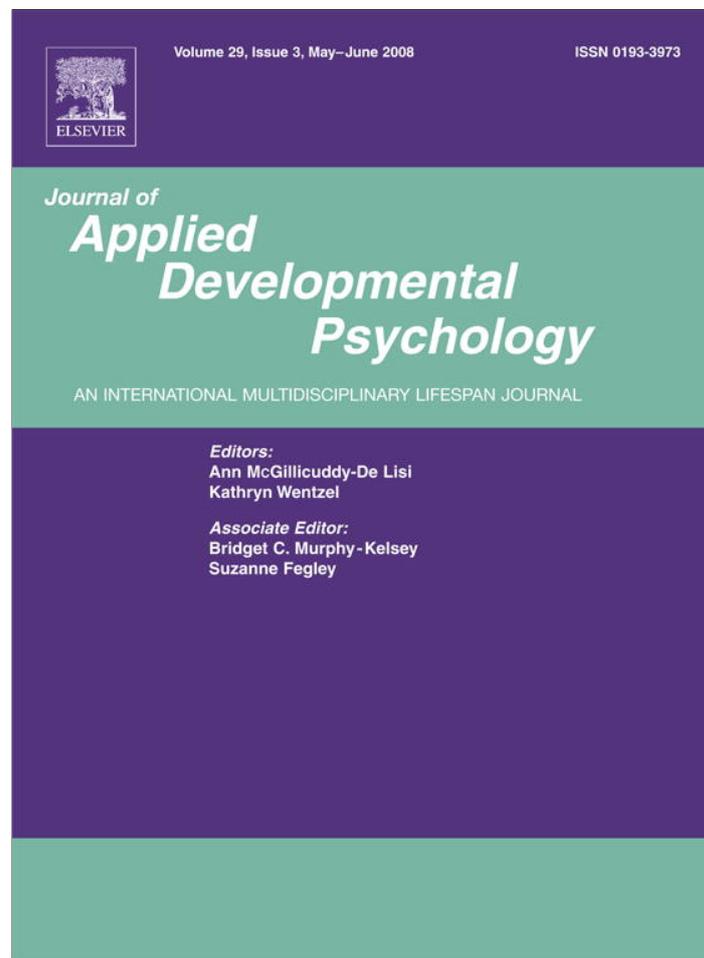


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Journal of Applied Developmental Psychology



Standing between two worlds in Harlem: A developmental psychopathology perspective of perinatally acquired human immunodeficiency virus and adolescence

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ARTICLE INFO

Available online 7 March 2008

Keywords:

Adolescence
Perinatal HIV
Developmental psychopathology
Behavioral and adjustment problems
Minority youth
Autonomy, Peer relationships
Self-concept

ABSTRACT

Perinatal HIV infection in the US continues to evolve from a fatal pediatric illness to a chronic medical condition of childhood and adolescence. Although navigating this period is influenced by multi-leveled deprivations commonly experienced by low-income minority families, HIV alters the timing and experience of developmental milestones for many adolescents with perinatal HIV. This selective review of the growing developmental psychopathology literature and the authors' clinical work at a pediatric HIV program in Harlem, NY provide an overview of how developmental psychopathology offers an integrative framework that elucidates how autonomy, peer relationships, and self-concept evolve among 13–21 year old adolescents. This paper highlights the importance of considering influences of both perinatal HIV and the culture of poverty on adolescent development, and of adopting multilevel interventions and research to address how interactions among biologic, environmental, and HIV-related stressors (serostatus disclosure, medical treatment adherence, illness stigma) influence the development of adolescents with perinatal HIV.

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“I stand between two worlds. I am at home in neither and I suffer the consequences” (Thomas Mann, 1929, “Tonio Kröger”)

1. Introduction

Since the peak of perinatal HIV infection in 1992 until the precipitous decline in perinatally-acquired cases of AIDS between 1993 and 1997 in the United States (US), the emergence of behavioral and adjustment problems in children living with perinatal HIV infection has gradually eclipsed medical management issues. For example, decisions about initiating and discontinuing antiretroviral treatment are determined largely by familial, individual, and psychosocial factors in addition to markers of HIV progression. However, advances in the medical treatment and prevention of maternal to infant transmission of HIV in the US have been tempered by several alarming realities. First, children perinatally infected and “affected” by HIV/AIDS in the early 1990s are disproportionately urban ethnic minorities and the offspring of crack-cocaine abusers who contend with multiple socioeconomic

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stressors (Havens & Mellins, 2008; Rodriguez et al., 1996). Second, with the advent of highly active antiretroviral therapy (HAART), many HIV-infected children live longer and transition into adolescence ill-prepared to face developmental challenges they are not expected to meet (Abrams et al., 2001; McConnell et al., 2005; Thorne et al., 2002).

Maternal to infant HIV transmission in New York City (NYC) decreased from 327 cases in 1990 to five cases in 2003 (NYCDOH, 2004). The decreasing numbers of HIV-infected women delivering babies and the use of prenatal antiretroviral therapies to prevent transmission culminated in a news headline: "US is close to eliminating AIDS in infants, officials say" (Santora, 2005). This long-awaited pronouncement, however, has been greeted with tempered optimism as an emerging generation of adolescents begins to struggle with their unexpected future. As of December 2005, 62% of children infected HIV before the age 13 ($n = 2474$) have survived into adolescence and young adulthood (NYCDOH, 2007). Many more are expected to reach this age as HIV-related mortality continues to decline in the US. Among 3194 adolescents 13–24 years of age with HIV or AIDS in NYC, 46% acquired the virus perinatally (NYCDOH HEP, 2007).

Adolescents living with perinatal HIV-infection face normative developmental issues that are common among minority adolescents living in poor urban cities. Descriptive studies on the mental health needs of children living with perinatal HIV-infection suggest significant emotional and behavioral challenges (Dodds et al., 2003; Lwin & Melvin, 2001; Pao et al., 2000). In Mellins, Brackis-Cott, Dolezal, and Abrams' (2006) descriptive study of 47 perinatally-infected adolescents medically treated at our clinic, 55% met criteria for a DSM4-TR diagnosis – primarily anxiety and behavior related disorders. Similarly, in a multi-center study of 274 HIV-infected children in the US, rates of behavioral problems related to ADHD (e.g., impulsivity and hyperactivity) were higher among clinically stable HIV infected children (20%) when compared with the general non-HIV infected population (5%–3%; Nozyce et al., 2006).

Although these studies identified clusters of behavioral problems that are largely attributed to both HIV-related and environmental risk factors, they are not intended to explain how maladaptive behaviors emerge among HIV-perinatally infected children. Thus they contribute minimally to elucidating the interplay of individual, environmental, and familial processes that underlie the range of problematic behavior (Rutter & Sroufe, 2000). As such, it is necessary to now cast a broader explanatory net that will capture the complex issues surrounding the development of problems in children living with perinatal HIV infection in the US. With a developmental psychopathology perspective in mind, we hope to shift the focus beyond identifying the range of problematic behavior to focus on understanding "patterns of adaptation and maladaptation during development" (Cummings, Davies, & Campbell, 2000, p. 5). The emerging field of developmental psychopathology provides a unique perspective on how HIV-related stressors (most notably serostatus disclosure of child, antiretroviral treatment adherence, and illness stigma), in conjunction with socioeconomic and urban family stressors, significantly alter the timing and experience of normative developmental milestones. HIV illness may heighten the negative influence of these stressors on developmental processes or serve a protective function that allows adolescents to excel in some developmental domains (Luthar, Cicchetti, & Becker, 2000; New, Lee, & Elliot, 2007). A clear understanding of these underlying mechanisms provides a critical basis for intervention and prevention initiatives that target malleable protective and risk factors that influence developmental outcomes (Luthar & Cicchetti, 2000; Luthar, Sawyer, & Brown, 2006).

This paper selectively reviews the developmental psychopathology literature that addresses how socioeconomically disadvantaged African-American adolescents navigate three developmental domains – autonomy, peer relationships, and self-concept – with the understanding that the findings reviewed are not meant to be representative of all African-American adolescents (McKenry, Everett, Ramseur, & Carter, 1996). Given the demographic profile of many adolescents living with perinatal HIV in the US, the studies are reviewed on the basis of their sampling of African-American adolescents living in urban US cities. In addition, eligible studies focused specifically on perinatal HIV infection and excluded studies on adolescents with behaviorally acquired HIV infection. We integrate this research literature with our clinical work at a pediatric HIV program at Harlem Hospital Center (HHC) in NYC to illustrate how adolescents with perinatal HIV (defined as 13 to 21 years of age by the American Academy of Pediatrics) negotiate these developmental tasks. The authors' clinical impressions are largely based on their work with African-American adolescents who received medical care and mental health services from an urban hospital-based HIV program, and are therefore limited to specific sub-groups represented by the program that may not necessarily apply to all adolescents living with perinatal HIV. Finally, implications and recommendations for future interventions and research are discussed.

2. HIV, poverty, and adolescent developmental trajectories

Studies on HIV perinatally infected adolescents have identified specific challenges of serostatus disclosure (e.g., Mellins et al., 2002; Wiener, Mellins, Marhefka, & Battles, 2007), medication adherence (e.g., Brackis-Cott, Mellins, Barmas, Reval, & Dolezal, 2003; Mellins, Brackis-Cott, Dolezal, & Abrams, 2004) and illness stigma (Battles & Wiener, 2002; Wiener, Battles, & Heilman, 2000; Wright, Naar-King, Lam, Templin, & Frey, 2007), each of which could complicate how adolescents negotiate autonomy, peer relationships, and self-definition. First, the transition from dependence on family members to more independence in illness management may influence the development of self-governance and autonomy. Second, decisions regarding who, what, and when to disclose their serostatus could further complicate how adolescents negotiate peer and romantic relationships. Third, HIV-stigma that perpetuate perceived self-inclusion into marginalized risk groups, most notably homosexuals and intravenous drug users, could influence the process of constructing self-identities.

In considering how adolescents with perinatal HIV navigate these three developmental domains, disentangling sociocultural factors (race, ethnicity, social class) from HIV-specific stressors is a challenge. Many African-American adolescents living with perinatal HIV infection in the US contend with the tripartite realities of HIV-stigma, poverty, and racism. Although African-

Americans accounted for approximately 13% of the population of the 33 HIV reporting states during 2001–2004, they accounted for 51% of the HIV/AIDS diagnoses (CDC, 2005). Moreover, African-Americans comprised 55% of 15–24 year olds diagnosed during this period. The overrepresentation of African-Americans among those infected with HIV is inextricably linked to their marginalized status often created and reinforced by poverty (Fullilove, 2006; Wilson, 1996).

These comorbid risk factors make it difficult to clarify the causal relationship between perinatal HIV and adolescent development. A few select longitudinal studies have compared behavioral and neurocognitive functioning between HIV perinatally infected children and control groups with similar socio-environmental backgrounds (ethnic minority, low socioeconomic class, high poverty neighborhoods). They found no significant differences in cognitive development (Smith et al., 2006), or behavioral problems (Mellins et al., 2003). Adding to cross-sectional findings with smaller sample sizes and comparison groups (e.g., Bachanas, Kullgren, & Swartz, 2001; Blanchette, King, Fernandes-Penney, & Read, 2002; Havens et al., 1994), these studies highlight the importance of considering chronic stressors related to both HIV and experiences of living in economically disadvantaged neighborhoods and families when refining our understanding of adolescents' developmental trajectory.

2.1. The Family Care Center: Boarder babies and adolescents

The Family Care Center (FCC) is a comprehensive pediatric HIV care and research program that provides multidisciplinary medical, psychological and social services to HIV-infected and affected children and their families. The program was started in 1986 at Harlem Hospital Center to address the emerging “boarder babies” crisis in NYC, particularly in Harlem where HIV exposed and infected infants and children were left to board at hospitals because of parental abandonment, post-partum complications, and an inadequate foster-care referral system (Nicholas & Abrams, 2002). Between 1983–1989, 3–5% of pregnant women at HHC were infected with HIV. Many of the newborns of these women were abandoned by their mothers and were referred to as boarder babies because they were cared for at hospitals until they were eventually placed with foster families. During this period of the crack-cocaine epidemic, nearly 10% of babies born in Harlem went directly to foster care, primarily due to maternal drug-related problems, and these babies were eight times more likely to be HIV exposed than those babies discharged to their mothers (Nicholas & Abrams, 2002).

The families served at FCC reflect the aging cohort of HIV perinatally infected children. In 2006, the median age of HIV-infected children ($n = 145$) treated at FCC was 14 years old. Sixty percent ($n = 87$) were 13 to 21 years of age, the majority of whom were African-American (86%, $n = 75$), male (54%, $n = 47$), and living with their adoptive parents (62%, $n = 54$). Forty-five percent ($n = 39$) of 13 to 21 year-olds had a history of a class B event (symptomatic conditions), and 25% ($n = 22$) had a history of a class C event (AIDS-indicator conditions).

2.2. Merits of a developmental psychopathology perspective

The primary goal of developmental psychopathology research is “to unravel the dynamic-process relations underlying pathways of normal development and the development of psychopathology” (Cummings et al., 2000, p. 17). The premise is that psychopathology results from a constant interplay of multiple individual and contextual influences that change over the course of human development. This framework guides the consideration of how changes in environment (home, neighborhood, school, service organizations), family constellations (adopted siblings, separation or reunion of parent, illness, death of family member), health (HIV progression, pregnancy, medication adherence), and community perceptions of HIV (chronic medical condition, African epidemic, gay men's disease) affect an adolescent's developmental trajectory.

Developmental psychopathology provides a relevant theoretical framework because the range of behavioral problems reported in the pediatric HIV literature may not be entirely attributable to HIV infection, but may also include other risk factors, such as the interrelationships between various dimensions of familial instability, parental histories of substance abuse and mental illness, prenatal drug exposure, and socioeconomic deprivations – all of which are common among urban poor minority families (Mellins & Ehrhardt, 1994). In one controlled study, Havens et al. (1994) found elevated rates of ADHD in a sample of prenatally drug exposed children, with no difference between HIV-infected and uninfected children. Another controlled study similarly found elevated rates of internalizing and externalizing symptoms in both HIV-infected children and demographically matched uninfected controls, where rates of symptomatology were actually higher in the control group (Bachanas et al., 2001). Mellins et al.'s (2003) study of 96 HIV perinatally-infected children and 211 seroreverters found that the higher prevalence of behavioral problems among HIV-infected children was not associated with HIV status or prenatal drug exposure, but rather to sociodemographic characteristics such as maternal education, primary caregiver status, and sex of the child.

2.3. Developmental trajectories for African American adolescents

Adolescence is a developmental period between childhood and adulthood marked by biological, psychological, and social role changes (Hamburg, 1990). This developmental period consists of two transition phases: from childhood to early adolescence and from late adolescence to adulthood (Steinberg & Morris, 2001). During this period, adolescents undergo puberty, develop new cognitive skills, begin to establish their self-identities, and learn to negotiate peer relations. However, due to shifting definitions of adolescent roles, culturally defined developmental milestones, poverty, and various environmental influences, the onset and length of this period are less clear for those who are economically disadvantaged (Burton, Obeidallah, & Allison, 1996). Studies show that those who experience a protracted adolescence in the US are more likely to be white Anglo Americans, and from middle-

or upper-class backgrounds (Steinberg & Morris, 2001). Those who do not experience adolescence at all are more likely to be urban African-American, Latino, or poor due to culturally defined developmental markers and life circumstances that usher children directly into adult roles (Burton et al., 1996). In their ethnographic review of African-American families, Burton et al. (1996) identified five contextual factors to consider when clarifying the developmental trajectories of adolescents: (1) inconsistent expectations of social roles placed by family and social institutions; (2) blurred developmental boundaries and roles in “age-condensed” families; (3) overlapping worlds of parents and adolescents; (4) accelerated life course based on shortened life expectancies; and (5) alternative definitions of successful developmental outcomes. Given the potential influences of these dimensions on adolescent developmental trajectories, the following sections review selected studies on socioeconomically deprived African-American adolescents and suggest how HIV-stressors could further complicate autonomy, peer relationships, and self-concept.

2.3.1. Autonomy development

Autonomy is an active process characterized by a desire to be independent and a need to meaningfully connect with family and community (Spear & Kulbok, 2004). This developmental tension of independence and connectedness is heightened during adolescence because of rapid cognitive and physical changes, and expanding social networks. The transition from dependence on adults to autonomy can be further complicated for perinatally HIV-infected adolescents who often rely on adult supportive networks beyond their immediate family that include nurses and medical providers who have served as proxy caregivers since they were children. A staff nurse at FCC explains that adolescents with HIV are accustomed to being treated with “kid gloves” by adults in anticipation of their shortened life span. Ample sources of support from within and beyond the family network foster, to some measure, a sense of dependence and even entitlement that possibly complicate the process of becoming autonomous and independent.¹

Pediatric HIV providers may be reluctant to relinquish their caretaking responsibilities, and perhaps question the readiness of adolescents to make more independent decisions about their care (Miles, Edwards, & Clapson, 2004). Some pediatric providers may also hold reservations about the quality of adult HIV care, and remain skeptical of whether the adult clinic environment is nurturing enough — all of which potentially hampers adolescent transition from FCC to adult medical care, and thus the autonomy process.

Shifts in the balance of decision-making responsibility between guardians and adolescents further disrupt the transition from parental regulation to autonomy. Discrepancies between parent-adolescent perceptions and expectations of autonomy could lead to escalating conflicts in regards to transfers of responsibilities and oversight of activities from parents to adolescents (Collins, Laursen, Mortensen, Luebker, & Ferreira, 1997). These conflicts are often prolonged by: (1) parental expectations of adult behavior in adolescents; (2) denial of adolescent's developing maturity; or (3) heightened anxieties related to adolescent's sexual maturity and ensuing increased parental control (Holmbeck, 1996). Moreover, Allen, Hauser, O'Connor, & Bell (2002) found that by inhibiting “strong, developmentally important autonomy strivings” (p. 124) parents lead adolescents to establish their autonomy vis-à-vis hostile means rather than by direct negotiations. It is noteworthy that despite findings that adolescent autonomy is best cultivated by parental flexibility and warm parent-adolescent relationships, this could pose a significant challenge for families living in poor urban neighborhoods confronted with crime, physical deterioration, and lack of resources (Mason, Cauce, Gonzales, & Hiraga, 1996; Taylor, 2000). Chronic poverty-related stressors (Li, Nussbaum, & Richards, 2007) and maternal psychological distress (McLoyd, 1990), for example, often undermine the capacity for supportive and consistent parenting that influence achievement of autonomy.

Parental discernment of how much autonomy and independence to grant adolescents poses a significant challenge for families at FCC, where children largely rely on their guardians to monitor their HIV treatment, which includes monthly medical visits and, for most, the administration of antiretroviral medications (Brackis-Cott et al., 2003). Guardians' conflicted feelings about adolescent autonomy often result in either curtailing supervision or exerting excessive control with minimal support. In a study of 75 maternal caregivers at our clinic, nearly a quarter reported that they expected their children (mean age = 8.0 year) to take responsibility for their own medication (Mellins et al., 2004). The study also found that non-adherence was not associated with the complexity or burden of the medication regimens, but rather with older child age, a finding consistent with studies of other adolescent chronic illnesses (Palardy, Geening, Ott, Holderby, & Atchison, 1998; Rianthavorn & Ettenger, 2005). Although adolescents with perinatal HIV may begin to develop skills to make more independent decisions about school and peers, they may not yet have the maturity and future orientation to fully manage the decisions and tasks required to independently take their medications (Brackis-Cott et al., 2003). Moreover, the high prevalence of behavioral challenges and neurodevelopmental delay among many adolescents with perinatal HIV would likely compromise their ability to make autonomous decisions about medical treatment (Mellins et al., 2004; Steele, Nelson, & Cole, 2007).

In Wrubel, Moskowitz, Richards, Prakke, and Folkman's (2005) qualitative study of 71 maternal caregivers of children with HIV, participants' perspectives of pediatric adherence revealed that adolescents' “autonomous strivings” were less salient than their guardian's expectations for their children to assume more responsibility for their medications. This narrative is shared by many guardians at FCC, especially aging second-generation guardians (e.g., maternal grandmothers and aunts) who are emotionally and

¹ Numerous studies argue that persons living with HIV in poor urban cities access supportive services that improve their quality of life beyond what is attainable for those who are not infected (e.g., Crane, Quirk, & van der Straten, 2002). The authors do not argue for any reduction of supportive services for HIV-perinatally infected adolescents, but rather argue for extending comparable provisions to poor urban adolescents who were HIV-negative. “It is not the provision of special medical entitlement to those with a fatal viral infection that renders them ethically problematical. Rather, it is the failure to extend medical protection to all in need that represents the ethical affront” (Bayer, 1999, p. 1047).

physically drained by the onerous responsibility of monitoring and supervising the administration of their child's medication. In reference to his 14-year old son's daily antiretroviral regimen of subcutaneous injections and 8 pills, an adoptive father couches his desire for his son to assume more responsibility over his medications as a normative developmental expectation – “allowing him (son) to fly after spreading his wings.”

Whereas some guardians at FCC hasten the autonomy process, others may be less inclined to encourage independent behavior and decision-making. Coyne and Anderson (1988) found that families of adolescents with type 1 diabetes exhibited “miscarried helping,” defined as a parent's overinvestment in helping his or her child achieve positive health outcomes. Ironically, this “helping” behavior resulted in the child feeling a sense of self-defeat and critical about their parent's support. Particularly as adolescents navigate their newfound autonomy, parental help with medical treatment shifts to parental demands that often result in increased doubt about the adolescent's motivation and commitment to treatment goals (Anderson & Coyne, 1993). This sets in motion a cycle by which the adolescent feels inadequate and incompetent in the face of their parents' expectations, heightening parental frustration and distress. Eventually, miscarried helping results in parents attributing their child's uncooperative behavior to negative character traits – the adolescent is perceived as ungrateful, lazy, and oppositional (Anderson & Coyne, 1993).

2.3.2. Peer relationships

In addition to increased autonomy, the emergence of peer groups is a prominent adolescent milestone that is characterized by a complex set of relationships that largely reinforce or redirect preexisting individual differences and family functioning (Brown, 1990). As adolescents shift their dependence from parents to peers for support and affirmation, peer groups function as a “substitute source of psychological dependence” (Brown, 1990, p. 180). Navigating peer relationships among adolescents living with perinatal HIV is further complicated by the disruption of social activities due to medical appointments and illnesses, decisions about onset of sexual behavior, and most notably by the dilemma of what, when, and to whom to disclose their serostatus (Derlega, Winstead, Greene, Serovich, & Elwood, 2002; Derlega, Winstead, Oldfield, & Barbee, 2003). Although younger children are often capable of negotiating peer relationships without revealing their diagnoses, this may become more challenging for adolescents, who spend more time with peers, form deeper friendships, and have stronger romantic feelings and interests (Hartup, 1996). The emergence of social competencies such as self-disclosure, provision of support, and intimacy are weighed against stigma and incurring the possible consequences of being estranged and the target of circulating rumors (Dodds et al., 2003; Wiener et al., 2000). Moreover, prevalent misconceptions of HIV transmission and discriminatory attitudes towards persons living with HIV are often voiced within cliques and crowds without knowledge of the adolescents' serostatus. Peers' casual references about fear of HIV acquisition and discriminatory remarks made about persons living with HIV/AIDS, heighten fears of rejection and isolation (Wright et al., 2007). Recent initiatives to introduce HIV education into school curricula are bringing HIV more to the forefront of peer awareness. However, peer reaction and response to classroom discussions of HIV may encourage receptivity or perpetuate more overt discrimination of persons living with HIV. A distraught 14 year-old adolescent girl from FCC, for example, shared her disappointment when her best friend to whom she hadn't disclosed her serostatus, remained seated when their teacher conducted an informal poll in class and asked those who would befriend someone with HIV to stand.

Peer negotiation is further complicated by the multiple types of peer groups, each characterized by distinct engagement rules and functions. Brown (1990), for example, highlights important distinctions between cliques and crowds. In contrast to cliques, which are small groups comprised of a limited number of adolescents who develop close relationships by informally “hanging out,” crowds are larger and collectively identified by similar activities and interests. Adolescents at FCC establish and maintain two primary peer networks, one of which is aware of their serostatus and the other, which is not. Within these networks are different types of groups. In addition to maintaining cliques and friendships at school, for example, adolescents with HIV negotiate peer groups within FCC where cliques and crowds are based on medication regimen, hospitalization history, frequency of medical visits, parental placement, onset of sexual activity, and level of involvement in clinic activities. However, the shared experience of being born with HIV becomes an unspoken and powerful source of affiliation. Adolescents often describe feelings of safety and reassurance that they will not be marginalized on account of their HIV, because they are among peers who face similar circumstances (Ledlie, 2001). The pediatric HIV program provides opportunities for adolescents to safely explore and discuss issues they would otherwise not raise with family members or peers outside the program – issues such as disclosure to sexual partners, potential risks of transmitting the virus to their next generation, anxiety over declining health, challenges of medication adherence, transitioning from pediatric to adult HIV care, being “singled out” among their non-infected siblings, and questions about why some peers are not on medications or are prescribed less challenging antiretroviral regimens. However, this doesn't imply that adolescents always raise these difficult issues in their conversations with each other, as one 16 year-old boy at FCC explained, “just because we don't talk about it with each other doesn't mean we don't think about it when we are together.”

Although support of peers, or lack of such support, can influence adolescents' decisions about treatment adherence and health-risk behaviors, it may not necessarily lead to positive outcomes (Naar-King, Templin, & Wright, 2006). For example, adolescents' shared experiences of medication side effects and having their daily routines disrupted by their medication schedule could reinforce poor adherence behavior. This underscores the importance of identifying specific areas of illness management and health education that are most positively influenced by peers (Brown, Dolcini, & Leventhal, 1997). Moreover, future research efforts are needed to examine how these specific “within-group” peer relationships mediate associations between risk factors and health outcomes (LaGreca, Bearman, & Moore, 2002).

Romantic relationships in adolescence are also a source of support, intimacy, and companionship. Dating is a normative experience that begins to emerge during early to middle adolescence and is largely influenced by adolescents' peer networks (Connolly, Furman, & Konarski, 2000; Furman & Wehner, 1997). Serostatus disclosure becomes particularly challenging in the

context of adolescent romantic relationships (Sturdevant et al., 2001). The risk of being rejected by romantic partners on account of one's serostatus often lead adolescents at FCC to pursue romantic relationships with other perinatally infected peers at the clinic. A number of guardians have even encouraged these relationships given the safety and assurance of not being rejected on account of one's serostatus. Some adolescents at FCC avoid romantic relationships entirely because of the inevitability and necessity of disclosure, and the possibility of risky sexual activity that will result in HIV or STI transmission. Fear of HIV and STI transmission is similarly identified as the primary motivator for condom use among a general cohort of adolescents in Harlem (Laraque, McLean, Brown-Peterside, Ashton, & Diamond, 1997). In a study of 638 perinatally HIV-infected girls enrolled in a US multisite clinical trials program, the pregnancy incidence rate of 33.5 per 1000 person-years among HIV-positive girls aged 15 to 19 years was lower than the documented rates for non-HIV infected girls of similar age in the US in 1999 (86.7 per 1000; Brogly et al., 2007). Further studies, particularly qualitative research, are needed to further clarify adolescents' decision making process regarding sexual initiation, condom use with casual or longstanding partners, and serostatus disclosure.

2.3.3. Self-identity development

Self-identity formation is another significant developmental milestone that poses a unique challenge for adolescents living with perinatal HIV (Hosek, Harper, & Robinson, 2002). Mid-adolescence (ages 14 to 15) is a period when introspection about personal traits looms large, and adolescents begin to reconcile different self-conceptions to determine “the real me,” a process Harter (1990) describes as “a major drama that unfolds on center stage during adolescence, with a complicated cast of characters who don't always speak with a single voice” (p. 353).

The developmental task of integrating multiple self-concepts into a unified self theory becomes particularly daunting for older adolescents with perinatal HIV, largely because of shifting individual and societal perceptions of adults living with HIV. Older adolescents' self-perceived inclusion to marginalized groups such as substance abusers (“crack heads”) and homosexuals conflict with internalized self representations as innocent victims born with HIV and robbed of their childhood (Rao, Kekwaletswe, Hosek, Martinez, & Rodriguez, 2007; Wright et al., 2007). As children, their serostatus is commonly framed as a “secret” maintained within the family and in many regards HIV is normalized as an illness acquired by no personal fault. However, as they become adolescents, formative negative perceptions and personal biases against adults with HIV become intrinsic to one's self-concept (Fife & Wright, 2000). As such, adolescents at FCC often set themselves apart from HIV-seropositive adults who behaviorally acquire the virus, heightening personal prejudices against homosexuals and intravenous drug users (Miles et al., 2004). This self-perception contributes, in part, to adolescents' apprehension of transitioning from FCC to adult HIV services, where the majority of the patients acquire the virus by engaging in high risk behavior.

Another dimension of identity formation extends beyond integrating personal identities to considering one's larger role in society. Grotevant (1987) describes the process of exploring one's self-identity as working to gather and interpret information about oneself or ones' environment in order to decide on significant life choices. He argues that adolescent identity formation is facilitated or constrained by individual characteristics (e.g., self-esteem, self-monitoring, intellectual ability), societal factors (e.g., culture, family), cognitive ability (e.g., formal operational reasoning), and life events. Among urban African-American adolescents, experiences of perceived racism and construction of one's ethnic identity could further limit their opportunities to form conceptualizations about themselves and set personal goals (Mann, 2006; Nyborg & Curry, 2003). Many older adolescent boys at FCC, for example, do not aspire beyond earning a General Education Development (GED) or high school degree, mirroring the bleak portrait of poorly educated black men in the US becoming more disconnected from mainstream society (Mincy, Lewis, & Han, 2006). Moreover, realization of living with a stigmatized illness as an emerging young adult could influence what adolescents believe are possible to accomplish due to contrasting societal perceptions of perinatal HIV infection and adult HIV infection – the former perceived as blameless victims and the later as belonging to marginalized groups (e.g., homosexuals, and intravenous drug users).

Although HIV-related constraints certainly influence how adolescents form conceptualizations about themselves and their future, the illness often converges with familial, social, and environmental stressors that render active exploration of possible selves difficult for many adolescents at our program. In many regards, this common urban dilemma can affect self-identity exploration to a greater degree than HIV-specific stressors (e.g., medication adherence, perceived stigma).

Wood (2003) appropriately shifts the discourse from the economics of poverty to the culture of poverty – highlighting that poor families live in neighborhoods that exacerbate rather than mitigate the disadvantages of poverty (see Fig. 1). As shown in Fig. 1, families living in extreme poverty are particularly vulnerable to the confluence of poor neighborhoods, single female-headed household, prenatal cocaine exposure, and HIV stressors. A constellation of factors compounded by HIV perpetuates a culture of poverty that influences the self-definition process for adolescents. First, for many adolescents at FCC who live in Harlem, the lack of public resources, economic investment, and political voice inherent in poor neighborhoods further isolates families from mainstream society, which minimizes opportunities for adolescents to develop requisite skills for identity formation (Fullilove et al., 1999). Jencks and Mayer (1990) proposed five processes whereby neighborhoods influence children's development: quality of neighborhood resources; competition for scarce resources; availability of adult monitoring, supervision, and role modeling; influence of other's behavior; and comparative deprivation. Second, single female-headed household is another socioeconomic index associated with various childhood outcomes (Jackson, 2003), suggesting that a single-parent household reduces the capacity for adults to monitor adolescent socialization activities (Brooks-Gunn, Duncan, Klebanov, & Sealander, 1993; Steinberg, 1987). Lareau (2003) characterizes child-rearing practices among working-class and poor families as the “accomplishment of natural growth,” whereby parents consider children's development as spontaneous as long as they are provided with the basic needs of food, shelter, and social support. Lareau (2003) further argues that this cultural practice leaves children at a disadvantage because of

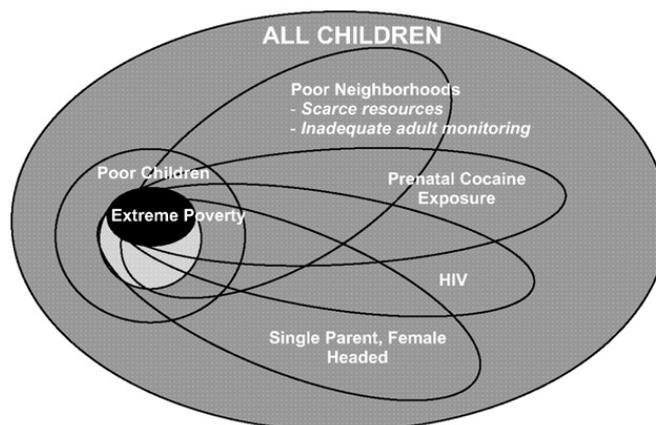


Fig. 1. Ecology of childhood poverty and HIV.

limited opportunities to learn how to negotiate the world beyond their familiar family network. Lastly, the detrimental effects of in utero exposure to cocaine and the contributions of a compromised caregiving environment affected by maternal use of cocaine on developmental outcomes are well documented (Luthar, Cushing, Merikangas, & Rounsaville, 1998; Singer et al., 1997; Volpe, 1992). Given the high prevalence of prenatal cocaine exposure among HIV perinataly infected adolescents (Havens & Mellins, 2008; Nicholas & Abrams, 2002), delayed neurocognitive functioning (attributed either to cocaine's direct effects on central nervous system or to related disruptive maternal caregiving) could further complicate adolescent problem solving skills necessary to constructing self-identities, determining personal goals, and devising a strategy for their realization (Mayes & Bornstein, 1997; Nurmi, 1991).

3. Conclusion

This paper highlights how the tripartite realities of urban poverty, racism and HIV-related stressors – most notably serostatus disclosure, medical treatment adherence, and illness-stigma – can collectively alter the experience of developmental milestones such as autonomy, peer relationships, and self-concept in adolescents living with perinatal HIV. The “full plate syndrome,” described by Morales & Bok (1992) as the competing demands of persistent poverty, racism, and HIV, raises the conundrum of determining how these sobering realities uniquely and collectively influence the developmental trajectory of adolescents living with perinatal HIV. The developmental psychopathology literature highlights the importance of conceptualizing intervention and research efforts within multiple and shifting frameworks of poverty, individual competencies, impoverished environment, and HIV. As such, a single-dimension-fits-all-approach to intervention and research will be inadequate and shortsighted. Several implications drawn from the overall perspective of this paper warrant attention.

3.1. Implications for intervention

First, given multiple influences on adolescent development, interventions designed to mitigate the stressors of HIV-stigma and poverty must independently or collectively address multiple risk factors – “the major implication of multiple risk models is that interventions need to be as complex as development itself” (Sameroff, Gutman, & Peck, 2003, p. 388). Several interventions that draw from this approach focus on socio-ecological and family systems theories of behavior (Steele et al., 2007). For example, CHAMP (Chicago HIV Prevention and Adolescent Mental Health Project), a parent-adolescent dyad group intervention recently adapted for inner-city adolescents with perinatal HIV infection (CHAMP+), focuses on issues of family communication, decision-making, and parental supervision and monitoring, as they specifically relate to medication adherence, illness stigma, and sexual risk behaviors (McKay et al., 2004, 2006).

Another particularly noteworthy intervention is multisystemic therapy (MST), an intensive short-term, home-based intervention for families of adolescents presenting with serious behavioral problems (Henggeler, Schoenwald, Borduin, Rowland, & Cunningham, 1998). MST theoretically maintains that problematic behaviors are multidetermined by transactions within and across different social contexts – in particular family and peer domains (refer to Henggeler et al., 1998 for a detailed description of intervention protocol). Cunningham, Naar-King, Ellis, Pejuan, and Record (2006) recently adapted MST treatment to improve medication adherence issues among adolescents living with perinatal HIV by identifying broad systemic barriers to poor adherence behavior and using appropriate mental health treatments to influence changes within and across systems (individual, family, peer, school, community) that directly and indirectly perpetuate poor medication adherence. Although substantial research supports the clinical effectiveness of MST with juvenile offenders (Borduin, 1999; Henggeler, Melton, & Smith, 1992) and adolescents with poorly controlled type 1 diabetes (Ellis, Naar-King, Frey, Rowland, & Greger, 2003; Ellis et al., 2007), randomized controlled studies with larger samples are needed to demonstrate treatment effectiveness with perinatal HIV-infected adolescents over time, particularly given their exposure to HIV- and poverty-related stressors which are distinctive from other childhood chronic illnesses.

Second, although HIV-related stigma has tapered to some extent in the past decade due to antiretroviral treatment access in the US, HIV stigma remains a reality particularly within the African American community and uniquely influences how adolescents at FCC navigate their formative adolescent years. In addition to interventions that address the individual dimensions of HIV stigma, measures addressing the structural and environmental constraints that African-Americans living with HIV face in the US are needed to assist adolescents set personal goals and construct self-definitions (Parker & Aggleton, 2003). Recent studies on stigma-reduction interventions highlight the importance of engaging HIV-positive adolescents in developing and implementing programs (Heijnders & Can Der Meij, 2006; Lyon & Woodward, 2003). The CHAMP+ intervention, for example, borrows similar tenets of community organizing by intentionally involving HIV-positive adolescents and their guardians in program development, implementation, and participation – a process integral to the intervention (McKay et al., 2006).

Third, informed by resilience-based interventions that aim to reduce the influences of negative factors and enhance positive adaptation most notably for heroin-addicted mothers and children of depressed mothers (Cicchetti, Rogosch, & Toth, 2000; Luthar, Suchman, & Altomare, 2007), interventions for perinatally HIV-infected adolescents would benefit from: (1) targeting salient protective processes that reduce the impacts of HIV- and poverty-related stressors on the development of autonomy, peer relationships, and self-identity, including extended family and kinship support (Chase-Landsdale, Brooks-Gunn, & Zamsky, 1994; Reese, Vera, Simon, & Ikeda, 2000), perceptions of neighborhood cohesiveness (Li, Nussbaum, & Richards, 2007; Sampson, Morenoff, & Fannon-Rowley, 2002), self-regulatory skills (e.g., executive function and emotional regulation; Buckner, Mezzacappa, & Beardslee, 2003), and quality of parental supervision (Brody, Dorsey, Foreland, & Armistead, 2002; Wyman et al., 1999); (2) considering sensitive periods of transition during which adolescents are responsive to interventions (Luthar & Cicchetti, 2000), such as entry into high school, college, or the workforce, initiation or discontinuation of antiretroviral treatment, or transitioning to adult HIV medical care; and (3) broadening social and economic opportunities that encourage responsible autonomous decision making and self-explorations (McHale, 1995).

Fourth, the complex interplay of social, familial, and individual influences that affect the lives of many adolescents with perinatal HIV necessitates mental health care providers at times to reconstruct and perhaps relinquish core myths of rescuing families from the demise of HIV and poverty. The multigenerational influences of poverty and substance abuse can be overwhelming, highlighting the limits of resilience among adolescents with perinatal HIV. The reality of living with a stigmatized illness under the daily grind of poverty-related stressors often tempers providers' expectations when working with persons with HIV illness. Although the scope of comprehensive medical, psychological, supportive, and advocacy services provided to adolescents at FCC rivals if not surpasses the pediatric care availed to more privileged families in the US, the detrimental effects of persistent poverty and deprivation on the development of adolescent self-identity proves at times insurmountable.

3.2. Implications for future research

Repeated measures studies with larger samples and appropriate comparison groups are needed to begin clarifying main and interaction effects between socioeconomic risks and HIV-related stressors, and adolescent developmental trajectories (Mellins et al., 2003; Smith et al., 2006). Once the relationship between risk or protective constructs and developmental outcomes are reliably established, it is important to further examine possible underlying mechanisms for the relationship by strategically considering mediators (Luthar et al., 2006). For example, potential mediators that underlie the relationship between maternal mental health factors and behavioral outcomes for HIV-perinatally infected adolescents might include: (1) maternal HIV-related stressors (Mellins, Kang, Leu, Havens, & Chesney, 2003); (2) social support and family functioning (Mellins, Ehrhardt, Rapkin, & Havens, 2000); (3) maternal serostatus disclosure (Mellins, Brackis-Cott, Dolezal, & Meyer-Bahlburg, 2005; Tompkins, Henker, Whalen, Axelrod, & Comer, 1999); or (4) maternal monitoring and supervision (McLoyd, 1990; Pittman & Chase-Lansdale, 2001).

In addition, within-group analyses with perinatal HIV-infected adolescents are necessary for establishing intervention priorities (Luthar et al., 2006). As highlighted in this paper, the developmental trajectories for autonomy, peer relationships, and self-identity vary according to age, sex, social class, health status, and environmental exposure. Within-group analyses shifts the focus from determining whether perinatally-HIV infected adolescents differ from a socioeconomically matched comparison group to clarifying which salient factors in the lives of HIV-infected adolescents influence normative development. For example, adolescents who are not on antiretroviral treatment nor have been hospitalized for an AIDS-defining illness, may transition to autonomy differently than adolescents with more advanced HIV illness who require more adult supervision over a complex medication regimen.

Finally, careful consideration of neighborhood influences is critical in refining our understanding of how adolescents with perinatal HIV negotiate developmental tasks related to autonomy, peer relationships, and self-identity formation. Because Wilson's (1996) seminal argument that the plight of inner cities is largely perpetuated by the lack of "social capital" in neighborhoods, numerous developmental studies have shifted focus from family and peer group factors to ecological systems that influence the adolescent development and adjustment – namely neighborhood, community, and institutions (Brooks-Gunn et al., 1993). Although specific recommendations for neighborhood research is beyond the scope of this paper and have been more thoroughly examined by previous researchers (Leventhal & Brooks-Gunn, 2000; Raudenbush & Sampson, 1999), the influences of neighborhood structural factors such as poverty, residential instability, single parenthood, or household educational attainment on adolescent development warrant further attention.

In conclusion, developmental psychopathology underscores the importance and application of interactive models and multidisciplinary approaches in clarifying how adolescents living with perinatal HIV negotiate normative developmental transitions, and how they weather the harsh realities of living with a stigmatized illness in poor urban environments. Multilevel

approaches to both intervention and research are needed to address the interactions between biologic, environmental, and HIV-related stressors — intervening at only one level is inadequate. The complexities of “standing between both worlds” plagued by these multilayered interactions necessitate nothing less.

Acknowledgements

The authors acknowledge Maxine Frere, Jacquelyn Brinney, Monica DiGrado, Susan Champion, Bruce Jackson, Kathy Nguyen, and Natalie Humphrey for their tireless efforts to ensure that children at FCC transition to become adolescents against tremendous odds, and to the young adults at FCC who remind us that it could be done.

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