



Navigating Stigma Trajectory and Mental Health Among Young Adults Living with Perinatal HIV in New York City

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Abstract

Perceived HIV stigma and mental health are fluid across the lifespan for people living with perinatally-acquired HIV (PHIV). The process of navigating discredited identities over time in the context of other life demands potentially exerts a toll on the mental health of adolescents and young adults living with PHIV (AYAPHIV). Based on data from a longitudinal study in New York City examining mental health and health risk behaviors among 182 AYAPHIV, we examined if increased perceived HIV stigma predicted mental health, future orientation, HIV-disclosure, and healthcare transition over time (2003–2018). Findings from linear mixed-effects modeling indicated that older age predicted poorer mental health, less future orientation, more HIV-serostatus disclosure, and adult medical services utilization. Perceived stigma was the only significant predictor of mental health and mediated the association between age and mental health—highlighting the importance of addressing stigma across development for AYAPHIV while addressing systems that perpetuate them.

Keywords Perinatal HIV · Youth · Stigma · Mental health · Young adult

Introduction

Living with perinatal HIV (PHIV) across the life-span is challenging in ways that are both normative and unique, and fluid in the United States [1, 2]. These challenges have arguably been shaped by the advancement of antiretroviral therapy (ART) and shifting societal regard for people living with or at risk for acquiring HIV infection. By the end of 2015, people 18–25 years-old in the United States (US) accounted for the largest percentage of people living with PHIV (48.7%), followed by people 26-years or older (20.6%) [3]. Despite declining mortality rates, less than

two-thirds were retained in care and less than half of people living with PHIV were virally suppressed, with those of Black race the least likely to have a suppressed viral load. Coupled with managing a chronic condition, many people of color (particularly Blacks) living with PHIV continue to navigate converging stigma based on HIV, race, and social class [4]. Alonzo and Reynolds elaborated that “the shape of the stigma trajectory is intrinsically entwined with the disease course but is uniquely tied to the response of the broader society” (p. 305) [5]. As such, the social labeling of children with PHIV as victimized in the early nineties differentiated how people living with HIV infection were stigmatized [6]. Goffman’s description of how shifting circumstances and life experiences shaped how people with severe mental illness viewed themselves and others, offered a useful heuristic to help us understand how people living with HIV learn to negotiate their socially discredited identities over their lifespan [7, 8]. Cruz et al.’s study of children living with PHIV in Rio de Janeiro [9], for example, proposed that children enveloped lifelong treatment into their identity based on the timing of their serostatus disclosure and history of HIV-related illnesses. In addition to individual circumstances, the “social patterning” of HIV and societal definitions of moral and biological deviance critically influenced

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how people living with PHIV managed their stigmatized condition (p. 48) [10].

This was strikingly evident in the US during the mid-1980s when an alarming number of children temporarily “boarded” at hospitals in New York City (NYC) due to prenatal crack-cocaine exposure, drawing public outcry against mothers living with HIV and sympathy for their newborns [11, 12]. However, as the children aged into adolescence, with many being told about their HIV-serostatus later in childhood, they confronted mounting threats of peer rejection and concealed their HIV serostatus with heightened vigilance. This pattern persisted into the late nineties when HIV prevalence spiked among young Black men who have sex with men and Black females in US cities. The innocence that society once ascribed to children with PHIV quickly morphed to speculative blame towards young adults living with PHIV who were now perceived as culpable for their HIV infection. Society *presumed* that they acquired the virus by sharing injecting needles or engaging in high-risk sexual behaviors—both deemed deviant and highly discredited in Black communities [13].

Consistent with previous findings that link HIV-stigma with poor mental health in adults living with HIV [14], several studies have found that elevated perceived stigma among people with PHIV in the US was associated with more depressive and anxiety symptoms [15], alcohol use [16], and poor adherence to ART [17] and medical visits [18]. Similarly, a study of children and youth (9–18 years old) living with PHIV in Sweden showed that higher perceived HIV-stigma was associated with poorer health-related quality of life [19]. Collectively, the escalation of stigma and its potential adverse consequences coincided with expanded social networks that required people with PHIV to manage decisions about when, how, and to whom they should disclose their serostatus [20]. Despite mounting evidence of the negative mental health outcomes associated with HIV stigma, cross-sectional studies have been unable to address the fluidity of stigma and its potential impact on mental health over time among people with PHIV.

Although few longitudinal studies exist, research focused on mental health outcomes in aging people with PHIV indicated that a large percentage will develop mental health problems at some point during adolescence or young adulthood [21]. Several factors have been implicated in this trajectory, including gender [22], age, ethnicity, caregiver mental health, and neighborhood stressors [23]. Major negative life events and greater number of neighborhood stressors were also positively associated with increased mental health problems and substance use [21, 22, 24]. To our knowledge, no studies have examined how HIV stigma may impact this mental health trajectory for people with PHIV in the context of shifting developmental demands for self-care and negotiating newly formed relationships—most notably serostatus

disclosure with sexual and romantic partners as they age [25, 26]. Moreover, the extent to which they have internalized perceived and actual HIV stigmatization conceivably shape how they plan for their future [2]. Understanding the fluidity of stigma and its impact on people with PHIV merits careful consideration of how stigma potentially permeates all these domains of life.

Although a substantial number of studies have underscored the relationship between stigma and mental health as people with PHIV age over the life course, it remains unclear if *changes* in perceived HIV stigma contribute to shifts in their mental health in the context of navigating other life demands. Clarity on this relationship will guide the delivery of tailored interventions for an emerging generation of adults living with PHIV in the US and across the globe. As such, we drew from one of the largest longitudinal studies of PHIV in the US, to examine whether mental health and self-care management (i.e., serostatus disclosure, future planning, and healthcare transition) shifted as youth with PHIV aged from childhood to young adulthood (18–25 years old) in NYC and to determine if their perceived HIV-stigma accounted for such changes.

Method

Data for this secondary data analysis were drawn from the Child and Adolescent Self-Awareness and Health (CASA) Study, a longitudinal study investigating mental health and health risk behaviors of PHIV and perinatally HIV-exposed but uninfected (PHEU) youth [27]. Study methods have been extensively described in previous studies [28]. Briefly, child-caregiver dyads were initially recruited between 2003 and 2008 from four medical centers in NYC. Inclusion criteria at enrollment were (1) youth aged 9 to 16-years with perinatal exposure to HIV; (2) cognitive capacity to complete the initial psychosocial interview; (3) fluent in English; and (4) had adult caregivers who could legally sign consent for youth participation and were fluent in either English or Spanish. Trained bi-lingual interviewers conducted the sessions with youth in English and with caregivers in either English or Spanish at their homes, medical clinics, or the research offices. With additional funding, we continued recruiting from this cohort for multiple follow-up (FU) interviews at FU2–FU4 (2008–2013) and FU5–FU7 (2013–2018). Written informed consent for youth caregivers and youth ≥ 18 years and assent for youth < 18 years were obtained. Youth and caregivers each received \$40 and transportation costs after completing their respective interviews. The study was approved by the Institutional Review Board at all study sites.

Among the original 443 eligible participants, 11% refused contact and 6% could not be contacted. A total of 367 caregiver–youth dyads were approached, 340 enrolled (206

PHIV+ and 134 PHEU) at baseline (BL). For the current analysis, we used data from PHIV youth at enrollment to FU7 (2013–2018). The median time interval between BL and follow-up (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), FU2 and FU3 was 1.3 years (IQR = 1.1–1.8); FU3 and FU4 was 1.2 years (IQR = 1.0–1.4); FU4 and FU5 was 2.2 years (IQR = 1.3–2.8), and between FU5 and FU6 was 1.1 years (IQR = 0.9–1.09); and between FU6 and FU7 was 1.0 years (IQR = 1.0–1.2).

Measures

Mental health was measured using the interviewer-administered Youth Self Report (YSR, 11–18 years) and Adult Behavior Checklist (ABCL, ≥ 19 years)—Achenbach's older-age counterparts to the *Child Behavior Checklist* (CBCL)—which are well-validated and widely used symptom checklists of emotional and behavioral problems [29]. On a three-point scale, youth rated how “true” the items were in describing their behavior. A total standardized score based on age and gender was used for our analysis with higher scores indicating more externalizing and internalizing behavioral problems.

Stigma was assessed using the *Social Impact Scale* (BL–FU6) [30] and the *HIV Stigma Scale* (FU6–7) [31] two well-validated measures of perceived HIV stigma. Given that two measures were used throughout the study to address dimensions of stigma that were developmentally tailored to participants as they aged (e.g., disclosure concerns in the workplace was not relevant to younger participants), we selected 7-items for our analysis that were consistently administered across the timepoint interviews (BL—FU4 and FU7). On a four-point Likert scale, participants reported how much they agreed with statements regarding perceived social responses to HIV and perceptions of being stigmatized (“I fear someone telling others about my HIV without my permission;” “I feel I need to keep my HIV a secret;” and “I do not feel I can be open with others about my HIV”). Higher scores indicated higher perceived stigma. In this study, the Cronbach's alphas were 0.543 at baseline and ranged from 0.624 to 0.744 at follow-up administrations.

Future Orientation was assessed with a 7-item measure that focused on educational/ vocational expectations (e.g., how likely would you be employed [current or past] with a well-paid job that you enjoy) and concerns about self and others (e.g., how likely will you stay in good health) [32]. Psychometric properties of this measure were based on a US representative sample of 10th–12th grade and high school dropout students (12% African-American) Participants responded on 5-point Likert Scale (1 = Very Low to 5 = Very High) with higher scores indicating greater

expectations for the future. In this study, the Cronbach's alpha was 0.765 at the first administration.

HIV Disclosure was assessed with a 7-item measure that asked how many household/ family members and partners across different sexual situations (i.e., with casual and/or steady partners when using and not using condoms) were told of the participants' serostatus. Responses were 5-point Likert Scale (0 = none to 4 = all) with 5 = not applicable. In this study, the Cronbach's alpha was 0.896 at the first administration.

Healthcare Transition was measured using a 6-item scale to which participants responded yes or no: (1) do you have a primary care physician that you see at least once a year?; (2) do you feel comfortable asking questions at your appointments?; (3) do you have a copy of health records, current med, provider contact?; (4) do you have a method of keeping track of your health care appointments?; (5) are you responsible for making your appointments?; (6) are you responsible for filling your medications? Scores ranged from 0 to 6 with higher scores indicating a more successful healthcare transition.

Statistical Analysis

We employed a linear mixed-effects model to investigate whether each of the four outcomes—mental health, future orientation, HIV disclosure, and healthcare transition—changed as people with PHIV aged and whether such changes were attributed to HIV-related stigma. The main reason for adopting this model was to address intrapersonal dependence across repeated measurements taken over each person's multiple visits. This analytic approach also allowed us to describe the linear trend of each outcome variable at both population and individual-participant levels.

The model assumed that the structural variability in data was explained by a linear combination of fixed-effect and random-effect terms and that the unexplained variability (i.e., regression residual) was independent and normally distributed with constant variance. In our application, given the small number of per-individual observations for some variables (e.g., only three measurements of both stigma and mental health), checking these assumptions on the individual-level residuals was not relevant. Similarly, any complex variance-covariance structure of random effects was not supported—the reported models were chosen by likelihood-ratio tests between them and alternative structures. As a result, all models assumed the typical, variance-components structure, and random effects in most of them were limited to intercepts only (i.e., random slopes were not supported by data). In case a random slope was significant, its correlation with a random intercept was not validated. Lastly, skewness or multimodality was not found on the distributions of estimated random effects.

Table 1 Descriptive summary of scores among young people living with PHIV in New York City (2003–2018)

Timepoints	Age	HIV-stigma	Mental health ^a	Future orientation	HIV disclosure	Healthcare transition
Follow-up (FU)	Mean (SD) n = 1218 ^b	Mean (SD) n = 829	Mean (SD) n = 748	Mean (SD) n = 750	Mean (SD) n = 812	Mean (SD) n = 731
Enrollment	12.83 (2.17) n = 182	1.93 (.421) n = 133	–	–	–	–
FU1	14.39 (2.31) n = 158	1.95 (.475) n = 125	–	–	–	–
FU2	17.99 (2/76) n = 173	2.00 (.496) n = 162	50.20 (9.49) n = 172	4.11 (.632) n = 173	1.22 (.858) n = 149	4.24 (1.36) n = 164
FU3	19.21 (2.62) n = 147	2.05 (.541) n = 140	50.33 (9.06) n = 147	4.07 (.685) n = 147	1.28 (.861) n = 136	4.31 (1.32) n = 141
FU4	20.47 (2.62) n = 145	2.07 (.532) n = 141	50.42 (10.31) n = 144	4.02 (.602) n = 145	1.30 (.854) n = 133	4.57 (1.31) n = 141
FU5	22.79 (2.62) n = 151	–	52.25 (10.02) n = 151	3.92 (.605) n = 151	1.39 (.870) n = 143	4.82 (.980) n = 151
FU6	23.79 (2.54) n = 134	–	52.20 (9.77) n = 134	3.88 (.622) n = 134	1.42 (.836) n = 126	4.81 (1.06) n = 134
FU7	24.94 (2.56) n = 128	2.31 (.503) n = 128	–	–	1.34 (.862) n = 125	–

^aYouth Self Report (YSR, 11–18 years) and Adult Behavior Checklist (ABCL, ≥ 19 years)—Achenbach's older-age counterparts to the *Child Behavior Checklist* (CBCL)

^bTotal cumulative sample

The statistical model for each outcome measure consisted of fixed-effect terms, which equally applied to all participants (i.e., population level), as well as random-effect terms, which explained the variability due to individual differences. Specifically, the following three models were fitted for each of the four outcome variables (mental health, future orientation, HIV disclosure, and healthcare transition):

$$\text{Outcome}_{ij} = (\beta_0 + \mu_{0i}) + (\beta_1 + \mu_{1i})\text{Age}_{ij} + \varepsilon_{ij} \quad (\text{with Age only})$$

$$\text{Outcome}_{ij} = (\beta_0 + \mu_{0i}) + (\beta_1 + \mu_{1i})\text{Stigma}_{ij} + \varepsilon_{ij} \quad (\text{with Stigma only})$$

$$\text{Outcome}_{ij} = (\beta_0 + \mu_{0i}) + (\beta_1 + \mu_{1i})\text{Age}_{ij} + (\beta_2 + \mu_{2i})\text{Stigma}_{ij} + \varepsilon_{ij} \quad (\text{with Age and Stigma})$$

where the subscript i referred to each participant, j referred to time point, the β s are fixed effects regression coefficient, and the μ s are the random effects (the random complement to the fixed β). Model fitting involved estimating the coefficient of each fixed effect (β_0 , β_1 and β_2) and the variance of each random effect ($\sigma_{\mu_{0i}}^2$, $\sigma_{\mu_{1i}}^2$, $\sigma_{\mu_{2i}}^2$ and $\sigma_{\varepsilon_{ij}}^2$). Covariances between random effects were assumed to be zero as none of them were supported in likelihood ratio tests. The analyses were performed using the 'lme4' package for R [33]. We also used a bootstrapping procedure in the 'mediate' package

for R to conduct the mediation analysis to examine whether stigma mediates the effect of age on mental health.

Results

At enrollment, participants included 182 youth living with PHIV, 9–16 years-old (mean age= 12-years-old), the majority of whom were Black (65%); Latinx comprised 46% of the sample, with 23 identifying as both Black and Latinx), and male (51%). The mean age of participants at subsequent follow-up are indicated on Table 1. Table 2 shows the mixed-effects analysis results in which age, stigma, or both age and stigma (three rows labeled as such) predict each of the four outcomes (columns labeled accordingly). Estimated coefficients for fixed and random effects are shown together with their 95% confidence intervals. All coefficients are standardized for interpretability.¹

Mental health scores tend to increase as age increases ($\hat{\beta} = 0.152$, 95% CI [0.063, 0.240]), indicating an overall age effect at the population level. Individual differences,

¹ In the results reported here, the *SD* of each variable used for standardization was calculated from the entire set of aggregate measurements and applied consistently to all regression results even if only a subset of data was analyzed. For example, the *SD* of age that standardized the coefficients of a model predicting mental health was obtained from *all* age measurements even if only a subset of those coincided with mental health measurements.

Table 2 Estimated coefficients of mixed-effects models predicting health outcomes

Predictor	Mental health (CBCL)		Future orientation		HIV disclosure		Healthcare transition ^a	
	Fixed ($\hat{\beta}$)	Random ($\hat{\sigma}$)	Fixed ($\hat{\beta}$)	Random ($\hat{\sigma}$)	Fixed ($\hat{\beta}$)	Random ($\hat{\sigma}$)	Fixed ($\hat{\beta}$)	Random ($\hat{\sigma}$)
Age only								
Intercept	– ^b	0.573*** [0.255, 0.792]	–	0.651*** [0.567, 0.747]	–	0.788*** [0.702, 0.889]	–	1.744*** [1.564, 1.971]
Age	0.152*** [0.063, 0.240]	0.138** [0.067, 0.189]	–0.299*** [–0.400, –0.198]	– ^c	0.191*** [0.117, 0.264]	–	1.894*** [1.661, 2.160]	–
Stigma only								
Intercept	–	0.776*** [0.682, 0.885]	–	0.676*** [0.573, 0.789]	–	0.775 [0.683, 0.883]	–	2.261*** [1.968, 2.655]
Stigma	0.184*** [0.108, 0.261]	–	–0.084 [–0.174, 0.006]	–	0.021 [–0.049, 0.090]	–	0.951 [0.844, 1.069]	–
Age & stigma								
Intercept	–	0.775*** [0.681, 0.884]	–	0.664*** [0.562, 0.777]	–	0.745*** [0.654, 0.849]	–	1.820*** [1.588, 2.114]
Age	0.033 [–0.134, 0.199]	–	–0.179 [–0.360, 0.004]	–	0.239*** [0.144, 0.334]	–	2.570*** [2.075, 3.192]	–
Stigma	0.183*** [0.105, 0.260]	–	–0.076 [–0.166, 0.013]	–	–0.034 [–0.106, 0.038]	–	0.913 [0.817, 1.018]	–

^aCoefficients are odds ratios obtained from binomial logistic regression

^bEstimates of fixed intercepts are irrelevant as regression coefficients are standardized

^cThis coefficient is fixed at zero based on likelihood-ratio test

* $p < 0.05$, ** $p < 0.01$, *** $p < 0.001$

however, are somewhat large as shown by the slope's random variability ($\hat{\sigma} = 0.138$, 95% CI [0.067, 0.189]). In contrast, the effect of stigma on mental health is relatively strong ($\hat{\beta} = 0.184$, 95% CI [0.108, 0.261]) and robust as evidenced by non-significant randomness.

When age and stigma are included in the model simultaneously, stigma was the only significant predictor of mental health, ($\hat{\beta} = 0.183$, 95% CI [0.105, 0.260]) and the effect of age is considerably reduced and no longer statistically significant. Also, non-significant random slopes of age and stigma suggest that this population-level trend holds consistently among individual participants.

To further clarify the three-way relationship between age, stigma, and outcomes we examined the correlation between age and stigma. Table 3 shows the results from the linear mixed-effects model predicting stigma from age. Findings suggest that stigma increases considerably with age ($\hat{\beta} = 0.267$, 95% CI [0.198, 0.336]), although there is some variability due to individual differences ($\hat{\sigma} = 0.115$, 95% CI [0.059, 0.157]).

The findings from these two regression models (i.e., mental health predicted from stigma and age, and stigma predicted from age) led us to further examine whether stigma mediates the effect of age on mental health, as it may explain why the age effect is eliminated while adjusting for stigma. From 5000 bootstrap draws, the sampling distribution of

Table 3 Estimated regression coefficients of mixed-effects model predicting stigma from age

Predictor	Fixed ($\hat{\beta}$)	Random ($\hat{\sigma}$)
Intercept	– ^a	0.360 [0.000, 0.546]
Age	0.267*** [0.198, 0.336]	0.115** [0.059, 0.157]

^aFixed intercept is irrelevant as regression coefficients are standardized

* $p < 0.05$, ** $p < 0.01$, *** $p < 0.001$

indirect effects (i.e., the effect of age on stigma multiplied by the effect of stigma on mental health controlling for age) indicated a significant mediation effect with size $P_M = 0.552$ (ratio of indirect effect to total effect, $p = 0.024$).²

Unlike mental health, the analysis of the other three outcome variables, (i.e., future orientation, HIV-disclosure, and healthcare transition), resulted in similar findings. The age effect is consistently present in all three outcomes but no stigma effect is found for any of the three outcomes. More specifically, after adjusting for stigma, age remains significantly associated with HIV disclosure and healthcare transition; however, its association with future orientation becomes non-significant.

Discussion

Our findings highlighted mental health challenges among people with PHIV as they aged and provided new evidence that their mental health decline was hastened by heightened perceived stigma. Stigma was the only significant predictor of mental health for all participants and it mediated the relationship between aging and poorer mental health. This analysis further underscored the fluidity of stigma formation and its impact on people with PHIV over time. Understanding this necessitates considering the context of transitioning to adult medical care, managing decisions about HIV-serostatus disclosure, and planning for their future. Several implications of these findings are noteworthy.

First and foremost, behavioral health interventions for adolescents and adults living with PHIV remain a priority. Previous findings of comparable high rates of mental health needs among people with PHIV and those affected by familial HIV (e.g., youth with PHEU) suggested that social and systems-level stressors accounted for mental health problems more so than HIV infection per se [21–24, 28, 34–36]. Our current findings, however, suggest that perceived HIV-stigma also contributes to mental health decline as youth with PHIV age. Other studies on emerging adults with concealable stigmatized identities (e.g., mental illness) similarly showed that an increase in anticipated stigma predicted a slower decline in depressive symptoms over time [37].

The anticipation of being stigmatized can also be shaped by one's immediate social contexts. For example, heightened scrutiny of HIV-serostatus based on societal presumptions of blame that adults with PHIV acquired the virus behaviorally can perpetuate stigma based on HIV-status,

HIV transmission behaviors (e.g., injection drug use), and individual characteristics (e.g., race, gender, sexual orientation)—all of which adversely affect mental health [38]. As noted earlier, many Black adults with PHIV, in particular, contend with layered stigma associated with HIV, sexual practices, (e.g., men having sex with men), which is arguably deemed more stigmatizing in Black communities than living with HIV [39, 40]. Recent cross-sectional studies have found that adults with converging concealable stigmatized identities (e.g., mental illness, sexual orientation, incarceration history) ruminated more about potential mistreatment than those with visible stigmatized marks which resulted in poorer quality of life [41]. Coupled with this anticipation, increased negative self-appraisal and the salience of stigma to self-identity (e.g., living with HIV) further heightened psychological distress [42]. Of benefit are future studies that can untangle the potential cumulative effects of stigmatized identities layered on PHIV-serostatus that include (but not exclusively) racial/ethnic minority status, sexual orientation, and mental illness (i.e., substance use dependence). Moreover, it merits consideration of how people with PHIV potentially deplete self-regulatory resources to manage the threats of holding devalued identities—a process that can undermine their mental health over time [43, 44].

The frequency and intensity of anticipated and enacted mistreatment can also become more challenging to manage as many people with PHIV negotiate intimate and sexual relationships in early adulthood. This was evidenced by our participants' more frequent voluntary serostatus disclosure to sexual partners as they age. For the first time, many people with PHIV faced more nuanced decisions about when and how to disclose their serostatus to romantic or sexual partners [20]. Expectedly, this rendered them more vulnerable to mistreatment and rejection. However, we found that HIV-stigma was not associated with frequency of disclosure, suggesting that anticipated stigma had negligible effects on the rate of serostatus disclosure. Similarly, a prior cross-sectional analysis of our third follow-up interview (2009–2014; mean age = 20.2 years) found that fear of stigma and rejection was not associated with intention to disclose to sexual partners [26]. Yet qualitative studies have found that people with PHIV carefully considered the potential consequences of disclosure to romantic or casual sexual partners, suggesting that fear of stigma arguably shaped *how* rather than *what* disclosure decisions were made [45–47]. Fair and Albright, for example, found that young adults with PHIV were inclined to delay dating, slow down intimacy, or prematurely terminate relationships in anticipation of being rejected by partners when they disclosed their HIV-serostatus [45]. In other words, the decision to disclose one's HIV-status did not imply that the process of arriving at this decision was necessarily straightforward.

² The size of data used for this mediation analysis was smaller than that used for the analysis of the age effect on mental health reported separately. The number of per-individual measurements of both stigma and CBCL was only three.

Lastly, despite the accessibility of mental health services for children living with PHIV in the US, the continuity of services is often disrupted for people with PHIV as they transition to adult clinics. This may be expected as they adjust to less family-centered provider relationships and people with PHIV perceive less urgency for mental health services, all of which account for lower rates of mental health counseling among young adults in the US [48, 49]. Also, people with PHIV in our study were less future-oriented over time, which may be developmentally normative and attributed in part to their unexpected transition to adulthood and experiences of perceived (and actual) racism in poor racially segregated spaces [2]—all of which collectively limit what they believe are possible to accomplish [50]. This diminished motivation to work toward identified goals can further discourage their utilization of services and compromise their health and well-being [51]. Taken together, mental health support that complements or extends the reach of conventional psychotherapeutic interventions for AYAPHIV warrant careful consideration. Peer-to-peer support and online social media interventions, in particular, are promising approaches that tap into the cohesiveness of informal AYAPHIV networks. These interventions uniquely draw from natural connections formed in countless pediatric HIV clinics in the early 1990s that remain strong until this day. Designing and evaluating such peer-led programmes [52, 53] with the aim to re-connecting and fortifying existing AYAPHIV support networks to minimize isolation and hopelessness from heightened perceived or actual stigmatization deserves careful consideration.

Limitations

Several methodological limitations of our study warrant consideration. First, our convenience sample of people with PHIV recruited from four urban medical centers cautions against generalizing our findings to people not linked to nor retained in care, or in more rural settings. Second, the small estimated effect sizes of the associations between age, future orientation, and serostatus disclosure tempered our interpretation of how age predicted these select outcomes. That being said, the notable size of the indirect effect of age on mental health via stigma was more conclusive. Third, our HIV stigma and serostatus disclosure scales had slight variations in wording and were not exactly equivalent across time points which might impact results. Although scales commonly used in life-span studies are modified over time due to age-appropriateness and questionable validity of the prior version of scales [54], we cannot rule this out as a limitation. Fourth, by measuring a narrow scope of stigma we were unable to address how pertinent dimensions of stigma associated with HIV (e.g., enacted, structural, provider-stigma)

and other socially discredited identities may affect people with PHIV—the majority of whom are Black and Latinx and living in the US. Lastly, the small number of concurrent individual observations for select variables (e.g., stigma and mental health) rendered insufficient power to formally test these assumptions.

Conclusion

Notwithstanding these limitations, our findings highlight the continued importance of mental health interventions that address the burden of managing the fluidity of stigma in the context of living with PHIV as an emergent adult, while addressing systems that generate and perpetuate them [55, 56]. People with PHIV continue to confront changing landscapes in their lives that promote resiliency and pose formidable challenges. Concurrent realities of shifting medical treatment demands, serostatus disclosure, and future planning in the context of livelihood disparities in the US are relevant and critical considerations when addressing the mental health of the vast majority of people with PHIV. Furthermore, it is sobering that as we approach the third decade of the epidemic, HIV stigma remains a persistent reality that compromises the mental health of people with PHIV—underscoring the renewed importance of carefully integrated mental health and stigma-reduction programming and addressing barriers to accessing these services.

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Compliance with Ethical Standards

Conflict of interest The authors declare that they have no conflict of interest.

Ethical Approval The research has been approved by the institution review boards of all sites involved in the longitudinal study.

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