Commentary: HIV Infection and Family Processes: Toward the Next Generation of Research

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Over the past decade, advances in the medical treatment of children with HIV infection have resulted in greater control over symptoms associated with the virus, greater latency between infection and onset of AIDS-defining conditions, and increased length of life (Rogers, Lindgram, Simmonds, Gwinn, & Bertolli, 1998). Unfortunately, identification and amelioration of the psychosocial and psychoeducational correlates of HIV infection have not progressed as quickly, or with the same degree of impact on children's lives. Although emotional, behavioral, and cognitive problems have been identified among children who are HIV-infected (see Armistead, Forehand, Steele, & Kotchick, 1998), findings across investigations have not been consistent, and pathways by which HIV affects children's functioning are not yet well understood (see Brown, Lourie, & Pao, 2000). In this context, the four articles in this issue examining children with HIV and their families (Bachanas, Kullgren, Schwartz, Lanier, et al.; Bachanas, Kullgren, Schwartz, McDaniel, et al.; Coscia et al.; Wiener, Vasquez, & Battles) represent significant steps toward understanding the nature of the relationships between HIV infection and emotional, behavioral, and cognitive sequelae.

The most obvious common theme across the studies is the examination of intrafamilial factors that may affect emotional and cognitive functioning of children with HIV. Yet, to a greater extent than is often seen in the pediatric AIDS literature, the authors have moved beyond identifying an association between pediatric HIV infection and psychosocial adjustment (or psychoeducational performance) and have attempted to identify mechanisms that may explain these associations (e.g., predominant coping strategies, caregiver attitudes and practices, caregiver emotional distress). In an attempt to encourage further research on these mechanisms, this commentary will focus on factors identified by the four investigations that may hold promise for future intervention research.

The findings of Coscia et al. are particularly noteworthy in that they identify both a mediating and a moderating mechanism in the relationship between HIV infection and cognitive functioning in children. As highlighted by the authors, the literature has identified a variety of central nervous system (CNS) outcomes associated with pediatric HIV infection. These outcomes include both changes in the structural integrity of the infected CNS (Campbell, 1997), as well as changes in neurochemical processes within the CNS of infected individuals (Kraiselburd, 1995). Yet, despite these biological differences, reports in the literature on the cognitive functioning of children with HIV/AIDS are varied (e.g., Bisiacchi, Suppiej, & Laverda, 2000; Fishkin et al., 2000; Loveland et al., 2000). Perhaps contributing to the explanation of the varied findings, Coscia et al. have identified home environment as a mediator between HIV infection and neurocognitive outcomes. These results suggest a need for prevention efforts (i.e., prior to significant disease progression), as well as specialized intervention for families once the child's illness has progressed. A number of issues resulting from this finding will require further investigation, including whether, how, and when...
therapeutically driven changes in family environment will affect the cognitive development of the child.

Consistent with numerous studies in the adult and pediatric psychology literature (e.g., Compas, Worsham, Ey, & Howell, 1996; Moos & Shaef er, 1993; Steele et al., 1999) Bachanas et al. identified reliance on palliative coping strategies as predictors of emotional distress among both children and their caregivers. Some authors (e.g., Roth & Cohen, 1986) have suggested that palliative coping strategies are associated with increased distress because of the notion that they provide only temporary relief from the source of discomfort or distress. Unfortunately, the waters here are still murky, as many measures of palliative (i.e., emotion-focused) coping are “contaminated” by items that in and of themselves reflect emotional distress (e.g., “Cry or feel sad”; Schoolager’s Coping Strategies Inventory; Ryan-Wenger, 1990).

Inconsistent with the results presented in this issue, Stanton et al. (2000) examined emotional approach strategies among women with breast cancer and found a positive association between emotional approach and psychological adjustment to illness and to positive clinical outcomes. According to Stanton et al., emotional approach strategies are uncontaminated by emotional distress (e.g., “I take time to express my emotions”). In light of the various functions of coping behaviors, it may be necessary to examine the specific roles of coping strategies within the pediatric AIDS/HIV population. For example, palliative strategies may be used in an attempt to ameliorate distressing thoughts and feelings, but may also have the effect of decreasing adherence to medication. Further clarification of the roles of specific coping mechanisms in children’s adjustment to HIV infection is warranted.

Related to coping strategies, Bachanas and colleagues found that children who were not told of their illness reported more distress and had caregivers with higher self-reported distress. This finding is consistent with results among other disease types (e.g., cancer) wherein children who were not informed of their illness evidenced increased distress (Slavin, O’Malley, Koocher, & Foster, 1982; Waechter, 1971). To our knowledge, Bachanas and colleagues are the first to demonstrate this effect among children with HIV. Because of the unique characteristics of HIV infection (e.g., social stigma), a number of questions remain outstanding: Is there a causal association between disclosure and self- or caregiver-reported distress? For whom (age, coping style, cognitive level) is disclosure appropriate? By what process should children be informed of their HIV status? What are the requisite skills for optimal assimilation of this information? The growing number of perinatally infected children who are successfully reaching their teenage years underscores the need for empirical answers to the above questions.

A curious finding across both of the Bachanas studies was that children with HIV and their caregivers evidenced lower mean T-scores on measures of distress than children without HIV and their caregivers. In their discussion, Bachanas et al. suggested two hypotheses regarding the cause of this nonintuitive finding. First, it is possible that families with HIV benefit from mental health care services available to them, whereas uninfected families have more limited access to such services. Whereas it is true that patients of tertiary care centers often have access to specialized mental health services, there are few empirical data to indicate the extent to which HIV-infected patients use these services. Further, the differential use and effectiveness of traditional support systems (e.g., family, spiritual leaders) versus formal mental health services in this population have not been sufficiently examined empirically. Mental health care availability and utilization among the pediatric AIDS community appears to be an important area for further investigation.

Alternatively, Bachanas and colleagues proposed that children with HIV and their families might evidence a coping style (adaptive style) that minimizes the experience and reporting of distress or unpleasant emotions. This speculation is not inconsistent with results from some studies of children with cancer, in which patients reported less distress (i.e., anxiety, depression) than that expressed by children without cancer (e.g., Phipps & Srivastava, 1997). Furthermore, recent data (Phipps, Steele, & Elliott, submitted) suggest that African American children may employ a repressive adaptational style with greater frequency than other racial or ethnic groups. This finding was particularly strong among African American children with serious illnesses (e.g., cancer, juvenile rheumatoid arthritis). One concern is that children who may need additional support during difficult experiences will not be identified as such because of an adaptive style that conceals emotional distress. However, repressive
access to mental health care. In light of this possibility, Wiener and colleagues’ report that almost a third of their sample attended support group meetings, and that the majority of the sample reported seeing a need for mental health services, is intriguing. Again, more information regarding the utilization of mental health care services by families affected by HIV is needed. Whether utilization patterns covary with demographic variables within the pediatric HIV community has not been empirically addressed.

We began this commentary noting the similarities among the studies: they attempt to move the literature beyond noting differences between children who are healthy and those with HIV, and toward identifying mechanisms that explain the nature of the observed relationships. Although the studies in this issue represent progress, the literature remains far from developing empirically supported recommendations to ameliorate the psychosocial or psychoeducational comorbidities of pediatric HIV infection. As these studies have suggested, family environmental conditions will likely be a key focus of any such interventions. Specifically, factors pertaining to family coping mechanisms, communication about illness, and educational supports and resources available in the home may be particularly amenable to further research.

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References


