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## Caregiver Perceptions of Environment Moderates Relationship Between Neighborhood Characteristics and Language Skills Among Youth Living with Perinatal HIV and Uninfected Youth Exposed to HIV in New York City

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## Abstract

Despite the increased recognition of how neighborhood conditions bear on cognitive and academic outcomes, no studies have examined the influences of objective and subjective neighborhood indices on specific areas of cognitive functioning among youth living with perinatal HIV (PHIV). In the United States (US), this is of particular concern as HIV has disproportionately affected African American youth living in economically disadvantaged and racially segregated communities. Thus, based on a longitudinal cohort study of psychosocial and behavioral health outcomes in 340 perinatally HIV-exposed but uninfected (PHEU) and PHIV youth residing in New York City, ages 9–16 years at enrollment, we analyzed data from baseline and multiple follow-up (FU) quantitative interviews with youth and their primary caregivers, from when they were at least 13-years-old (approximately 4-6 years post enrollment). We examined the association between baseline neighborhood indices (2000 US census data and caregiver's perception of neighborhood stressors) and youth receptive language skills (PPVT; Peabody Picture Vocabulary Test) at FU2 and FU3. Census data (percentage of families in neighborhood living below the national poverty rate, median neighborhood household income, and percentage of residents professionally employed) were not independently associated with PPVT scores at both follow-ups. However, in the logistic regression model, the more caregivers *perceived* their neighborhood as stressful and subjected to violence, the stronger the relationship between census data indicators of low resource neighborhoods and lower PPVT scores for both groups. Findings support "place-based" policies and practices that alleviate caregiver experiences of neighborhood stressors which may contribute to improved cognitive outcomes for youth living with and affected by PHIV.

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#### Keywords

perinatal HIV; youth; neighborhood; neurocognitive; language

Neurocognitive impairment among children and adolescents with perinatal HIV (PHIV) infection has been shown in multiple studies in the United States (US), even when there is viral suppression and youth are on antiretroviral treatment (ART). Among school aged children living with PHIV, there have been reported delays in motor strength functioning (Blanchette, Smith, King, Fernandes-Penny, & Read, 2002; Gay et al., 1995), academic achievement, language skills (Brackis-Cott, Kang, Dolezal, Abrams, & Mellins, 2009; Coplan et al., 1998; Redmond et al., 2017; Rice et al., 2012) executive function (Malee et al., 2017), processing speed (Phillips et al., 2016), verbal memory (Nichols et al., 2016), and visual-motor tasks (Bisiacchi, Suppiej, & Laverda, 2000). However, the role of HIV neuropathogenesis is less clear. When compared to perinatal HIV exposed and uninfected (PHEU) youth, PHIV+ youth performed *similarly* – that is, below national averages in areas of language (Nichols et al., 2017; Rice et al., 2012), executive function (Llorente et al., 2014), learning and memory (Nichols et al., 2016), working memory (Brahmbhatt et al., 2017), and intellectual functioning (Smith et al., 2012). Socio-economic status (SES) may underlie findings of decreased cognitive outcomes for both PHIV and PHEU youth rather than virologic or ART factors, per se (SES is referenced in this paper as the status attained by a child's parents which is distinguished from that which is attained by a person in adulthood, Schibli et al., 2017). However, studies have not focused on SES determinants of cognitive functioning. Nor have studies of this population considered how the chronicity and timing of SES disadvantage (e.g., low parental education, environmental stressors) during childhood and adolescence potentially affect specific domains of neurocognitive function over time (Duncun, Magnuson, & Votruba-Drzal, 2017; Kang, Mellins, Ng, Robinson, & Abrams, 2008).

Neighborhood characteristics, which typically reflect SES disadvantage, in conjunction with child and parental factors influence cognitive development in children (Brooks-Gunn, Duncun, Klebanov, & Sealand, 1993; Caughy, Havslett-McCall, & O'Campo, 2007; Leventhal & Brooks-Gunn, 2000). Pattillo (2008) defined neighborhoods as "collections of individuals who vary to a greater or lesser degree on individual-level social and economic attributes, and neighborhoods both foster and take on identities based on the preponderance of residents' attributes" (p. 265). The influences of poor neighborhoods on youth cognitive development have been explained by inadequate access to resources and support from neighbors (Jencks & Mayer, 1990), persistent environmental stress, social disorganization, and lack of community involvement (Caughy, O'Campo, & Brodsky, 1999). For example, Caughy and O'Campo's (2006) study of 200 African American caregivers of children ages 3 to 4 years in Baltimore showed that a one standard deviation increase in neighborhood poverty (per census data) was associated with an approximated 8-point decline in children's mental processing score. Also, Sampson et al. (2008), in a longitudinal study of 772 African American children in Chicago, found that living in concentrated disadvantaged neighborhoods reduced child verbal ability by approximately four points, which is comparable to missing school for one year.

While it is well established that neighborhood SES factors influence cognitive development and outcomes, more recent research has also examined how perception of one's neighborhood affects youth outcomes (Minh, Muhajarine, Janus, Brownell, & Guhn, 2017; O'Neil, Parke, & McDowell, 2001). Previous studies have argued that objective measures (i.e., census data) and subjective perceptions of neighborhood (i.e., individual ratings of neighborhood environments) are distinct factors that affect the health of residents (Wen, Hawkley, & Cacioppo, 2006). There is cursory evidence that objective neighborhood condition affect health outcomes by way of resident's subjective perceptions of their neighborhood environment (Weden, Carpiano, & Robert, 2008; Wen et al., 2006). In a population study of 4,616 youths (aged 12-17 years) in California, those who perceived their neighborhood to be unsafe were 2.5 more likely to report psychological distress compared to youth who perceived their neighborhood to be safe, after adjusting for individual and family factors (Goldman-Mellor, Margerison-Zilko, Allen, & Cerdá, 2016). However, youth who lived in neighborhoods *objectively* characterized as high risk for violent crimes were no more likely to report psychological distress than those who lived in lower risk neighborhoods. Bronfenbrenner's (1977) well established ecological model was often referenced to support the relationship between caregiver perceptions of neighborhood stressors and their children's behavioral and cognitive development, suggesting that individual characteristics filter experiences of risks such that some caregivers are better able to buffer the adverse effects of toxic environments than others (Jackson, 2003).

In the US, neighborhood effects on youth developmental outcomes are of particular concern since HIV has disproportionately affected African American children living in high poverty neighborhoods. In New York City (NYC), HIV is among "an overlapping cluster of epidemics" marked by poverty and social disintegration (p. 274; Jonsen, Stryker, & National Research Council, 1993). With advances in treatment and prevention, PHIV has become an adolescent and emergent young adulthood epidemic largely affecting racially segregated communities of low SES. Of the 9,525 adults and adolescents (aged 13 and older) living with PHIV at the end of 2014 in the US, 60% were black/African American and 23% were Hispanic/Latino (Center for Disease Control and Prevention, 2017)

Despite findings of neurocognitive impairment among youth with PHIV and the increasing recognition of how neighborhood conditions bear on these outcomes in other populations, no longitudinal studies to date have examined the influence of objective and subjective residential neighborhood indices on specific areas of cognitive functioning in youth living with PHIV in the US. As such, in this study, we hypothesize that both PHIV and PHEU youth living in neighborhoods characterized by higher poverty rates, lower household income, and lower residential professional employment as defined by the 2000 Census at baseline, will be associated with lower receptive language skills in youth at follow-up interviews approximately 4–6 years post enrollment. We further hypothesized that adult caregiver perceptions of higher neighborhood stress at baseline will independently moderate the relationship between objective measures of neighborhood poverty (higher percentage of households living below poverty, lower median household income, and lower percentage of professionally employed residents) and lower receptive language skills for PHIV and PHEU youth at both follow-ups.

## Methods

Data for this secondary data analysis were drawn from the Child and Adolescent Self-Awareness and Health (CASAH) Study, a longitudinal study investigating the mental health and health risk behaviors of PHIV and PHEU youth (Mellins et al., 2009). Participants were recruited between 2003 and 2008 from four medical centers in NYC that provided primary and tertiary care to HIV-affected families to participate in two interviews, 18 months apart. Although not initially planned, additional funding for CASAH was obtained through a competing continuation of our NIMH-funded grant to support following the cohort for the three additional follow-up (FU) interviews (FU2, FU3, FU4), 12 months apart. This frequency for follow ups was selected in consultation with participants, providers, and behavioral experts to balance the rigorous capture of change with data quality and participant acceptability and retention. Inclusion criteria for youth at baseline were (1) youth aged 9 to 16-years-old with perinatal exposure to HIV; (2) cognitive capacity to complete the initial psychosocial interview; (3) fluent in English; and (4) have adult caregivers who can legally sign consent for youth participation and who were fluent in either English or Spanish. Among 443 eligible participants, 11% refused contact and 6% could not be contacted by the clinics. A total of 367 caregiver-youth dyads were approached, 340 enrolled (206 PHIV+ and 134 PHEU) at baseline (BL). Data was collected from 283 participants (178 PHIV+ and 105 PHEU) with 2000 Census data and caregiver perceptions of neighborhood stress at BL; and PPVT standardized scores at FU2 or FU3 were analyzed for this paper. The median time interval between BL and FU1 was approximately 1.5 years (*interquartile range* [IQR] = 1.4-1.7); between FU1 and FU2 interviews was 2.9 years (IQR) = 1.9–4.0), between FU2 and FU3 was 1.3 years (IQR = 1.1-1.8).

Youth and their primary caregivers (adult legal guardians) were interviewed at their homes, medical clinics, or the research offices. All youth interviews were conducted in English and caregivers were interviewed in either English or Spanish (67 were completed in Spanish). Written informed consent and assent were obtained. Youth and caregivers each received \$40 and transportation costs after completing their respective interviews. HIV RNA viral load were obtained by medical chart reviews. Institutional Review Board approval was granted from all study sites.

### Measures

#### **Dependent Variable**

<u>Receptive language</u> was measured with the Peabody Picture Vocabulary Test - 3<sup>rd</sup> Edition (PPVT-III; Dunn & Dunn, 1997), a widely used and well-validated test of receptive language abilities for individuals 2-years-old to 90-years-old. The PPVT-3 was primarily selected to control for cognitive function in the larger study that had as its primary aim examining mental health, and health risk behaviors among adolescents living with PHIV as compared to PHEU. The PPVT has been used in previous studies that examined the relationship between urban neighborhood characteristics and cognitive functioning among children and adolescents of color in the US (Caughy, Nettles, O'Campo, & Lohrfink, 2006; Chase-Lansdale, Gordon, Brooks-Gunn, & Klebanov, 1997; Keyes, Keyes, March, & Susser, 2011; Kohen, Leventhal, Dahinten, & McIntosh, 2008). The interviewer read each word aloud and

the youth chose which of four pictures best illustrated the word. Standard scores ranged from 40 to 160 with a mean score of 100 and a standard deviation of 15. The PPVT-4 replaced the PPVT-3 half way through data collection for FU3 and the PPVT-3 materials were no longer available. Therefore, rather than using the raw scores from different forms, a dichotomous variable indicating whether the scores were two standard deviations below the national mean was created. It is noteworthy that 75% of the test items in the PPVT-4 were already in the PPVT-3 forms, suggesting minimal psychometric differences between the two versions.

#### **Independent Variables**

<u>US Census Data</u>. Neighborhood is defined as a geographically defined residential area and operationalized as census tracts (Roosa, Jones, Tein, & Cree, 2003). Residential zip codes were collected as part of the interview and geocoded to a US Census tract, which was comprised of approximately 3,000 to 8,000 residents (U.S. Census Bureau, 2000). Based on previous studies that examined the relationship between socioeconomic measures and children's intellectual and cognitive abilities (Caughy et al., 1999; Leventhal & Brooks-Gunn, 2000), we selected the following variables from the 2000 US Census – percentage of families in neighborhood living at or below the national poverty rate, median household income for the neighborhood, and percentage of civilians employed in professional occupations. These data points were retrieved by entering each participant's residential zip code in the US Census Bureau American Fact Finder website (accessed November 2016).

<u>Perceived Neighborhood Stress</u> was measured using the16-item City Stress Index (CSI; Ewart & Suchday, 2002) assessing neighborhood disorder and exposure to violence, herein referred to as perceived city stress (PCS). The CSI was validated with a sample of 212 public high school students who underwent a school-wide cardiovascular risk assessment (Ewart & Suchday, 2002). The racial composition of the sample reflected that of the schools, which, like the surrounding city, is predominantly African American – a sample comparable to our study cohort. Caregivers were asked to rate how often they experienced stressful events that occurred in their residential neighborhood in the past year by selecting responses scored 0 (never) to 3 (often), with higher scores indicating greater perception that one's neighborhood was stressful and subjected to violence.

<u>Biomedical Markers</u>. HIV RNA viral load data were abstracted from medical charts at each interview timepoint. The viral load closest to the interview date was used for analysis.

#### Statistical Analysis

Descriptive statistics were generated for the variables defined in the measure section to describe the characteristics of study participants. The primary outcome of interest was the dichotomous variable PPVT standardized scores greater than two standard deviations below the national average (0=No, 1=Yes). We examined the bivariate association between PPVT scores (at FU2 and FU3) and the neighborhood they lived in at baseline by conducting a logistic regression analysis using SPSS Statistics 24. Participants' age, gender and HIV status at baseline were also included in the regression model to adjust for potential confounding effects. In addition, we evaluated if the strength of the above bivariate

associations differed by caregivers' reports on the CSI at baseline. To present the findings, we showed the adjusted odds ratio for bivariate associations and the adjusted ratio of two odds ratios for the potential moderation effect of CSI on the bivariate associations.

## Results

Baseline characteristics of the sample by HIV-serostatus are presented in Table 1. The mean log<sub>10</sub> viral load count for PHIV youth at BL was 3.33 (SD=1.20), and 3.29 (SD=0.86) and 3.25 (SD=0.88) at FU2 and FU3 respectively. At baseline 83% of PHIV youth were on antiretroviral medication. The mean CSI score for caregivers at baseline was 0.77 (SD=0.55). The pooled proportion of youth who score two SD above the national mean on the PPVT were 11% and 13% respectively at FU2 and FU3. There were no significant differences in PPVT scores between PHEU and PHIV youth at FU2 or FU3. There were also no statistically significant bivariate associations between youth's receptive language skills, HIV serostatus, caregiver type (i.e., biological), and their neighborhood characteristics as measured by census data. Caregivers who perceived their neighborhood as stressful and violent lived in neighborhoods with higher poverty rates (r=.167, p=.006), and lower household income (r=-0.173, p=.005). While the strength of association did not reach the significance level of 0.05, the relationships were trending in the expected direction (i.e., youth who lived in neighborhoods with the higher percentage of households living below poverty, lower median household income, or lower percentage of professionally employed residents had higher odds of scoring two SD below the national norm on the PPVT). Nevertheless, the more caregivers perceived their neighborhood as stressful and subjected to violence (PCS) the stronger the relationship between the census characteristics of their neighbourhood and their child's receptive language skills. Specifically, we found that after adjusting for youth's age, gender, and HIV-serostatus, the strength of association between the children's PPVT scores and the percentage of families living in poverty in the neighborhood increased by 1.15 (95% CI=1.04, 1.25; p=0.005) and 1.21 (95% CI=1.08, 1.35; p=0.001) at FU2 and FU3 respectively for caregivers who perceived their neighborhoods as more stressful (vs. one unit lower PCS). For household income, the association increased by a factor of 1.15 (95% CI=1.03, 1.30; p=0.012) and 1.18 (95% CI=1.04, 1.33; p=0.008), at FU2 and FU3 respectively, and for percentage of nonprofessionals who lived in the neighborhood, the association increased by a factor of 1.16 (95% CI=1.02, 1.30; p=0.018) at FU3 for caregivers who perceived their neighbourhoods as more stressful.

## Discussion

The disproportionate number of youth living with PHIV in economically and racially segregated communities in the US warrants a clearer understanding of the complex relationship between neighborhood and youth cognitive outcomes. Our findings indicate that objective neighborhood indices were not independently associated with youth receptive language skills. However, objective indices of high-poverty neighborhood environment were associated with poorer receptive language skills for PHIV and PHEU youth whose caregivers perceived their neighborhood as more stressful and frequently subjected to violence. This finding is consistent with previous studies with older adults in the US that

showed significant associations between low subjective ratings of neighborhood and poorer self-rated general health, suggesting that residents' perceptions of their neighborhood are more *proximally* related to well-being than the objective demographics of where they live (Wen et al., 2006). Although it is unclear how individual differences and varying exposures to the same neighborhood could account for caregivers' perceptions in our study, it is important to underscore that simply restructuring individual perceptions without changing poor neighborhood conditions misses the point of our finding. Noteworthy are neighborhood regeneration programmes in the United Kingdom (White et al., 2017) and the US (Oakley & Tsao, 2006) that address environmental concerns such as crime (by installing street lighting), housing (conducting housing maintenance and repairs), and community (building public facilities) that have been associated with improved mental health functioning among residents. Collectively, such initiatives suggest that "place-based" policy and practice are feasible and implementable, such that the impact of environmental stressors on caregivers can be alleviated, which potentially contribute to improved developmental outcomes for youth (Villanueva et al., 2016).

Our study is the first to our knowledge that examined the long-term impact of both objective residential poverty rate and subjective measures of neighborhood disadvantage on cognitive outcomes among PHIV and PHEU youth. Extending previous cross-sectional findings in the US and Canada that have found associations between neighborhood socioeconomic disadvantage (Chase-Lansdale & Gordon, 1996), residential education level, and low PPVT scores among young children (Froiland, Powell, Diamond, & Son, 2013; Rowe, 2008), our findings suggest the *longevity* of neighborhood effects on receptive language skills specifically among children whose caregivers perceive their neighborhood conditions as a source of stress. A plausible explanation is that perceptions of opportunities and threats in one's neighborhood potentially influence how caregivers regulate their children's activities (O'Neil et al., 2001; Pace, Luo, Hirsh-Pasek, & Golinkoff, 2017) and how they verbally engage with them. Caregivers may, for example, curtail children's social interactions in a neighborhood they perceive as unsafe, which minimizes opportunities for children to develop requisite reciprocity skills for language. Moreover, caregivers who contend with elevated environmental stress, conceivably have less bandwidth to consistently engage children in speech that helps to promote the acquisition and application of vocabulary that are foundational for receptive and expressive language (Shneidman, Arroyo, Levine, & Goldin-Meadow, 2013; Zauche, Thul, Mahoney, & Stapel-Wax, 2016; Zimmerman et al., 2009). For example, Hirsh-Pasek et al. (2015), showed that joint engagement, shared routines and rituals, and connectedness of caregiver-child exchanges at age two predicted expressive language one year later among low-income families in the US. Also of interest are findings that the use of imperatives and directives in family communication shifts the child's attention from mutual interaction to complying with a target behavior which adversely affects their language acquisition (Rowe, 2008; Topping, Dekhinet, & Zeedyk, 2013).

Consistent with previous cross-sectional studies, PHEU youth in this study performed similarly low on the PPVT compared to children with PHIV. Although objective and subjective neighborhood factors indiscriminately affect both PHIV and PHEU youth in our sample, it is noteworthy to consider how the *implications* of poor language skills bear

differently for both groups. Poor caregiver-child communication, for example, has been associated with inconsistent ART adherence – a unique challenge for children with PHIV (Mellins, Brackis-Cott, Dolezal, & Abrams, 2004). Also, while acknowledging the unique developmental stressors of living with PHIV (Kang et al., 2008), our findings further suggest that interventions and policies that alleviate environmental stressors on caregivers will benefit *both* PHIV and PHEU youth – an important consideration in light of findings that PHEU youth are equally vulnerable to mental health challenges as PHIV youth (Malee et al., 2011; Mellins et al., 2012).

## Limitations

Several limitations of our study are noteworthy. First, we underscore the complexity of pathways between neighborhood poverty conditions and outcomes among youth living with PHIV because poverty does not always affect families, and when it does, the outcomes and casual associations vary (Duncun et al., 2017). Second, several factors that potentially mediate the relationship between neighborhood conditions and child outcomes were not examined, including the social fabric of a neighborhood (Miller & Sperry, 2012), individual child factors (e.g., timing and acuity of exposure to stressful neighbourhood conditions, school achievement and attainment, nutritional status, mental health), and guardian functioning (e.g., caregiver mental and physical health status). In other words, "poverty may be neither a necessary or sufficient means to characterize the social processes by which neighborhoods influence outcomes" (p. 623; Caughy et al., 1999). Third, our findings did not consider the potential influence of multiple residential moves on language skills during the study period. However, given that neighborhoods effects on developmental outcomes are not static and may have lagged or cumulative effects especially for poor African American residents (Sampson et al., 2008), our baseline neighborhood predictors of language skills at follow time points still carry interpretative relevance. Finally, prior history of antiretroviral treatment, encephalopathy, and other factors involved in HIV neuropathogenesis were not assessed, which taken together may contribute to language impairment for PHIV youth (Wolters, Brouwers, Moss, & Pizzo, 1995).

There are several noteworthy directions for future research. First, there is a need to examine more proximal measures of environment beyond neighborhood census to include household and schools. Moreover, solely using objective measures of neighborhood without considering the meaning that neighborhoods carry for residents, may not adequately draw out the potential link between environment and cognitive outcomes. As such, mixed-quantitative and qualitative studies will provide a more nuanced understanding of how neighborhood conditions interact with caregiver-child engagement to affect youth language outcomes (Minh et al., 2017).

Findings from this study highlight the relevance of further clarifying the "black box" of neighborhood effects on cognitive functioning among youth exposed to PHIV in economically and racially segregated neighborhoods, and reifies the importance of "considering place not as context but within context" reminding us that "places form people" (p. 8; Tunstall, Shaw, & Darling, 2004). We would be remiss to forget this, as youth with PHIV are becoming adults in such places in greater numbers.

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#### Table 1.

Baseline demographic characteristics of youth stratified by HIV-serostatus (N=283)

Measures	PHIV+ n=178	PHUE n=105	p-value <sup>C</sup>
Age <sup>a</sup>	12.79 (2.20)	12.24 (2.34)	0.049
Gender			0.625
Male <sup>b</sup>	86 (48%)	54 (51%)	
Female	92 (52%)	51 (49%)	
Race/Ethnicity			0.169
African American	61 (34%)	48 (46%)	
Black Hispanic	86 (48%)	46 (44%)	
Hispanic	23 (13%)	7 (7%)	
Other	8 (5%)	4 (4%)	
2000 US Census Profile			
% of Families Living Below Poverty Rate	29.22 (11.21)	29.04 (10.44)	0.897
Median Household Income (in \$1,000)	27.34 (11.49)	27.03 (9.89)	0.822
% of Professional Employees	25.70 (9.02)	26.44 (9.70)	0.531
Caregiver Gender			0.432
Male	21 (12%)	9 (9%)	
Female	157 (88%)	96 (91%)	
Biological Caregiver			< 0.001
Yes	61 (34%)	71 (68%)	
No	117 (66%)	34 (32%)	
Caregiver HIV-positive status			< 0.001
Positive	51 (30%)	69 (67%)	
Negative	120 (70%)	34 (33%)	

<sup>a</sup>Mean (standard deviation)

*b* Frequency (percentage)

 $^{c}$  p-values corresponding to  $\chi^{2}$ /Fisher's exact tests for categorical variables and t-tests for continuous variables