Commentary: Coping Over the Long Haul: Understanding and Supporting Children and Families Affected by HIV Disease

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In the video, What’s Best for You: Families Living With HIV Talk About Disclosure (1994), a 6-year-old boy living with HIV asks the question: “I just want to know, can this stuff go away?” As we approach the third decade of the HIV/AIDS epidemic, we still face the reality that HIV does not go away. However, we have learned that it is a chronic, treatable illness. Advances in medical care have demonstrated that the virus can be reduced to undetectable levels and disease progression can be significantly slowed. Thus, people with HIV are living much longer and healthier lives. The children we once thought would not live beyond age 7 are now living into their teenage years and beyond. I personally have the privilege of knowing children with perinatally acquired HIV infection who are now in their early twenties. The 6-year-old who asked the question about a cure for HIV infection is now in his early teens facing adolescent developmental issues. Thus, over the course of the epidemic, the developmental needs and issues faced by children and families have changed, producing new challenges in parenting and planning for the future.

Although the medical accomplishments are exciting, offering hope for even brighter days, treatment regimens can be complex, creating adherence difficulties. As with other chronic illnesses, there are a number of psychological sequelae including emotional and behavioral difficulties, interaction with multiple medical and social service providers, developmental delays, disruption of daily activities such as school attendance, and premature death (Yoos, 1987). Other distinguishing issues associated with HIV/AIDS are secrecy, stigma, isolation, and multiple losses. Among children and families, we add to this list multigenerational disease, multigenerational loss, and interaction with previous family problems such as substance abuse. Further, many families affected by HIV/AIDS are also dealing with social issues such as poverty, homelessness, and inadequate access to medical, social, and educational resources (Lewis, Haiken, & Hoyt, 1994; Steiner, Boyd-Franklin, & Boland, 1995). Any one of these issues has the potential to cause psychological distress and poor adjustment. In combination, they pose increased risk for children and families affected by HIV disease.

The confluence of medical, psychological, and social factors in HIV gives rise to a breadth of issues. Among the most critical are the developmental needs and issues faced by children and families, impact of HIV infection on parenting, psychosocial problems parents face, stress and coping among children and families, family functioning, changes in family structure and functioning related to disease progression, permanency planning, disclosure of HIV diagnosis, treatment adherence, management of loss and grief, and HIV prevention, as well as interactions among these issues. This seemingly unending list accentuates the
The work presented here (this issue: Bachanas, Kullgren, Schwartz, Lanier, et al.; Bachanas, Kullgren, Schwartz, McDaniel, et al.; Coscia et al.; Weiner, Vasquez, & Battles) is responsive to this urgent need. Their research is family-focused, examining adjustment and functioning among children and parents. The multigenerational impact of HIV disease makes this essential. Indeed, whereas most pediatric HIV cases result from perinatally acquired infection, these authors’ work confirms that our investigation of “families” must reach beyond mothers to include extended, adoptive, and foster parents. Further, as noted by Bachanas, Kullgren, Schwartz, McDaniel, et al., in their study of adjustment among caregivers, research must include fathers. Weiner et al. answer this call with a groundbreaking investigation of parenting and other psychological matters for fathers caring for a child with HIV infection. Although the fathers in the Weiner et al. sample do not reflect the disproportionate presence of HIV among African Americans and Latinos, this work reminds us to keep sight of the essential role fathers play in their children’s lives. It also points us toward exploring the gender-specific concerns of both HIV-positive and uninfected fathers.

The impact of HIV on the nervous system can create changes in the behavioral, emotional, and cognitive development and functioning of children. Bachanas, Kullgren, Schwartz, Lanier, et al. demonstrated that a considerable number of HIV-positive children have adjustment problems, though not necessarily at significantly higher rates than their noninfected, demographically matched peers. Their research indicates that caregivers reporting higher levels of psychological distress also reported more internalizing and externalizing behavior problems in their children. However, there was a discordant relationship between parents’ assessment of children and children’s self-assessment of their adjustment. Thus, caregivers with greater stress may also tend to see their children as having more difficulties. Given the multigenerational nature of HIV infection, this research underscores the importance of understanding how a parent’s disease progression may affect his or her ability to characterize and respond to his or her children’s behavior.

Coscia et al. highlighted the relationship between the home environment and children’s cognitive functioning. They demonstrated that the home environment can be a protective factor against or a risk factor for the detrimental effects of poverty on cognitive functioning. They found that children with HIV infection living in poverty also tended to live in homes with less stimulating environments and may be at increased risk for developmental problems. This risk seemed to increase with disease severity, suggesting that parents’ interactions with children may change as the child’s disease progresses, leaving them more vulnerable to the negative impact of less stimulating home environments. Coscia et al. note that further investigation of the contribution of disease factors is necessary to fully understand this phenomenon. However, this finding may also be indicative of parents’ responses to loss related not only to fears about death but loss of the dreams and goals they hold for their children who may be physically and cognitively declining. Future research should address the influence of parent’s level of hope/optimism and degree of concern about loss on their interactions with their children.

Sherwin and Boland (1994) and Cohen (1994) called for research addressing family structure and functioning. Both Bachanas, Kullgren, Schwartz, McDaniel, et al. and Weiner et al. found significant levels of psychological distress among caregivers likely to have a detrimental impact on family functioning. This, coupled with the data on children and the interaction between parents’ and children’s functioning, signifies a need for family-focused interventions that increase coping resilience over the long haul. All the authors in this issue make suggestions for services and interventions including support groups, parenting education, Internet chat rooms for parents, case management, stimulating toys for the home environment, and patient education about medical and insurance issues. There is a wealth of clinical publications (see Adnopoz & Berkowitz, 2000; Bauman & Weiner, 1995; Boyd-Franklin, Steiner, & Boland, 1995; Tasker, 1992) documenting the effectiveness of individual, family, and group psychotherapy, case management, home-based therapy, and multisystems approaches to pediatric and family HIV.

A logical next step is empirical investigation of intervention strategies. I agree with Weiner et al. that the chronic nature of HIV disease makes it prudent that some of these investigations be longitudinal. With children growing older, changing developmental needs, disclosure of diagnosis and treatment adherence will be important areas for effective
intervention. The decrease in rates of perinatal transmission will make the well-being of affected children even more prominent. Investigation of services and interventions aimed at enhancing coping and adjustment over time as well as permanency planning will be a priority.

Last, it is important to note that the research of Bachanas, Kullgren, Schwartz, Lanier, et al.; Bachanas, Kullgren, Schwartz, McDaniel, et al.; and Coscia et al. acknowledges and even documents the impact of social issues such as poverty, substance abuse, and inadequate access to resources on the adjustment and functioning of families affected by HIV. Further, Bachanas and colleagues (Bachanas, Kullgren, Schwartz, Lanier, et al.; Bachanas, Kullgren, Schwartz, McDaniel, et al.) demonstrated that there was no significant difference in adjustment problems among parents and children living with HIV and their demographically matched healthy peers. This magnifies the exigency for integrated, multidisciplinary services in pediatric primary care along with mental health, social, and policy interventions that seek to improve quality of life for all families. Perhaps an unexpected, yet enlightening by-product of the HIV epidemic is the fact that it has written in bold letters the need for increased access to integrated systems of care for all children and families.

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References


