



Original article

A Prospective Longitudinal Study of Mental Health Symptoms Among Perinatally HIV-Infected and HIV-Exposed but Uninfected Urban Youths



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ABSTRACT

Purpose: Significant gaps persist in our understanding of the etiological factors that shape the progression of mental health symptoms (MHS) among perinatally HIV-infected (PHIV+) and perinatally HIV-exposed but uninfected (PHEU) youths. This study sought to assess the changes in MHS among PHIV+ and PHEU youths as they transition through adolescence and to identify the associated psychosocial factors.

Methods: Data were drawn from a longitudinal study of 166 PHIV+ and 114 PHEU youths (49% male, ages 9–16 years at baseline) in New York City. Individual interviews were administered at baseline and subsequently over a 5-year period. MHS were assessed using the youth version of the Diagnostic Interview Schedule for Children. Predictive growth curve analyses were conducted to assess longitudinal changes in MHS and identify the relevant factors. Level I predictors included: time, major life events, household poverty, caregiver mental health, and neighborhood stressors. Level II predictors included youths' sociodemographic characteristics (e.g., age, gender, HIV status) and baseline future orientation scores.

Results: The changes in youths' MHS followed a quadratic growth curve and were positively associated with the number of major negative life events and neighborhood stressors experienced. Youths' HIV status, household poverty, and caregiver mental health were not significantly associated with youths' MHS.

Conclusions: Findings suggest that irrespective of youths' HIV status, major life events and neighborhood stressors increase MHS among PHIV+ and PHEU youths. There is a need for interventions to reduce the impact of stressors on the mental well-being of PHIV+ and PHEU youths.

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IMPLICATIONS AND CONTRIBUTION

These findings highlight the centrality of contextual factors such as negative life events and neighborhood stressors in the evolution of mental health problems among perinatally HIV-infected and perinatally HIV-exposed but uninfected youths as they transition through adolescence.

Perinatally HIV-infected (PHIV+) and perinatally HIV-exposed but uninfected (PHEU) youths exhibit higher rates of mental health problems (MHPs) including psychiatric disorders such as

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depression, anxiety, and behavioral disorders than youths in the general population [1–3]. A 2006 systematic review found higher rates of MHPs among PHIV+ youths compared to noninfected youths, including behavioral disorders such as attention-deficit/hyperactivity disorder (28.8% vs. 8.7%), and mood disorders such as depression (25% vs. 14.3%) [3]. MHPs have been associated with nonadherence to antiretroviral therapy in PHIV+ youths and sexual

risk taking among PHIV+ and PHEU youths, which increase the risk for transmitting (in PHIV+) or acquiring (in PHEU) HIV [4,5]. Thus, understanding pathways to MHPs is critical in both groups given the potential consequences.

MHPs among PHEU and PHIV+ youths have been attributed to a complex array of biogenetic and psychosocial factors including neurological deficits, low self-esteem, stigma, stressful life events (e.g., bereavement, family conflict, and dissolution), caregiver HIV status, and poor caregiver mental or physical health [6–8]. Neighborhood factors such as poverty, violence, victimization, and racism, common among inner city neighborhoods in which HIV infection has been concentrated in the United States [9], have also been associated with youth MHPs [6,10]. However, significant uncertainty remains about the role of pediatric HIV in the etiology of MHPs across the developmental continuum. In some studies, researchers have reported significantly higher rates of MHPs among PHIV+ youths compared with PHEU youths [1], whereas other studies have found higher rates among PHEU youths compared with PHIV+ youths [11], and still others have found no difference at all [2,12]. Little is known about how individual and contextual-level factors influence the progression of MHPs among PHIV+ and PHEU youths across adolescence, yet such information is critical to tailoring preventive and treatment interventions to the needs of this population. Moreover, studies of MHPs among PHIV+ and PHEU youths are largely cross sectional [1,11,13], constrained by small sample sizes [14,15], and focus on psychiatric disorders only [1,13].

The sole focus on psychiatric disorders may be problematic, as youths who experience mental health symptoms (MHS) but do not meet the diagnostic criteria stipulated in the Diagnostic and Statistical Manual of Mental Disorders may be lumped with youths without any problem. This obscures the impact that MHS may have on youths and on the prediction of psychiatric disorders in later adolescence or adulthood [16]. To advance our understanding of MHPs among PHIV+ and PHEU youths, this article uses MHS counts rather than psychiatric diagnoses. These MHS counts are classified into two primary behavioral symptom typologies—internalizing symptoms (e.g., depressive and anxiety symptoms) and externalizing symptoms (e.g., conduct disorder, attention deficit, and hyperactivity disorder), to enable examination of common symptom patterns [17] and assessment of group effects (e.g., age, sex).

Explicating the changes in youths' MHS across adolescence and associated risk factors is critical to understanding the etiology of MHPs among PHIV+ and PHEU youths and could inform the development of evidence-based mental health services for this population [7]. This article seeks to expand the current literature on the mental health of PHIV+ and PHEU youths by using data from a longitudinal study to assess prospective changes in MHS and identifying the contextually relevant factors that influence these changes as youth transition through adolescence. To inform these exploratory analyses, we used key elements of Social Action Theory [18]. Specifically, we examined the association between changes in MHS and youths' socio-demographic characteristics, their context, and their self-regulation. Consistent with prior research, we hypothesized that PHIV+ youths would have higher rates of increase in MHS compared to PHEU youths [1]; changes in youths' MHS across adolescence would be positively associated with greater exposure to negative contextual factors (e.g., greater environmental stress, caregiver distress, and household poverty) [6–8,10] and negatively associated with self-regulation factors (e.g., future orientation) [19,20].

Methods

Participants and procedures

This article uses data from the Child and Adolescent Self-Awareness and Health Study (CASAH), a multicenter longitudinal study of PHIV+ and PHEU youths recruited from four medical centers in New York City. Participants included the youths and their primary caregiver who met the following inclusion criteria: (1) youths aged 9–16 years with perinatal exposure to HIV (as confirmed by medical providers and charts); (2) cognitive capacity to complete the interviews; (3) English or Spanish speaking; and (4) caregiver with legal ability to sign consent for child participation. To isolate the effect of HIV on mental health and behavioral health outcomes, we included a comparison group of children from similar environments who were perinatally HIV exposed but uninfected. In the absence of a large enough pool of PHEU youths in study clinics, multiple children were recruited from the same family, providing they met eligibility criteria. Participants were recruited between 2003 and 2008. Of the 443 eligible participants, 11% refused contact with the research team and 6% could not be contacted by the site study coordinators. A total of 367 (83%) caregiver–youth dyads were approached, of whom $N = 340$ were enrolled at baseline (77% of eligible families; 206 PHIV+ and 134 PHEU youth).

Data were collected using caregiver and youth interviews, conducted separately, but simultaneously whenever possible conducted at the youth's/caregiver's homes, their medical clinics, or our research office, by trained bachelor-level interviewers. Based on participant preference, all youths were interviewed in English and 67 caregiver interviews were conducted in Spanish. Consistent with standard procedures for translation and back translation [21], all study instruments were translated and certified by an institutional review board approved expert translator. Institutional review board approval was obtained from all study sites. All caregivers provided written informed consent for themselves and their youths who were <18 years of age; youths provided written assent (if <18 years) or consent if ≥ 18 years. Monetary reimbursement for each completed session (\$25) and public transport was provided.

These analyses used three waves of data collection: CASAH-1 (baseline and follow-up: FU1) and CASAH-2 (FU2). The baseline and FU1 interviews were completed approximately 18 months apart (mean $[M]_{\text{years}} = 1.65$, standard deviation $[SD] = .45$). CASAH-2 was not initially planned; data collection was initiated when authors secured additional funding to follow the CASAH-1 cohort. CASAH-2 involved rerecruiting families from CASAH-1. Families were eligible for CASAH-2 interviews if the youths were at least 13 years, and it had been at least 1 year since their FU1 interview. All youth and their caregivers who were re-enrolled in the study at FU2 provided written consent and assent, as necessary. Overall, the retention rates were high: 82.4% (166 PHIV+ and 114 PHEU youths) between baseline and FU1, and 79% (166 PHIV+ and 104 PHEU) of youths who were initially enrolled in CASAH-1 were successfully recruited for CASAH-2. The median time interval between FU1 and FU2 was 3 years ($M_{\text{years}} = 2.89$, $SD = 1.29$). At FU2, youths' ages ranged from 13 to 24 years ($M_{\text{age}} = 16.73$, $SD = 2.74$).

Because of the missing data on one or several key covariates at follow-up, only 325 youths (196 PHIV+ and 129 PHEU) were included in these analyses. There were no significant differences by youths' HIV status, gender, race/ethnicity, age, and mental

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