for youths and their families than the later stages of HIV, which are marked by immune compromise (Hilgartner et al., 1993; Loveland et al., 1994). Declines in cognitive and adaptive functioning associated with advancing immune compromise and illness (Loveland et al., 2000; Nichols et al., 2000) could severely stress the family and reduce resources for coping, leading to poorer outcomes. Moss et al. (1998) found that, in children with HIV, negative life events were associated with poorer psychosocial outcomes, but that psychological resilience to stress had a stabilizing effect. Five children with HIV who died within 1 year of baseline were found to have more negative life events and less resilience to stress, as well as greater progression of HIV disease. Taken together, these findings suggest that psychosocial adjustment and family functioning in youths with hemophilia may be adversely affected both by the presence of HIV infection and by the lowered immune functioning that characterizes later stages of HIV disease.

The purpose of this study was to examine the relationship of youth and family psychosocial functioning to both HIV serostatus and the extent of immune compromise in male youths with hemophilia. This hemophilia cohort was stratified into two groups based on youth HIV serostatus: a group with HIV (HIV+; n = 86) and a group with no HIV (HIV–; n = 76). The HIV+ group was further divided into subgroups based on degree of immune dysfunction: (a) HIV+ with CD4+ t-cell counts (CD4 cells/mm3) < 200 (HIV+ group with lower immunity; n = 37), and (b) HIV+ with CD4+ t-cell counts ≥ 200 (HIV+ group with higher immunity; n = 49). Caregivers completed three standardized instruments measuring youth psychosocial adjustment, family resources and stress, and family social environment. Caregiver-report only was obtained for this study because of the already high burden of testing placed on youth participants in the HGDS. Concurrent measures of youths’ HIV status, immune status, and intelligence and family demographic characteristics were available from the HGDS; these variables have been described earlier in detail (Loveland et al., 1994; Stehbens et al., 1997). They are summarized in Table 1.

The primary research questions of this study were the following. Do youth and family psychosocial problems differ between families whose sons have both hemophilia and HIV infection and those whose sons have
hemophilia alone? Are greater youth and family psychosocial problems associated with immune compromise in youths with hemophilia and HIV infection? Hypothesis 1: Families with sons who have both hemophilia and HIV infection will have greater psychosocial problems than families with sons who have hemophilia alone, as measured by youth psychological adjustment, family resources and stress, and family social environment. Hypothesis 2: Severe immune compromise in sons with hemophilia and HIV will be associated with greater psychosocial problems, as measured by youth psychological adjustment, family resources and stress, and family social environment.

**Method**

**Participants**

FSCS participants were the caregivers or legal guardians of 162 youths with hemophilia ages 8 to 20 (M = 14.0 years, SD = 3.0). Respondent caregivers were almost all mothers, with 3% fathers and 4% other. All were the primary caregiver. Characteristics of the caregivers and youths are given in Table I, including youth age, full-scale IQ, and CD4 cell count, along with mean years of education for mothers and fathers.

Of 14 HGDS centers, 10 enrolled caregivers in the FSCS. Not all eligible centers chose to participate, because of the time and training required for professional staff. FSCS participants represented 63% of all HGDS caregivers and 81% of HGDS caregivers at the participating FSCS sites. Eleven caregivers (13.6%) had two sons enrolled; 10 of them had both sons in the HIV− group. The eleventh caregiver’s sons were both HIV+, and both had CD4 cell counts ≥ 200.

Family structure was coded in the HGDS baseline history. At enrollment, 78% were two-parent families, 20.4% were single-mother-headed families, and the remainder were single-father-headed or other (grandparent or other legal guardian). SES was estimated using the Revised Socioeconomic Index of Occupational Status (SEI), with possible scores from 13.8 to 90.4 (Stevens & Feath-erman, 1981; see Stehbens et al., 1997, for discussion of methods). Families in the FSCS had an average SEI of 34.2 (SD = 18.5) (middle class). On average, respondent caregivers had completed high school (M = 12.6 years of education, SD = 2.7). Neither the SEI nor the caregiver education values differed significantly from those of the HGDS full sample (Stehbens et al., 1997).

Study measures and HGDS medical and neuropsychological evaluations were obtained between March 1992 and November 1993, on average about 10 years since infection (see Loveland et al., 1994, 2000, for discussion of how time of infection was estimated). For all but six families, data were collected at the third annual follow-up assessment past baseline, and for the other six families, at the fourth annual follow-up. Following institutional review board approval, caregivers gave informed consent. Informed consent/assent by sons was required for caregiver participation.

FSCS youths were representative of boys with hemophilia in the United States who were at risk for acquiring HIV disease through contaminated blood clotting factor products before 1985: 53% were HIV+, 67% Caucasian, 17% African American, and 16% Hispanic (Daar et al., 2001). For the purpose of analysis, ethnic status was classified into majority (Caucasian) and minority (African American, Hispanic, Latino, and Chicano) groups. No families of Asian ethnicities volunteered to enroll in the FSCS.

The HGDS sample (n = 333) was representative of the total population of boys with moderate to severe hemophilia at the 14 HGDS centers (Hilgartner et al., 1993). Because the FSCS respondents were a self-selected subset of HGDS caregivers, analyses were conducted using t tests and the chi-square statistic to compare characteristics of the HGDS participants at baseline who were or were not enrolled in the FSCS. FSCS youths were significantly younger (M = 14.0 vs. 15.6 years, SD = 2.97 and 3.40, re-
spective), t(332) = 3.70, p < .0003, than those in the HGDS full sample. This difference may reflect the fact that many older participants came to HGDS study visits without their parents, reducing the opportunity for participation in this study. Based on CD4+ t-cell counts, youths in the FSCS were of similar immune status to youths whose caregivers did not participate (22.8% FSCS vs. 22.2% HGDS with CD4+ cells/mm³ < 200). No significant differences were found in type of hemophilia diagnosed (A or B), ethnic status, youth intelligence (Wechsler Intelligence Scale for Children-Revised or Wechsler Adult Intelligence Scale-Revised) or social maturity (Vineland Adaptive Behavior Scales Composite Score).

**Procedure**

Study measures were selected based upon empirical evidence validating their use in measuring youth psychosocial adjustment, family stress and resources, and family environment.

**Personality Inventory for Children-Revised (PIC-R; Lachar, 1982; Lachar & Kline, 1994).** This empirically derived 280-item true/false instrument (caregiver report) assesses psychosocial adjustment in preschool through adolescent youths. Caregivers completed the PIC-R with reference to their child who was enrolled in the FSCS. Twelve scales measure three development dimensions (achievement, development, intelligence) and nine adjustment dimensions (anxiety, depression, delinquency, family relations, hyperactivity, psychosis, social skills, somatic concern, withdrawal). The scales are interpreted through actuarial guidelines derived for T-score ranges that vary by scale (Lachar & Gdowski, 1979).

**Questionnaire on Resources and Stress-Long Form (QRS; Holroyd 1974, 1987).** This 285-item true/false caregiver questionnaire with 15 scales measures the impact of childhood chronic illness or disabilities on stress in the caregiver, family, and youths. Caregivers completed this scale with reference to the youths enrolled in the FSCS and the family. Caregiver scales include Poor Health/Mood (role discontent and sadness), Excess Time Demands, Negative Attitude (about youths), Overprotective/Dependency (of youths), Lack of Social Support, Overcommitment/Martyrdom, and Pessimism (about the youth's future). Family stress scales are Lack of Family Integration, Financial Problems, and Limits on Family Opportunity. Scales describing the youths with illness (Index Case Problems) are Physical Incapacitation, Difficult Personality Characteristics, Social Obtrusiveness, Limited Activities, and Occupational Limitations for Index Case.

**Family Environment Scale (FES; Moos & Moos, 1981).** This 90-item true/false questionnaire measures three dimensions: family relationships (family cohesion, conflict, and expressiveness), emphasis on types of personal growth (achievement orientation, independence, intellectual-cultural orientation, active-recreational orientation, and moral-religious emphasis), and family system maintenance (organization and control). Caregivers completed this scale with reference to the family as a whole.

**Statistical Methods**

Multivariate and univariate analyses of variance (MANOVA, ANOVA) were used to evaluate the two hypothesis-relevant group comparisons (HIV+/HIV– and greater/lesser immune compromise) across each of the three sets of scales provided by the PIC-R, QRS, and FES. Because age differed significantly between participants with and without HIV infection, age was entered as a covariate in the parametric comparisons conducted by HIV status. Because of the unique, nonreplicable nature of these data, an exploratory approach was applied to data analysis. ANOVAs of individual scale dimensions were conducted regardless of the statistical significance of the associated MANOVA. However, caution was introduced into these analyses through the additional estimation of the magnitude and pragmatic value of all statistically significant ANOVAs by the application of two other procedures. The magnitude of statistically significant univariate group differences was assessed through the calculation of a standardized effect size (d), in which values reflect either small (d = .20), medium (d = .50), or large (d = .80) effects (Cohen, 1988). A second procedure estimated the practical value of statistically significant group differences through the classification of individual subjects. Chi-square was applied to evaluate differences in proportions of clinically elevated scale T-scores. For the PIC-R, clinical elevations were defined empirically by Lachar and Gdowski (1979) for individual scales, as either T > 59, T > 69, or T > 79. For the QRS and FES, for which comparable actuarial guidelines were not available, a liberal criterion of one standard deviation from the normative mean was used, as presented in the measure’s manual (T > 59). Because the HIV– group included 11 sibling pairs, we also repeated the parametric analyses with these 22 participants removed. Results were the same as those obtained from analyses of the full sample.

**Results**

**Comparison of HIV+ and HIV– Samples**

The three sets of caregiver scales were first analyzed to evaluate the caregivers’ perception of the effect of HIV on their sons with hemophilia. PIC-R scales differed signifi-
significantly by HIV status when age was entered as a covariate (Wilks $\lambda = .852$), $F(12, 140) = 2.02$, $p = .03$. Significant ($p < .05$) ANOVAs were obtained for 5 of 12 PIC-R substantive profile scale T-score values (Table II). Youths with HIV were described as having more evidence of compromised health (Somatic Concern) and relative isolation (Withdrawal); these differences represented a medium effect. Significant differences were also found for PIC-R scales reflecting dysphoria (Depression), tension and worry (Anxiety), and poor peer relations (Social Skills), although they represented only a small effect. When frequency of clinically elevated scores was examined for these five scales, two PIC-R scales differed significantly between groups, although neither was descriptive of the majority of HIV+ youths (40% of HIV+ youths had an elevated Somatic Concern scale, while only 24% had an elevated Withdrawal scale).

QRS scales differed significantly by HIV status when age was entered as a covariate (Wilks $\lambda = .725$), $F(15, 138) = 3.14$, $p = .0001$. Significant ($p < .05$) ANOVAs were obtained for 9 of 15 scales (Table II). Of the seven scales that describe the caregiver’s adjustment, experience, and attitudes, four differed significantly by HIV status and represented at least a medium effect. Caregivers of HIV+ youths were more likely to describe themselves as more distressed (Poor Health/Mood), fearful about their son’s future (Pessimism), concerned over the amount of care necessary for their son (Overprotective/Dependency), and having negative parenting attitudes (Negative Attitude) compared to caregivers of HIV– youths. Although the QRS manual provides norms based only on a sample of 52 caregivers, scale scores equivalent to $T = 60$ are given. Classification of QRS scale scores based on these values resulted in a significantly higher proportion of elevated values for the caregivers of HIV+ youths for two of these scales, Pessimism (68%) and Negative Attitude (54%).

Two of three QRS scales that describe family status (Limits on Family Opportunity and Lack of Family Integration) differed significantly by HIV status, although these differences represented a small effect and resulted in

Table II. HIV Status Differences in Caregiver Descriptions of Youths With Hemophilia

<table>
<thead>
<tr>
<th></th>
<th>HIV–</th>
<th>HIV+</th>
<th>$F$</th>
<th>$d$</th>
<th>$\chi^2$</th>
</tr>
</thead>
<tbody>
<tr>
<td>Personality Inventory for Children, Revised</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>(HIV– $n = 74$; HIV+ $n = 80$)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Somatic Concern ($T &gt; 69$)</td>
<td>56.9 (13.2)</td>
<td>64.2 (13.9)</td>
<td>9.65**</td>
<td>.54</td>
<td>12.1**</td>
</tr>
<tr>
<td>Depression ($T &gt; 69$)</td>
<td>54.0 (13.1)</td>
<td>59.4 (14.2)</td>
<td>7.28**</td>
<td>.39</td>
<td>1.8</td>
</tr>
<tr>
<td>Withdrawal ($T &gt; 69$)</td>
<td>53.4 (12.1)</td>
<td>59.7 (15.0)</td>
<td>8.90**</td>
<td>.46</td>
<td>5.6*</td>
</tr>
<tr>
<td>Anxiety ($T &gt; 69$)</td>
<td>53.2 (10.9)</td>
<td>55.5 (12.4)</td>
<td>4.54*</td>
<td>.20</td>
<td>2.0</td>
</tr>
<tr>
<td>Social Skills ($T &gt; 69$)</td>
<td>46.9 (10.7)</td>
<td>48.9 (11.6)</td>
<td>3.90*</td>
<td>.18</td>
<td>1.9</td>
</tr>
</tbody>
</table>

| Questionnaire on Resources and Stress: Parent Problems |      |      |      |      |          |
| (HIV– $n = 74$; HIV+ $n = 81$) |      |      |      |      |          |
| Poor Health/Mood ($T > 59$) | 3.2 (2.9) | 4.8 (3.1) | 13.12** | .53 | 1.5 |
| Negative Attitude About Youth ($T > 59$) | 5.5 (2.4) | 7.1 (2.9) | 17.64** | .60 | 7.5** |
| Overprotection/Dependency ($T > 59$) | 3.6 (2.3) | 4.9 (2.6) | 14.59** | .53 | 2.8 |
| Pessimism About Youth ($T > 59$) | 2.7 (1.5) | 4.7 (2.1) | 35.89** | 1.09 | 18.0** |

| Questionnaire on Resources and Stress: Family Functioning Problems |      |      |      |      |          |
| Lack of Family Integration ($T > 59$) | 3.0 (2.4) | 4.0 (2.8) | 4.78* | .38 | 3.5 |
| Limits on Family Opportunity ($T > 59$) | 1.2 (1.8) | 1.8 (1.9) | 4.71* | .32 | 3.9 |

| Questionnaire on Resources and Stress: Index Case Problems |      |      |      |      |          |
| Physical Incapacitation ($T > 59$) | 2.4 (1.3) | 3.1 (1.6) | 7.66** | .48 | 6.7** |
| Limited Activities ($T > 59$) | 0.8 (1.3) | 1.5 (1.4) | 12.56** | .52 | 9.3** |
| Difficult Personality Characteristics ($T > 59$) | 4.3 (4.2) | 5.3 (4.2) | 4.58* | .24 | 0.7 |

| Family Environment Scale: Personal Growth Dimension |      |      |      |      |          |
| (HIV– $n = 75$; HIV+ $n = 83$) |      |      |      |      |          |
| Independence ($T > 59$) | 45.7 (11.2) | 50.9 (12.1) | 4.79* | .45 | 4.4* |

Detail for significant ANOVAs only; $T$ values in parentheses are clinical elevations.

% = proportion in clinical range, $F$ = difference in group means adjusted for age, $d$ = standardized effect, $\chi^2$ = difference in elevated score group proportions.

* $\leq .05$.

** $\leq .01$. 
no difference in proportion of cases classified within the clinical range. Three of five QRS scales describing study youths differed significantly by HIV status, and two of these obtained a group difference that represented a medium effect (Physical Incapacitation and Limited Activities). The QRS measure of poor personal adjustment (Difficult Personality Characteristics) also suggested that HIV infection represents additional threat to youth adjustment over hemophilia alone, although this scale obtained only a small effect and did not obtain a greater proportion of clinically elevated scores in HIV+ youths.

MANOVA of the FES did not generate a statistically significant effect for HIV status when age was entered as a covariate (Wilks $\lambda = .905$), $F(10, 146) = 1.54$, $p = .13$, although 1 of 10 scales (Independence) obtained a statistically significant ANOVA by HIV status (Table II). The families of HIV+ sons were described as more likely to promote personal growth through an emphasis on independence.

**Comparison of HIV+ Samples of High and Low Immune Compromise**

Comparable analyses of caregiver scales were conducted within the sample to compare youths with substantial immune compromise ($CD4 < 200$, $n = 33$) with the remainder of the HIV+ sample ($n = 47$). MANOVA of the 12 PIC-R scales was not significant for the main effect of HIV+ immune compromise (Wilks $\lambda = .905$), $F(10, 146) = 1.54$, $p = .13$, although 1 of 10 scales (Independence) obtained a statistically significant ANOVA by HIV status (Table II). The families of HIV+ sons were described as more likely to promote personal growth through an emphasis on independence.

**Table III. CD4 Status Differences in Caregiver Descriptions of HIV+ Youths With Hemophilia**

<table>
<thead>
<tr>
<th></th>
<th>CD4 ≥ 200 ($n = 47$)</th>
<th>CD4 &lt; 200 ($n = 33$)</th>
<th>$F$</th>
<th>$d$</th>
<th>$\chi^2$</th>
</tr>
</thead>
<tbody>
<tr>
<td>Personality Inventory for Children, Revised</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Somatic Concern ($T &gt; 69$)</td>
<td>60.2 (13.3) 26</td>
<td>69.4 (13.3) 61</td>
<td>8.07**</td>
<td>.69</td>
<td>9.9**</td>
</tr>
<tr>
<td>Questionnaire on Resources and Stress: Parent Problems</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Pessimism About Youth ($T &gt; 59$)</td>
<td>4.1 (2.0) 57</td>
<td>5.4 (2.1) 82</td>
<td>6.10*</td>
<td>.64</td>
<td>5.6*</td>
</tr>
<tr>
<td>Questionnaire on Resources and Stress: Family Functioning Problems</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Lack of Family Integration ($T &gt; 59$)</td>
<td>3.3 (2.5) 26</td>
<td>5.0 (2.9) 56</td>
<td>7.36**</td>
<td>.64</td>
<td>7.7**</td>
</tr>
<tr>
<td>Limits on Family Opportunity ($T &gt; 59$)</td>
<td>1.4 (1.7) 34</td>
<td>2.3 (2.0) 50</td>
<td>4.85*</td>
<td>.49</td>
<td>2.1</td>
</tr>
</tbody>
</table>

Detail provided only for significant scale ANOVAs; T value in parentheses designates clinical elevations.

% = proportion in clinical range, $F$ = differences in group means; $d$ = standardized effect size; $\chi^2$ = difference in % elevated scores.

* $p \leq .05$.

** $p \leq .01$

Discussion

We hypothesized that caregivers of youths with hemophilia and HIV would report greater psychosocial problems for both the son and family compared to caregivers of sons with hemophilia alone. The groups differed on measures of youth psychological adjustment, particularly health concerns and social withdrawal (PIC-R) and adaptive limitations associated with illness (QRS). They also differed on measures of the caregiver’s adjustment to the youth’s illness, particularly pessimism about the son’s future and negative attitudes about parenting (QRS). The groups did not differ on most aspects of family social environment. These results support previous studies that
have suggested that youths with both hemophilia and HIV and their families are at greater risk for psychosocial problems than those youths and their families with hemophilia alone (Drotar et al., 1997; Nichols et al., 2000). Our results also clearly indicate concerns by parents of HIV+ youths regarding effects of advancing illness associated with HIV, beyond those concerns related to hemophilia itself.

Greater immune compromise (CD4 cells/mm³ < 200) in sons with HIV was hypothesized to be associated with differences in youth adjustment and family stress and coping resources. Caregivers of HIV+ youths with greater immune compromise did report significantly greater concerns about health, and since severe immune deficiency is associated with a late stage of illness, it is not surprising that 82% of caregivers with immune compromised sons also expressed greater pessimism about their sons’ future. The fact that a greater proportion of these same caregivers reported lower levels of family integration may suggest that stress related to the son’s advancing illness may adversely affect relationships within the family. These results indicate that families and youths were aware of health risks and that their concerns were realistically linked to the presence and progress of HIV disease.

The lack of differences in family environment found between groups with and without HIV and with and without significant immune compromise suggests that differences in caregiver perceptions of their sons were probably not due to differences in family relationships, organization, or activities they value. Rather, these findings are consistent with research that suggests that negative life events and advancing HIV illness are important determinants of family stress and psychosocial adjustment in youths with HIV (Drotar et al., 1997). These findings also emphasize that future studies must assess both healthy and medically compromised youth to capture the psychosocial impact of the full HIV disease spectrum.

Conclusions from this study are limited by the fact that results are based only on caregiver report. It is reasonable to expect that youths with HIV disease might view their own behavior and emotional state, as well as family functioning, somewhat differently than would their parents (Drotar et al., 1996.) Thus, our findings reflect caregivers’ perception of the extent of youth and family problems associated with HIV infection and advancing disease course. Because of their day-to-day role in managing the medical care of their sons with hemophilia, these caregivers, largely mothers, may have a perspective on youth and family problems that differs both from that of the youths themselves and from that of fathers. Also, some research suggests that caregivers who are themselves distressed may be more likely to report distress or other psychosocial problems in their sons with chronic illness (Bachanas, Kullgren, Schwartz, McDaniel, et al., 2001; Chilcoat & Breslau, 1997; Renouf & Kovacs, 1994.) Thus, future studies should include both self-report and caregiver-report measures to address the perceptions of youths with HIV of their own adjustment and family functioning, as well as differences between self- and parent-report.

These findings indicate that caregivers’ perceptions of the psychosocial functioning of youths with HIV and their families, including the functioning of the caregivers themselves, are related to the youth’s degree of illness. Coping strategies focused on problem solving rather than emotions have been associated with better psychosocial outcome among youths with HIV and their caregivers (Bachanas, Kullgren, Schwartz, Lanier, et al., 2001; Bachanas, Kullgren, Schwartz, McDaniel, et al., 2001). Thus, psychosocial interventions to improve coping with HIV illness and the negative events associated with disease progress may be a critical need for families of HIV+ youths with hemophilia.

Appendix

HGDS Center Directors, Study Coordinators or Committee Chairs

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