SOCIAL WORK PRACTICE WITH CHILDREN PERINATALLY-INFECTED WITH HIV: CONSIDERATIONS REGARDING DIAGNOSTIC DISCLOSURE

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The development of antiretroviral therapies (ARTs) has significantly lengthened the lifespan and changed the life course of most individuals infected with HIV and AIDS in the United States. Furthermore, ART use during pregnancy has significantly reduced the rate of mother-to-child (perinatal) HIV transmission. While perinatal infection rates among children in the United States have declined since the 1990s, ART regimens became standard treatment protocol, there remains a population of children entering adolescence who were born HIV-positive. This paper discusses: 1) the importance of diagnostic disclosure of HIV and AIDS status to infected children, 2) stigma and the disclosure process with children, and 3) the role of clinical social workers in facilitating the disclosure process.

The most common means of human immunodeficiency virus (HIV) transmission to children in the United States is through mother-to-child vertical transmission during pregnancy (Center for Disease Control [CDC], 2006a). Perinatal transmission increased throughout the 1980s and peaked during the early-to mid-1990s, during which time an estimated 1,750 children were born perinatally-infected each year (CDC, 2004; Lindegren, et al., 1999). Since the beginning of the HIV and AIDS epidemic in the United States, about 57% of perinatally-infected children have died as a result of AIDS-related complications (CDC, 2004; 2006a). Since the mid-1990s, the introduction of ARTs combined with HIV and AIDS testing among pregnant women has significantly reduced the risk of mother-to-child HIV transmission (CDC, 2006a; Lindegren, et al., 1999). By the year 2000, the number of perinatal HIV and AIDS infections had decreased to about 325 annually. Currently, an estimated 9,419 perinatally-infected children are living in the United States (Wiener & Battles, 2006). Still, disclosure of an HIV and AIDS diagnosis remains a challenging topic for parental caregivers. Research indicates that 25 to 75% of school-aged children with HIV or AIDS do not know their status (Blasini, et al., 2004; Lester, et al., 2002; Mellins, et al., 2002). The American Academy of Pediatrics recommends that all HIV-infected and AIDS-positive school-aged children be disclosed to and educated regarding their diagnosis and health status (Committee on Pediatric AIDS, 1999). The majority of perinatally-infected children living with HIV and AIDS are African American (60%) and Latino (20%) (CDC, 2004; CDC, 2006a).

Stigma and HIV and AIDS Diagnostic Disclosure

The use of ARTs has made perinatally- and adult-acquired HIV a disease comparable to cancer in terms of its clinical course as a chronic, long-term, sub-acute, yet life-threatening disease (Mellins, et al., 2002; Brown, Laurie, Pao, 2000). However, unlike cancer, HIV and AIDS has greater social stigma, perhaps related to the high HIV transmission rates and short-term life expectancy of AIDS-infected homosexual and substance abusing populations during the 1980s and 1990s (Fife & Wright, 2000). The stigma is highly related to the fact that the virus is often transmitted through sexual contact (Valdiserri, 2002). Though male-to-male sexual contact remains a risk factor, the risk of HIV transmission through heterosexual sex and drug use is greater still. Moreover, research has shown that many misconceptions exist about the actual modes of HIV transmission (Herek, Capitanio, & Widaman, 2002).

Several factors affect a caregiver's decision to tell a child of his or her HIV or AIDS status. Social stigma is a primary reason why parents are reluctant to disclose. A desire to protect the infected child from social ostracism combined with a sense of guilt related to mother-to-child transmission of the virus may plague the family system (Committee on Pediatric AIDS, 1999; Blasini, et al., 2004). In addition, parents may be concerned that the child may then disclose to others, jeopardizing the social standing of all family members (Nehring, 2000; Lashley & Malm, 2000). Fife and Wright (2000) noted that the social stigma associated with HIV and AIDS is related to internalized feelings of shame and social isolation.

The current literature examining HIV and AIDS disclosure to children has posited contradictory research findings about the impact of disclosure on a child's health and mental health outcomes. Some studies have shown that HIV and AIDS status disclosure to children generally results in positive outcomes for both children and their parental caregivers. Parental caregivers have reported a sense of relief after disclosure, as well as lower levels of stress, compared to parental caregivers who have not disclosed (Blasini, 2004; Committee on Pediatric AIDS, 1999). Contrary to caregivers' concerns related to social stigma, there are no indications that knowledge of HIV and AIDS diagnosis significantly increases psychological distress or mental health problems among children (Wiener & Battles, 2006). A growing body of literature suggests that children who are disclosed to have higher self-esteem and are less depressed compared to their non-disclosed to counterparts (Mellins, et al., 2002; Committee on Pediatric AIDS 1999).

Mellins, et al. (2002) suggested that the burden of an "unknown secret" may be psychologically taxing and create worrisome thoughts for a child. Another study suggested that the occurrence of psychiatric disorders among perinatally-infected youth were comparable to the occurrence in non-infected youth, suggesting that perinatally-infected HIV youth were not at greater risk for mental health difficulties (Mellins, 2006). Furthermore, disclosure seems to be an important factor in garnering social support around the diagnosis and the child's care. The earlier children learn about their HIV status, the more people they disclose to by the time they reach adolescence (Wiener & Battles, 2006). Having friends and relatives who know these children's medical status is important for social support. Children and adolescents living with HIV and AIDS who are not disclosed to exhibit more confusion about their illness and medication compliance (Abadia-Barrero & LaRusso, 2006). Over time, these children may become cynical about their care and develop attitudes of shame and anger.

Other research, however, has highlighted the negative outcomes of disclosure. For example, disclosing HIV and AIDS status to friends and family may heighten caregiver and child stress levels and feelings of anger, particularly because disclosure to family and friends may be only in response to the child's declining health (Ledlie, 1999). These increased feelings of stress and anger, in turn, may decrease medication adherence (Garvie, 2006). Furthermore, some parental caregivers have reported that, following disclosure, their child experienced emotional distress due to concerns about his or her own long-term reproductive and family planning (Mellins, 2002). Contrary to other findings regarding perinatally-infected children, Gaughan, et al. (2004) reported a higher incidence of psychiatric hospitalizations among children and adolescents living with HIV and AIDS along with a significantly higher occurrence of depression and behavioral disorders. Still, despite the lack of consensus, Battles and Wiener (2002), in a review of the literature, noted that most researchers found that disclosure is positively related to social support, feelings of self-competence, and decreased behavioral problems among children.

The Diagnostic Disclosure Process

As children perinatally-infected with HIV and AIDS age, disclosure of their HIV and AIDS status by caregivers, medical professionals, social workers, and psychologists becomes a sensitive yet important clinical issue that must be addressed. Disclosure of HIV and AIDS status at an early age is important for several reasons. First, children perinatally-infected with HIV and AIDS are most likely to be urban, low-income, and African American or Latino (CDC, 2004). Studies have shown that this population is especially at risk for an early onset of sexual activity and drug use (CDC, 2004). As a result, this HIV and AIDS infected sub-population is at an increased risk of transmitting the virus via sexual intercourse and drug use (Browning, Leventhal, & Brooks-Gunn, 2004).

In addition, research has suggested a significant correlation between disclosure and positive health status as measured by viral load. Children who know their health status are more likely to adhere to an ART and have a lower viral load, demonstrating a better health status (Blasini, et al., 2004). This is important because failure to adhere to an ART regimen may result in treatment resistance, therefore compromising the child's long-term health prognosis (Matsui, 1997). In this way, disclosure is closely related to transmission prevention and the child's health maintenance.

Ideally, disclosure should be conducted gradually throughout the child's development and include the support of health and mental healthcare providers. Disclosure should never occur as a "single revelation" (Domek, 2006). Parental, peer, and mental health staff support are all key to successful disclosure (Blasini, et al., 2004). As with grieving around other chronic, potentially terminal illnesses, children and adolescents with HIV and AIDS will likely go through the following stages of grieving: anger, bargaining, depression, and ultimately, acceptance (Blasini, et al., 2004; Kindy-McPherson, 2005). Immediately following disclosure, children report feeling shocked, sad, angry, worried, and confused (Mellins, et al., 2002). Over time, children's anxious feelings generally become more neutralized, and many have reported feeling hopeful about their prognosis. Domek (2006) noted that it may take children some time to understand the nature of their diagnosis, necessitating an ongoing, open dialogue of what the disease is and what the diagnosis means. In addition, disclosure may provide a context to reveal other family secrets, such as other infected family members, the child's biological parents, the child's health prognosis, and that the child was perinatally-infected.

Though families may be in denial and refuse to disclose to their children, it is not uncommon for children to "accidentally" learn of their diagnosis by overhearing conversations or reading something related to their health status (e.g., medical charts, insurance paperwork, or school medical records). Or, for example, a child may discern that he or she has a medical condition based on family members' behaviors, a consistent medication regimen, and ongoing medical care (CHAMP+, 2007; Lester, et al., 2002). This type of accidental disclosure is dangerous and should be avoided because emotional isolation may develop as children independently attempt to make sense of what their diagnosis means and why it has been hidden from them (Blasini, et al., 2004).

Despite these risks, social work clinicians should not force a parental caregiver to disclose to a child, and they should remain non-judgmental about the guardian's decision around disclosure; clinician respect for each family's right to self-determination is most important. The clinician's first and foremost role is to provide ongoing support to the family system, taking into consideration the family's community and ongoing stressors (Kindy-McPherson, 2005; Lester, et al., 2002). Less expressive and less communicative families, who are also less likely to disclose to their children, may need additional support (Lester, et al.).

The disclosure process should take into consideration the child's age, maturity, cognitive functioning levels, and ability to handle the diagnosis (Committee on Pediatric AIDS, 1999; Lester, et al., 2002). While younger children should receive simple explanations about their medical condition, older children should be provided with full disclosure and be encouraged to actively participate in their own medical care (Committee on Pediatric AIDS, 1999). Due to developmental differences, children and preadolescents understand that HIV and AIDS are serious illnesses, but they do not relate it to their future, as adolescents do (Blasini et al., 2004). This likely reflects adolescents' emotional, social, and physical development, and their general interests in romantic relationships and considerations around family planning.

Implications for Social Work Practice

Social workers may encounter perinatally-infected youth in a number of contexts, including hospitals, outpatient pediatric AIDS clinics, child welfare agencies, and schools. Within these settings, where there are few interventions tailored to the needs of perinatally-infected children, social workers are in a unique position to provide mental health service support for this population's ongoing and emerging mental health needs. Social workers' skill sets in the areas of engagement, assessment, advocacy, case management, and crisis intervention, combined with their conceptual grounding in ecosystems theory, make them especially qualified to assist families facing enormous psychosocial-environmental problems related to the disclosure process.

A full understanding and consideration of the child's particular family circumstance and health status is imperative. The child's family represents a group directly affected by HIV and AIDS. At a social worker's point of contact, the child may be living with an infected parent, a non-infected parent, within the foster care system, or with another family member, such as a grandmother or uncle. Furthermore, the child may also have infected siblings and other family members, or be the only infected person within the entire family. In addition, some perinatally-infected children may be very healthy; others, however, may be chronically ill, very symptomatic, and present with significant immunological deterioration (Lester, et al., 2002). The mental health status and daily concerns of these two populations may be very different.

Psychodynamic, emotional peer support groups for HIV-infected adolescents can help reduce the risk of depression and increase medication adherence (Funck-Brentano, 2005). Disclosure to preadolescents and adolescents should include a psycho-educational component and at least some discussion about self-care and responsibility related to future independent living (Battles & Wiener, 2002). Clinical work with this population should include a thorough sexual education component and foster the development of communication skills related to negotiating safe-sex practices and disclosing HIV and AIDS status to sexual partners. Furthermore, "one stop care" that offers counseling and social support, case management services, standard medical care, reproductive care and education, enables social service and medical providers to collaborate and offer responsive, comprehensive care along a continuum that addresses this population's unique needs (Levine, Aaron, & Foster, 2005).

Conclusion

The onset of adolescence combined with the uncertainty of a chronic, life-threatening, and highly stigmatized illness undoubtedly creates a context for fear, anxiety, and feelings of isolation among perinatally-infected HIV and AIDS positive children and adolescents. Disclosure, especially early on, may buffer these feelings, providing the child with an increased sense of hope, confidence, and self-esteem. These children are likely to confront a host of other issues, including poverty, discrimination, mental health issues, violence, sexual abuse, limited access to health care, and lack of familial support. Responsible, clinician-led support may serve as the basis for the development of self-agency, resiliency, self-advocacy, and self-actualization among these children (Battles & Wiener, 2000; Brown, Lourie, & Maryland, 2000, Domek, 2006; Kindy-McPherson, 2005).

References

Abadia-Barrero, C. & LaRusso, M. (2006). The disclosure model versus a developmental illness experience model for children and adolescents living with HIV/AIDS in Sao Paulo, Brazil. *AIDS Patient Care and STDs*, *20*(1), 36-43.

Battles, Haven B. & Wiener, Lori S. (2002). From adolescence through young adulthood: Psychosocial adjustment associated with long-term survival of HIV. *Journal of Adolescent Health*, *30*(3), 161-168.

Blasini, I., Chantry, C., Cruz, C., Ortiz, L., Salabarria, I., & Scalley, N., et al. (2004). Disclosure model for pediatric patients living with HIV in Puerto Rico: Design, implementation, and evaluation. *Journal of Developmental & Behavioral Pediatrics*, *25*(3), 181-189.

Brown, L., Lourie, K., & Pao, M. (2000). Children and adolescents living with HIV and AIDS: A review. *The Journal of Child Psychology and Psychiatry and Allied Disciplines, 41*(1), 81-96.

Browning, C., Leventhal, T., & Brooks-Gunn. (2004). Neighborhood context and racial differences in early adolescent sexual activity. *Demography*, *41*(4), 697-721.

Centers for Disease Control and Prevention. (2006a, May). CDC HIV and AIDS fact sheet: Mother-to-child (perinatal) HIV transmission and prevention. Retrieved November 1, 2006, http://www.cdc.gov/hiv/resources/factsheets/perinatl.htm

Centers for Disease Control and Prevention. (2006b, April). CDC HIV and AIDS fact sheet: A glance at the HIV and AIDS epidemic. Retrieved November 1, 2006, http://www.cdc.gov/hiv/resources/factsheets/At-A-Glance.htm

Centers for Disease Control and Prevention. (2004). Youth risk behavior surveillance - United States, 2003. *Morbidity and Mortality Weekly Report*, 53(SS-2), 1–29.

Centers for Disease Control and Prevention. (2004). Cases of HIV Infection and AIDS in the United States, 2004. Retrieved November 1, 2006, http://www.cdc.gov/hiv/topics/surveillance/resources/reports/2004report/default.htm

Centers for Disease Control and Prevention. (2006, September). Revised recommendations for HIV testing of adults, adolescents, and pregnant women in health-care settings. Morbidity and Mortality Weekly Report, 1-17. Retrieved November 1, 2006, http://www.cdc.gov/mmwR/preview/mmwrhtml/rr5514a1.htm

CHAMP+: Supporting HIV-infected youth and families (January, 2007). [Data from interviews with HIV-Infected Youth] Mount Sinai School of Medicine. Unpublished raw data.

Committee on Pediatric AIDS. (1999). Disclosure of illness status to children and adolescents with HIV infection. *Pediatrics*, *103*(1), 164-166

Cooper, E., Charurat, M, & Mafenson, L., et al. (2002). Combination antiretroviral strategies for the treatment of pregnant HIV-1 infected women and prevention of perinatal HIV-1 transmission. *Journal of Acquired Immune Deficiency Syndrome*, *29*(5), 484-94.

Domek, G. (2006). Social consequences of antiretroviral therapy: Preparing for the unexpected futures of HIV-positive children. *The Lancet*, *367*(9519), 1367-1370.

Fife, B. & Wright, E. (2000). The dimensionality of stigma: A comparison of its impact on the self of persons with HIV and AIDS and cancer. *Journal of Health and Social Behavior*, *41*(1), 50-57.

Funck-Brentano, Dalban, C., Veber, F., Quartier, P., et. al (2005). Evaluation of a peer support group therapy for HIV-infected adolescents. *AIDS*, *19*(14), 1501-1508.

Garvie, P., Cremeens, J., Rai, S., An, Qian, Hadley, W., & West, R. (2006, April). *Disclosure of children's perinatally-acquired HIV-1 diagnosis in relation to medication adherence, physical functioning, & parental psychological functioning: A prospective pilot study of process & outcome. Paper presented at the Biannual Conference on Children's Health Psychology*, Gainesville, FL.

Gaughan, D., Hughes, M. Oleske, J., Malee, K., Gore, C., &Nachman, S. (2004). Psychiatric hospitalizations among children and youths with human immunodeficiency virus infection. *Pediatrics*, *113*(6), 544-551.

Herek, G., Capitanio, J., & Widaman, K. (2002). HIV-related stigma and knowledge in the United States: Prevalence and trends 1991-1999. *American Journal of Public Health*, *92*(3), 371-377.

Kindy-McPherson, J. (2005). To tell or not to tell: Bereaved undisclosed children and HIV and AIDS. *Relational Child & Youth Care Practice*, *18*(1), 75-79.

Ledlie, S. (1999). Diagnosis disclosure by family caregivers to children who have perinatally acquired HIV disease: When the time comes. *Nursing Research*, *48*(3), 141-149.

Lester, P., Chesney, M., Cooke, M., Weiss, R., Whalley, P., Perez, B et al. (2002). When the time comes to talk about HIV: Factors associated with diagnostic disclosure and emotional distress in HIV-infected children. *Journal of Acquired Immune Deficiency Syndromes*, *31*(3), 309-317.

Levine, A., Aaron, E., Foster, J. (2005). Pregnancy in perinatally HIV-infected adolescents. *Journal of Adolescent Health, 38*(6), 765-768.

Lindegren, M., Byers, R., Thomas, P., Davis, S., Caldwell, B., et al. (1999). Trends in perinatal transmission of HIV and AIDS in the United States. *Journal of the American Medical Association*, *282*(6), 531-538.

Matsui, D.M. (1997). Drug compliance in pediatrics: Clinical and research issues. *Pediatric Clinics of North America*, *44*(1), 1-14.

Mellins, C.A., Brackis-Cott, E., Dolezal, C., Richards, A., & Abrams, E. (2002). Patterns of HIV status disclosure to perinatally infected HIV-positive children and subsequent mental health outcomes. *Journal of Child Psychology and Psychiatry*, *7*(1), 101-114.

Mellins, C.A., Brackis-Cott, E., Dolezal, C., & Abrams, E. (2006). Psychiatric disorders in youth with perinatally acquired human immunodeficiency virus infection. *Pediatric Infectious Disease Journal*, *25*(5), 432-437.

Nehring, W., Lashley, F., & Malm, K. (2000). Disclosing the diagnosis of pediatric HIV infection: Mother's views. *Journal of the Society of Pediatric Nurses*, *5*(1), 5-14.

Thorne, C., Newell, M., Botet, F., Bohlin, A., Ferrazin, A., Giaquinto, C., et al. (2002). Older children and adolescents surviving with vertically acquired HIV infection. *Journal of Acquired Immune Deficiency Syndromes*, *29*(4), 396-401.

UN AIDS. (2006). Fact sheet: North America, Western, and Central Europe. Retrieved November 1, 2006, http://www.unaids.org/en/HIV_data/2006GlobalReport/press-kit.asp

Valdiserri, R. (2002). HIV/AIDS Stigma: An impediment to public health. *American Journal of Public Health*, *92*(3), 341-342.

Wiener, L., & Battles, H. (2006). Untangling the web: A close look at diagnosis disclosure among HIV-infected adolescents. *Journal of Adolescent Health*, (3), 307-309.

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