

Running Head: HIV POSITIVE FATHERS' PERCEPTIONS OF CHILDREN'S NEEDS

A Transactional Ecosystems Framework of HIV Positive Fathers' Perceptions of their Children's
Psychosocial and Health Needs:
Implications for Family and School-Focused Therapeutic Interventions for Children Affected by

HIV

By

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A Doctoral Project Submitted in Partial Fulfillment of
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Author Note and Acknowledgements

The author, Soye Zaid-Muhammad of Pace University's Department of Psychology, was affiliated with the Family Access to Care Study (FACS) formerly of Memorial Sloan-Kettering Cancer Center, Department of Psychiatry and Behavioral Sciences, from 2003 to 2006. He is now affiliated with the New York City Department of Education as a School Psychologist, serving as the chair of a School-Based Committee on Special Education. He is also affiliated with the City College of the City University of New York as an Adjunct Lecturer of Psychology.

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ABSTRACT

The current doctoral project analyzed archival data from a larger NIMH-funded study, entitled the Family Access to Care Study (FACS), to examine a subsample of its participants, in order to determine links between ecosystems affecting HIV-positive fathers and their concerns regarding factors affecting their children. A sub-sample of 143 HIV+ fathers, mostly of African American descent was examined, from the theoretical perspective, to determine the degree to which their ecosystems interacted with those of their children. Using this paradigm, fathers' life experiences, participation in HIV-related services, and current systems were expected to predict concerns regarding outcomes for their children. Chi-square analyses and logistic regression models were used to discern these predictions. Findings revealed significant relationship between HIV+ fathers' income levels and concerns regarding their children's learning abilities. In addition, fathers' years with HIV predicted concerns regarding medical problems or injury, concerns regarding disclosing HIV status to their children, and concerns regarding keeping HIV status hidden from their children. HIV+ fathers' past negative feelings predicted concerns regarding emotional and behavioral problems in the home and school settings. Finally, fathers' utility of HIV-related mental health services also predicted d concerns regarding their children's substance use. Implications for transactional ecosystem-based interventions were discussed.

A Transactional Ecosystems Framework of HIV Positive Fathers' Perceptions of their Children's

Health Needs:

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The Human Immunodeficiency Virus (HIV), the causative viral agent for Acquired Immune Deficiency Syndrome (AIDS), was first recognized as an epidemic in the United States in 1981 (Center for Disease Control and Prevention [CDC], 2006; 2008). AIDS is an end-state of HIV infections (CDC, 2006; 2008). According to the CDC (2006; Hall, Song, Rhodes et al., 2008), 56,000 new HIV cases were estimated in 2006. In addition, the CDC's (2008) analysis revealed an estimated 1.1 million adults and adolescents in the U.S. living with HIV by the end of 2006. Furthermore, most persons living with HIV are between the ages of 25 and 49 years (70%) and male (75%), with only about one quarter infected persons being women (CDC, 2008). Moreover, while Blacks or African-Americans make up only 12% of the U.S. population, they account for almost half of all HIV cases (46%; CDC, 2008). Also, HIV infection in the U.S. occurred at a rate of 18.5 per 100,000 persons (CDC, 2006; 2008; Hall et al., 2008).

Despite the rising HIV incidence and prevalence rates, HIV/AIDS-related mortality has decreased since its inception. Between 2002 and 2006, AIDS mortality in the U.S. decreased by 17 percent (CDC, 2008). Once ranked one of the deadliest diseases to humankind, HIV/AIDS has been downgraded to a serious chronic illness with adequate treatment (Pequegnat & Szapocznik, 2000). This is particularly due to the advent of life-prolonging medical treatments such as azidothymidine (AZT), nucleotide reverse transcriptase inhibitors (NRTI), protease inhibitors, non-nucleotide reverse transcriptase inhibitors, highly active antiretroviral therapy (HAART), and genotypic antiretroviral therapy (GART), all of which have contributed to the significant reduction in the mortality rates of AIDS (Yarhouse, 2003). As a result, many people living with HIV/AIDS are living longer, and are much healthier than they have been in the past (Pequegnat & Szapocznik, 2000). Although people living with HIV/AIDS (PLWHAs) and their

family members no longer face the immediate threat of death and bereavement, they are now faced with HIV-related individual and familial life stressors. Because of this, HIV/AIDS-related issues affect not only the PLWHAs, but also members of the family constellation, including the children (Boyd-Franklin, Aleman, & Lewis, 1995; Rapkin, Bennett, Murphy, & Munoz, 2000; Pequegnat & Szapocznik, 2000). Given this trend, it is important not only to address the HIV-related life factors affecting PLWHAs, but also those affecting their family members and children. The current doctoral project focused on a subsample of PLWHAs from a larger NIMH-funded study entitled the Family Access to Care Study (FACS; Grant # 5R01-MH063045; Bruce Rapkin, Principal Investigator). The main purpose of the FACS study was to explore ways in which service providers can better provide health and mental health-related services to families affected by HIV/AIDS. The general focus of this doctoral project study was to examine the association between life factors and systems affecting a particular group of PLWHAs and the concerns they may have regarding potential issues and systems affecting their children.

Literature Review

There is a growing body of literature focusing on familial systems affected by HIV/AIDS. Much is known about the needs of families affected by HIV/AIDS (Boyd-Franklin et al., 1995; Rapkin, Bennett, Murphy, & Munoz, 2000; Pequegnat & Szapocznik, 2000). There is also an expanding literature source focusing on issues faced by parents living with HIV and their children (Andrews, Williams, & Neil, 1993; Bunting, 2001; Demarco, Lynch, & Board, 2002; Faithfull, 1997; Hackl, Somlai, Kelly, & Kalichman, 1997; Marcenko & Samost, 1999; Murphy, Marelich, Dello Stritto, Swendeman, & Witkin, 2002; Regan-Kubinski & Sharts-Hopko, 1995; Sharts-Hopko et al., 1996; Songwathana, 2001). From this literature, flows a body of work depicting many of the factors affecting mothers living with HIV/AIDS. Less has been reported about those affecting fathers living with HIV/AIDS. In many ways, HIV positive (HIV+) fathers are characterized by “invisibility”, a term adapted by Franklin (2004), which generally refers to the social disregard of a given group in the face of societal prejudices targeting that group. The

apparent invisibility of HIV+ fathers leaves many unanswered questions, particularly regarding the provision of psychosocial support for them and their families. Of the various issues that might be explored, three focal research questions are studied in this doctoral project. They are as follows: (1) What life events and systems uniquely impact HIV+ fathers? (2) What are fathers' specific concerns for their children? And, (3) how do the life events and systems affecting these fathers correlate with their perceptions and concerns regarding the needs of their children?

Antle, Wells, Goldie, DeMatteo, and King (2001) indicated that children of HIV-affected families are likely to suffer the more than others whose family life is affected by members with other chronic health conditions. This is particularly because, unlike with other chronic conditions, multiple family members, including their parental caregivers, are likely to be infected with HIV and affected by its related health compromising agents (Antle et al., 2001). Despite the impact of HIV on multiple members in the family system, this doctoral project will primarily focus on the relationship between issues affecting HIV+ fathers and their concerns regarding issues affecting their children. This association will be theoretically explored from a transactional ecological systems perspective as proposed by Bronfenbrenner (1988/2005b, 1992/2005)

As indicated previously, much of the current literature focuses on the thoughts, feelings and attributions of HIV+ mothers, with regard to issues and life events affecting their children. Less is known about the roles, perceptions, attributions, and concerns of HIV+ fathers. From a transactional ecosystems standpoint, fathers play a critical role in any family ecology (Bronfenbrenner, 1988/2005a). Furthermore HIV/AIDS affects every member of the family constellation including fathers (Boyd-Franklin et al., 1995; Rapkin et al., 2000; Pequegnat & Szapocznik, 2000). Unfortunately, much of the research about families affected by HIV/AIDS does not exclusively focus on fathers (Pequegnat & Szapocznik, 2000). As a result, there is a vacuum in our understanding of not only issues affecting HIV+ fathers, but also their perceptions of issues affecting their children. So, this doctoral project aimed to remedy this limitation in the literature by exploring this issue from the standpoint of transacting as presented by Bronfenbrenner (1988/2005b, 1992/2005).

Transactional Ecosystems

Ecological Systems Theory

Bronfenbrenner's (1992/2005) notion of Ecological Systems Theory is the foundation for his attempt to achieve an understanding of how the ecological forces within the society, sub-population, community, and family system interact with the maturational processes within the individual. In an earlier publication, Bronfenbrenner (1979, as cited by Bronfenbrenner, 1992/2005) coined the idea entitled "Ecology of Human Development", which he defined as the scientific study of the progressive mutual accommodation between an active growing human being, and variables within the various settings where the developing individual lives. He further posited that this process is affected by interactions between an individual's immediate settings and the larger context under which these settings operate. In simpler terms, as people grow and develop, they interact with and are affected by every aspect of these surroundings, including their families, friendships, communities, and cultures. For example, it is reasonable to assume that the children who are growing up in families affected by HIV/AIDS are likely to have relationships with HIV-infected family members, and in so doing, may face a similar core of issues related to coping with HIV within the family unit and its ecology. The developmental trajectories of these children may ultimately be shaped, to a degree, by the issues that affect the PLWHA and others within the family system.

Bronfenbrenner's ecological model derives from Lewin's (1935) demonstration that human behavior is a joint function of the person and the environment ($B=f(PE)$). Bronfenbrenner (1992/2005) adapted this theory by substituting human development for human behavior ($D=f(PE)$), thereby positing that development is a joint function of a person's interaction with the environment. For Bronfenbrenner, (1988/2005b), the three critical and determining factors in this process are (1) the possible developmental outcomes of children, (2) their unique characteristics, and (3) the environmental factors, which impinge on their lives. These include relational, community, and societal dynamics. When applied to families affected by HIV, it is reasonable to

theorize that children of such families develop in the context of relationships with HIV-affected persons and caregivers, exposure to community resources such as HIV service providers, and entitlement laws intended to serve HIV-affected families.

Bronfenbrenner (1992/2005) takes this notion a step further by including time as a factor when studying the transactions between individuals and their interpersonal relationships, their community settings, and their societies over the course of their development. Within his paradigm, he highlighted the importance of what he termed the *chronosystem model* (Bronfenbrenner, 1988/2005b, 1992/2005), a research model that takes into account whether specific factors in individuals and their respective environments have or have not changed over time, and determines whether the examined changes had an impact. Bronfenbrenner identified three typical investigative chronosystem models utilized in the social sciences. The most frequently used is the cross-sectional design, wherein developmental outcomes are compared between subjects within stage cohorts. Another is the short-term longitudinal design. The last and most robust is the long-term longitudinal model. The cross-sectional design is of particular interest and will later be explored for the purpose of this doctoral project.

Human Development: Interacting Systems

Bronfenbrenner (1988/2005b) identified the person-context model as an investigation of the interaction of personal attributes in the context of not only relational, community, and societal factors, but also individuals' primary geographical locations and social addresses. The social address is described as the social location within which individuals function. Multiple forces within children's social addresses may also interact with other ecosystem factors. For example, children growing up in HIV-affected families may reside within catchment areas with high HIV incidence and prevalence.

Bronfenbrenner (1988/2005b, 1992/2005) underscored from his previous work a hierarchy of four specific transactional systems, which influence individuals' development, adjustment, and functional processes. He termed these systems the *Microsystem*, *Mesosystem*, *Exosystem*, and *Macrosystem*. Microsystems were originally defined as systems involving

structures and processes that influence proximally the activities, roles, and interpersonal relationships experienced in immediate settings by developing persons. This definition was later revised to include influential others (Bronfenbrenner, 1992/2005). For example, the microsystems of children from HIV-affected families would include their relationships with HIV+ parents, the home setting, and school or community-based programs aimed at HIV intervention and prevention.

According to Bronfenbrenner (1988/2005b, 1992/2005), mesosystems are comprised of the linkages and processes between two or more of the individual's microsystems. For example, parents create mesosystems when they are actively monitor dating and sexual behaviors among their teens to prevent risky behaviors, some of which could potentially lead to HIV infection. Parental involvement in school-related issues may also be considered a mesosystem.

Exosystems are comprised of linkages and processes between two or more settings, at least one of which do not ordinarily include the individual, but does influence processes within the microsystems that contain and influence the individual (Bronfenbrenner, 1988/2005b, 1992/2005). For example, in a family affected by HIV, ancillary care facilities attended by parents may provide services and support to the parents, which may ultimately influence parent-child interactions in the home setting.

Bronfenbrenner (1988/2005b, 1992/2005) defined macrosystems as overarching patterns of beliefs and practices and social institutions that are common to a particular culture or subculture. Macrosystems are usually comprised of the three aforementioned systems. A macrosystem in a family affected by HIV can include the spiritual or religious belief that faith in God will mitigate life events or crises associated with the HIV. Macrosystems may also include laws and entitlements aimed at serving HIV-affected families. Summary definitions of the four ecosystems are included in Table 1 below. A diagrammatic representation of these systems is presented in Figure 1.

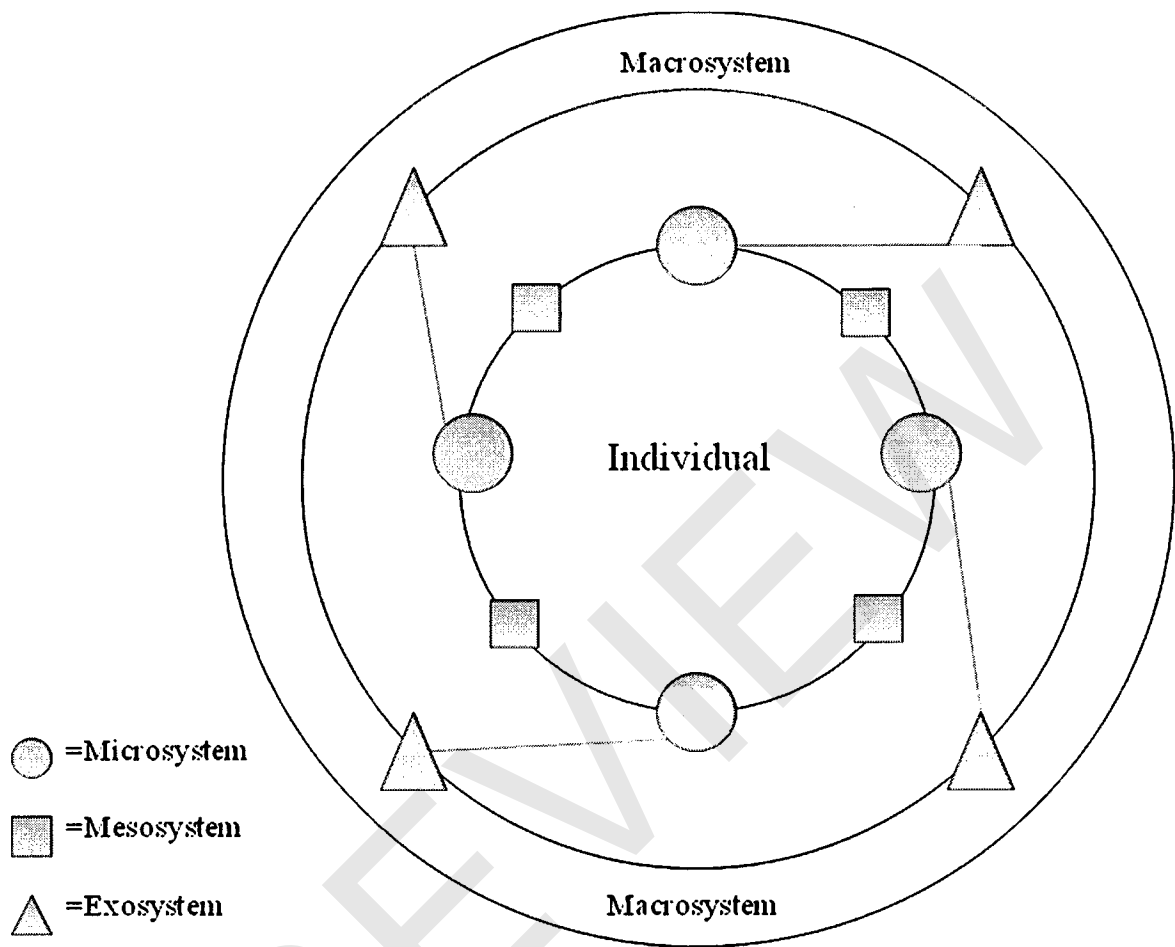
Table 1.

Hierarchy of Transactional Ecosystems: Definitions and examples (Adapted from Bronfenbrenner, 1988/2005b, 1992/2005).

Ecosystem	Definition	Example
Microsystem	A system involving structures and processes, which includes the activities, roles, and interpersonal relationships experienced in immediate settings by the developing persons	May include the home setting including relationships with HIV+ parent, parent-child interactions; the school setting including the classroom, and interactions with classmates; and some community settings such as after-school programs
Mesosystem	A system comprised of the linkages and processes that occur between two or more of the individuals microsystems.	May include parent-teacher interactions, parental involvement in health care, or assistance with class work or family crises in an afterschool program
Exosystem	A system comprised of linkages and processes that occur between two or more settings, which doesn't necessarily include the individual, but influences processes within the individual's Microsystems	May include a parents job or source of income; mental health services provided to the parent, such as counseling or parenting classes, or programs design to raise teacher-awareness of HIV-related issues.
Macrosystem	A system comprised of ideologies, practices, governing rules, and organization of social institutions that are common specific cultures.	May include religious beliefs and practices, intergenerational cultural or familial traditions, school systems, or societal laws.

As previously mentioned, understanding the role of proximal mechanisms within an individual's microsystem is crucial to discerning transactional processes within that system. If development of the individual is to be fully understood, it is equally important to understand the role of those distal mechanisms, those processes beyond his or her immediate setting that influences the power and direction of proximal processes, which directly affect his or her development (Bronfenbrenner, 1988/2005b).

Figure 1.
Hierarchy of Transactional Ecosystems (Adapted from Bronfenbrenner, 1988/2005b, 1992/2005).



The aforementioned ecosystem processes were explored in the current project. That is, the father-child dyad in the family system is essentially a microsystem. Measuring HIV+ fathers' perceptions of their children's life events, behaviors, and activities not only offers a glimpse at potential developmental outcomes within this microsystem, but also reveals something about proximal and distal ecosystemic processes, which impinge on this microsystem. For example, impinging mesosystems may include HIV+ fathers' perceptions and concerns about their children's peer interactions and school activities. Exosystems interacting with the father-child microsystem may include the fathers' utility and perceptions of the HIV-related services offered at community-based organizations. Finally, HIV as an epidemic is an impinging macrosystem that affects the father-child microsystem.

Parenting in HIV+ Families

The parent-child dyads in HIV-affected families are smaller microsystem units within the familial system. As highlighted above in the review of transactional ecosystems, these familial and parent-child systems interact with a hierarchy of other systems. Such is the case with community service providers who interact with family systems to meet the needs of the individuals within the family and the microsystems therein. Thus, just as there are special services needs among families affected by HIV/AIDS (Boyd-Franklin et al., 1995; Rapkin et al., 2000; Pequegnat & Szapocznik, 2000), there are also special parental needs. This is particularly the case when the generation that is slated to parent the next generation, which includes young to middle adults between the ages of 25 and 44, are experiencing the highest infection rates, and are most severely affected by HIV/AIDS (Pequegnat & Szapocznik, 2000). Upon highlighting background literature on HIV-related parenting needs, Antle et al (2001) conducted a qualitative study of parenting experiences among 105 Canadian mothers and fathers who were diagnosed and living with HIV/AIDS. A review of the literature revealed parental reports yielded maladaptive themes such as chronic sorrow, stress, negative stigma, and issues surrounding familial secrecy and disclosure. On the other hand, the qualitative themes revealed that parenting was reported to be the basis of personal joy, albeit an additional obstacle in lives already complicated by HIV/AIDS. Additional qualitative themes reflected time devoted to family life, focus on parenting, understanding the effects of HIV/AIDS, and preparing HIV+ fathers for parenting. The sections that follow will highlight some of the literature that focuses specifically on HIV+ parents' perceptions of life events affecting their children. Keeping with the theme of the current project, these works will be viewed from a transactional ecosystems perspective.

HIV-Positive Mothers

The fact that women often take on the caregiver roles in HIV-infected familial microsystems is documented throughout the literature (Aleman, Kloser, Kreibick, Steiner, & Boyd-Franklin, 1995; Bunting, 2001; Demarco et al., 2002; Hackl et al., 1997; Songwathana,

2001). In addition, previous research has focused primarily on the perceptions of HIV-infected mothers with regard to issues affecting their children as well as microsystemic barriers to care (Boyd-Franklin et al., 1995; Rapkin et al., 2000; Pequegnat & Szapocznik, 2000). In one such study, Andrews et al. (1993) found that the mothers described their relationships with their children as strong attachments strengthened by secrecy bonds. Such mothers also appeared to have ambivalent relationships with their children, because the children were simultaneously perceived as sources of stress as well as support. The children were likely to assume or be assigned roles that assisted mothers; however, the burden of maternal care giving remained intact. Andrews, et al. posited implications for macrosystemic interventions citing that decisions regarding programs and policies for HIV-positive mothers should focus on maintaining the health of the mother-child dyad, providing respite care to mothers, and providing assistance with future planning.

Some researchers found that HIV-infected mothers were likely to prioritize needs within the family microsystem. Such is the case in a study by Demarco et al. (2002), which found that HIV-positive mothers perceived their children's needs to be more important than their own needs, including those needs that were HIV-related. These mothers were likely to self-silence (i.e. squelch their own needs in order to tend to the needs of their children). Self-silencing mothers are likely to present internalizing problems, which in turn may unknowingly have negative consequences for the children in their care. The researchers proposed a number of exosystem interventions. For example, they suggested that providers of HIV-related care identify self-silencing HIV-positive mothers and educate them with regard to the importance of their own physical and psychosocial needs.

Researchers have also examined how the HIV/AIDS epidemic, a pervading macrosystem, has impacted family microsystems. In this regard, Faithfull (1997) examined the effects of HIV/AIDS on HIV-positive mothers' capacity to rear their children. Disclosure, fear of infecting transmitting HIV through casual parental contact, and bereavement were identified as major themes affecting maternal parenting. It was suggested from the findings that HIV-positive

mothers be connected with exosystems, such as education and social service exosystems, to acquire assistance to cope with the aforementioned barriers to effective care-giving.

Other researchers examined interactions between individual characteristics of mothers and their roles within the familial microsystem, in the context of the quality of the home setting. Within this context, Murphy et al. (2002) conducted interviews with 135 HIV-infected or AIDS-diagnosed mothers of asymptomatic children between the ages of 6 and 11 to assess their psychological well-being, quality of their home life, and to assess their functioning as care-givers. The findings revealed that maternal depression was associated with poor cohesion, poor family sociability, and a lower capacity of mothers to perform daily household tasks. In addition, the children of more depressed mothers were likely to have increased household responsibilities, which may contribute to the strain in the parent-child relationship.

This section focused on familial issues faced by HIV+ mothers with regard to the parental relationships, role-sharing with the children, symptom presentation among mothers. Similar, albeit limited, empirical research regarding HIV+ fathers is highlighted in the section that follows.

HIV-Positive Fathers

Some researchers have elucidated the idea that child-developmental outcomes in HIV-affected families are associated with factors within and beyond the family microsystem. Behavior problems are among the many issues faced by the children of HIV+ fathers. Brook, Brook, Rubenstone, and Zhang (2006) examined aggressive behaviors in the adolescent children of 415 HIV-positive and HIV-negative drug-abusing fathers. Data were collected via individual structured interviews of low-income father-child dyads, that were predominantly African American and Hispanic (N = 415). Multivariate models were used to assess the associations between several latent constructs with respect to adolescent aggression. The results revealed that paternal HIV status mediated between environmental factors and father-child relational factors. This, in turn, affected proximal microsystem and endogenous constructs to child aggressive behavior, such as peer influences and the adolescents' personalities, respectively. In addition,

ecological social address factors, including neighborhood conditions, were directly associated with adolescent aggression, and were mediated by other microsystems such as children's peer influences (Brook et al., 2006).

Individual characteristics of parents were also found, as expected, to be associated with the individual traits of the children. Some research has focused on the interaction between the health status and behaviors of HIV positive fathers and the behaviors of their children. Brook, Brook, Whiteman et al. (2002) examined coping among 101 drug abusing fathers and their adolescent children, who were determined to be at risk for contracting HIV. Structured interviews were administered to the father-adolescent dyads regarding personality, drug use, relationships, coping, and sexual risk-taking behaviors. Findings indicated that adaptive coping among adolescents was associated with increased conventionality, decreased marijuana use, less peer-related social or interpersonal problems, paternal adaptive coping, and father-child cohesiveness. Furthermore, analyses of indicated risk factors revealed that maladaptive coping by the adolescents increased with the presence of distal as well as proximal psychosocial risks (Brook et al., 2002).

The decision to disclose HIV status is a difficult issue faced by individuals who have HIV/AIDS, particularly when infected individuals are parents, and the question is whether to disclose to their children (Boyd-Franklin et al., 1995; Pequegnat & Szapocznik, 2000). With regard to fathers, Armistead, Klein, Forehand, and Wierson (1997) examined age, demographic, and health factors related to the disclosure of HIV status among a sample of Caucasian families consisting of HIV+ fathers with hemophilia. Research specifically focused on the associations between paternal disclosure and child functioning. Findings indicated that paternal disclosure of HIV status occurred more commonly among families with older children, among Caucasian families, and among families in which fathers are more ill. When disclosure was considered in the context of familial microsystem processes, the parent-child relationship, but not disclosure, was significantly associated with child functioning. In addition, positive parent-child relationship was