

Association of Perceived Social Support with Viral Suppression Among Young Adults with Perinatally-Acquired HIV in the US-based Pediatric HIV/AIDS Cohort Study (PHACS)

Katherine Tassiopoulos¹, Yanling Huo², Deborah Kacanek², Kathleen Malee³, Sharon Nichols⁴, Claude A Mellins⁵, Stephan Kohlhoff⁶, Russell B Van Dyke⁷

On behalf of the Pediatric HIV/AIDS Cohort Study

¹Department of Epidemiology, Harvard T.H. Chan School of Public Health, Boston, MA, USA; ²Center for Biostatistics in AIDS Research, Harvard T.H. Chan School of Public Health, Boston, MA, USA; ³Departments of Infectious Diseases and Psychiatry and Behavioral Science, Northwestern University Feinberg School of Medicine, Chicago, IL, USA; ⁴Department of Neurosciences, University of California San Diego, La Jolla, CA, USA; ⁵Psychiatry and Sociomedical Sciences, Columbia University, New York, NY, USA; ⁶Division of Pediatric Infectious Diseases, SUNY Downstate Medical Center, Brooklyn, NY, USA; ⁷Pediatric Infectious Diseases, Tulane University School of Medicine, New Orleans, LA, USA

Correspondence: Katherine Tassiopoulos, Senior Research Scientist, Department of Epidemiology, Harvard T.H. Chan School of Public Health, 677 Huntington Ave, Kresge 817B, Boston, MA, 02115, USA, Tel +1 617 432 3265, Fax +1 617 566 7805, Email ktassiop@hsph.harvard.edu

Purpose: To determine the relationship between perceived social support and viral suppression among young adults with perinatally-acquired HIV (YAPHIV).

Participants and Methods: We included YAPHIV ≥ 18 years enrolled in AMP Up, a study of PHACS (Pediatric HIV/AIDS Cohort Study), with social support evaluations and ≥ 1 HIV viral load (VL) measured over the next year. We evaluated emotional, instrumental, and friendship social support via the NIH Toolbox. We defined social support, measured at study entry and year 3 (if available), as low (T-score ≤ 40), average (41–59) or high (≥ 60). We defined viral suppression as all VL < 50 copies/mL over the one year after social support measures. We fit multivariable Poisson regression models using generalized estimating equations, and evaluated transition from pediatric to adult care as an effect modifier.

Results: Among 444 YAPHIV, low emotional and instrumental support and friendship at entry were reported by 37%, 32% and 36%. Over the next year, 44% were virally suppressed. Of 136 with year 3 data, 45% were suppressed. Average or high levels of all three social support measures were associated with higher likelihood of viral suppression. Instrumental support was associated with viral suppression among those in pediatric (adjusted proportion suppressed among those with average/high vs low support=51.2% vs 28.9%; risk ratio (RR)=1.77, 95% confidence interval (CI)=1.37, 2.29), but not adult care (40.0% vs 40.8%; RR=0.98, 95% CI=0.67, 1.44).

Conclusion: Sufficient social support increases likelihood of viral suppression among YAPHIV. Strategies to enhance social support may promote viral suppression as YAPHIV prepare for adult clinical care transition.

Keywords: social support, perinatal HIV, young adults, viral suppression, clinical care transition

Plain Language Summary

Strong social support, which is support from family, friends and others, can improve mental and physical health. Some studies have shown that social support can help older adults living with HIV keep their virus levels low. There have not been any studies like this for young adults living with HIV. We wanted to look at this relationship in young adults born with HIV in PHACS, to help us find ways for young adults to keep their virus levels low. Four hundred forty-four young adults born with HIV from the PHACS AMP Up study participated. We examined three types of social support – instrumental, emotional and friendship. We then looked at participants' viral load to see if it was associated with the amount of social support they had. We found that young adults who said they had good

social support were more likely to have undetectable virus levels. This relationship was especially strong for young adults who were still getting their HIV care from pediatric clinics instead of adult clinics. Our study has shown that having strong social support can help young adults born with HIV to keep their virus levels low.

Introduction

In the general population, greater social support is associated with reduced all-cause mortality,¹ better diabetes control,² increased adherence to medical treatment,³ and decreased depression.⁴ Among individuals with HIV, social support has been studied for its associations with outcomes including medication adherence,^{5–11} HIV disclosure,^{12,13} mental health,^{14,15} HIV-related stigma,¹⁶ and HIV viral load suppression.^{17–22} All but one of these latter studies¹⁷ identified a positive association between viral suppression and social support, and these were all studies of older adults with HIV. Furthermore, none evaluated more than one type of social support, even though different types of social support are known to have differential impacts on a wide range of health outcomes.^{23–25} There have been few examinations of the role of social support in health outcomes among young adults with HIV. Social support has been studied in the context of adolescent and young adult disclosure of HIV infection.¹³ There have also been studies of the contribution of support from friends and family to antiretroviral treatment adherence in children and adolescents.^{5,8,9} However, to our knowledge, there are no studies of the relationship between social support and viral suppression in young adults with HIV, including those with perinatally-acquired HIV (PHIV). While social support has been linked to viral suppression in older cohorts of persons with HIV, the impact of social support on health outcomes may be different for younger populations.²⁶ Additionally, young adults with PHIV have lived with HIV since birth, have been engaged with health care providers throughout childhood and adolescence, and have taken medication since early childhood, which makes them unique in their level of engagement with health care. This long-term engagement, as well as the early loss of parents to HIV,²⁷ and increased risk for neurocognitive impairment and mental health comorbidities,^{28,29} may mean that they are more dependent than young people with non-perinatally acquired HIV on the social support of their pediatric health care providers. At the same time they are more likely to experience treatment fatigue,³⁰ and less likely to be virally suppressed than young adults with non-perinatally acquired HIV.^{31,32}

The transition from pediatric to adult clinical care is a stressful period for young people with chronic health conditions including perinatally-acquired HIV. The period leading up to this transition may be accompanied by anxiety about losing the long-standing and familiar care provided by pediatric clinicians.^{33,34} After transition, young adults might experience apprehension about their adult clinic or providers and may lack confidence in their ability to independently establish new relationships with these providers. The health care transition period may therefore be an important moderator of the role of social support in viral suppression.

There are several mechanisms through which social support might affect viral suppression – by improving medication adherence, emotional well-being, and retention in care, or by reducing harmful forms of substance use.³⁵ Because viral suppression is essential for the long-term health of young adults with PHIV, we need to identify factors that optimize the likelihood of sustained viral suppression even as young adults seek autonomy and become less reliant on others for management of their long-term HIV care. As a potentially modifiable factor clearly linked to other health-related outcomes, social support is an important focus of investigation.

Our aims were to assess perceived emotional and instrumental social support and friendship in a large cohort of young adults with PHIV, to evaluate the association of social support with viral suppression, and to explore whether this association is modified by the transition from pediatric to adult clinical care.

Materials and Methods

Participants

The Adolescent Master Protocol (AMP) Up study of the Pediatric HIV/AIDS Cohort Study (PHACS) network enrolls young adults with PHIV (≥ 18 years old) at 14 clinical research sites in the US, including Puerto Rico, for long-term follow-up.³⁶ There are annual remote visits and in-person visits at entry and every 3 years thereafter. AMP Up was approved by the institutional review boards (IRB) of each clinical site and the Harvard T.H. Chan School of Public

Health, and complies with the Declaration of Helsinki. Written informed consent is obtained from all participants, or from guardians for those unable to consent themselves.

All young adults with PHIV who completed social support evaluations at the entry visit and had ≥ 1 HIV RNA (viral load) measurement within 1 year after these evaluations were included. Data for these analyses were collected between 2014–2019.

Data Collection and Measures

Participants completed an annual web-based survey of multiple domains including demographics, healthcare, and the transition from pediatric to adult clinical care. Viral loads were abstracted annually from medical charts. Neurocognitive function (examiner-administered) and instrumental and emotional social support and friendship (self-administered) were assessed with computerized tasks and questionnaires from the NIH Toolbox Cognition and Emotion batteries. The NIH Toolbox is designed to provide brief assessment tools for the measurement of key domains of cognitive, sensory and emotional health in children and adults.³⁷

Perceived Social Support

Each social support measure consists of 8 items with response options of never, rarely, sometimes, usually, and always. The emotional support scale is designed to measure the perception that people are available to listen to one's problems with empathy, caring, and understanding. The instrumental support scale is designed to measure the perception that people are available to provide material or functional aid in completing daily tasks such as housekeeping, cooking and transportation. The friendship scale measures the perception of the availability of friends or companions with whom to interact or affiliate. The development and validation of the NIH Toolbox social support and friendship scales have been described in detail.^{38,39} Raw scores were converted to T-scores (mean=50, standard deviation=10) using 2010 census-weighted demographic data,⁴⁰ and higher T-scores indicate greater perceived social support. We evaluated each measure as a 1) continuous variable; 2) categorical variable defined as T-score ≤ 40 (low support), > 40 –59 (average support) and ≥ 60 (high support); and 3) dichotomous variable defined as T-score ≤ 40 vs > 40 (low vs average or high support).⁴¹ In these analyses we included social support measured at the entry and, if available, year 3 visits.

Viral Suppression

We included all viral load measures assessed in the one-year period (range 3–15 months) following the social support evaluations at entry and, where available, year 3. We defined viral suppression as all measures during the one-year post-social support evaluation period < 50 copies/mL.

Covariates

We included age and medical insurance at entry and year 3 and self-reported sex, race and ethnicity in all regression models. We evaluated the completion of transition to adult clinical care (chart abstracted; yes, in adult care vs no, in pediatric care) as a potential effect modifier of the association between social support and viral suppression. Care transition status was assessed at entry and year 3.

Statistical Analyses

We summarized mean (standard deviation; SD and min-max) and median (1st and 3rd quartiles; Q1, Q3) emotional and instrumental social support and friendship T-scores, and the proportions with low, average, and high social support, overall and by age, sex, race, and ethnicity.

To estimate associations of social support with viral suppression, we used Poisson regression models with generalized estimating equations to account for repeated measures, using an exchangeable correlation structure. We fit separate univariable and multivariable models for each categorical social support measure.

We examined whether the effect of social support on viral suppression varied by care transition status, estimating effect modification on both the multiplicative (relative) and additive (absolute) scales.⁴² Here we evaluated the social support measures as dichotomous variables (low vs average/high). We included an interaction term in the regression models with each social support measure (high/average support=1; low=0) and care transition status (pediatric care=1/

adult care=0). We tested for multiplicative effect modification by calculating the ratio of the stratum-specific risk ratios ($=RR_{11} / (RR_{10} \times RR_{01})$). We tested for additive effect modification by calculating the RERI (relative excess risk owing to interaction; $RERI = RR_{11} - RR_{10} - RR_{01} + 1$).⁴² We performed statistical analyses using SAS[®] 9.4 (SAS Institute, Cary, NC).

Results

Four hundred forty-four young adults with PHIV were included in this analysis. Their median age at entry was 21.3 years (Q1, Q3=19, 25.5). Sixty-four percent of participants were female, 70% Black, 26% Hispanic (Table 1). Table 2 summarizes social support measures at entry, overall and by age group, sex, race, and ethnicity. Thirty-seven percent of the cohort reported low, 47% average, and 17% high emotional support, respectively; 32%, 57% and 10% reported low, average, and high instrumental support, and 36%, 50% and 14% reported low, average, and high friendship. Mean social support T-scores for all 3 measures were below 50 overall and for all subgroups (age, sex, race, ethnicity). Mean instrumental social support and friendship were higher for those 18–20 years than for older participants, and mean friendship was higher for males than for females. A smaller proportion of the youngest age group reported low instrumental social support or friendship. Participants who identified as Black were more likely to report low levels of emotional and instrumental support than those identifying as White or other race, while participants who identified as Hispanic were less likely than those who identified as non-Hispanic to report low emotional support. Thirty-one percent (N=136) of participants also had social support measured at year 3 (Table S1).

A median of 3 (range=1–12) viral load measures were available in the one-year period after entry, and a median of 2 (range=1–9) in the one-year period after year 3. Forty-four percent of participants were virally suppressed throughout the one-year period post-entry; 45% of those with year 3 data were suppressed over the subsequent year.

Table 3 summarizes the results of univariable and multivariable models. Participants with average or high levels of all three social support measures were more likely than those with low support to be virally suppressed. There were no differences specifically between those with high (T-score ≥ 60) versus average (T-score 41–59) social support in the proportion virally suppressed (emotional: adjusted risk ratio [aRR]=1.09; 95% confidence interval (CI)=0.87, 1.36; instrumental: aRR=0.86; 95% CI=0.63, 1.18; friendship: aRR=0.93; 95% CI=0.70, 1.25).

Table 1 Characteristics of AMP Up Participants at Entry Visit (N=444)

Age, Median (Q1, Q3), y	21.3 (19.0, 25.5)
Age category, n (%), y	
18–20	207 (47%)
21–24	116 (26%)
≥ 25	121 (27%)
Female sex, n (%)	282 (64%)
Race ^a , n (%)	
Black	313 (70%)
White	103 (23%)
Unknown	23 (5%)
Hispanic ethnicity ^b , n (%)	116 (26%)
Completed transition to adult care, n (%)	101 (23%)
Medical Insurance ^b	
Public	315 (72%)
Private	27 (6%)
Uninsured	33 (7%)
Participant does not know	58 (13%)

Notes: ^aOther race (n=5); ^bMissing observations: ethnicity (n=5), insurance (n=11).

Table 2 Social Support Measures at Entry Visit, Overall and by Demographic Characteristics (N=444)

Social Support Measure	Total (n=444)	Age at Entry (Years)			Sex ^a		Race		Ethnicity	
		18–20 (n=207)	21–24 (n=116)	≥ 25 (n=121)	Male (n=162)	Female (n=282)	Black (n=313)	White/Other (n=108)	Hispanic (n=116)	Not Hispanic (n=323)
Emotional										
Mean T-score (s.d.)	44.4 (12.0)	45.4 (12.1)	43.6 (11.7)	43.3 (12.2)	44.4 (11.8)	44.3 (12.2)	43.4 (12.0)	47.1 (11.9)	45.9 (11.6)	43.8 (12.2)
Minimum, maximum	13, 62	13, 62	13, 62	18, 62	18, 62	13, 62	13, 62	23, 62	21, 62	13, 62
Low [T-score ≤40; n (%)]	162 (37%)	68 (33%)	45 (39%)	49 (41%)	64 (40%)	98 (35%)	123 (40%)	33 (31%)	35 (30%)	125 (39%)
Average [T-score >40–59; n (%)]	207 (47%)	98 (48%)	56 (48%)	53 (44%)	72 (45%)	135 (48%)	143 (46%)	49 (45%)	60 (52%)	144 (45%)
High [T-score ≥60; n (%)]	73 (17%)	40 (19%)	15 (13%)	18 (15%)	25 (16%)	48 (17%)	45 (14%)	26 (24%)	21 (18%)	52 (16%)
Instrumental										
Mean T-score (s.d.)	45.1 (10.1)	47.7 (8.7)	43.2 (9.9)	42.4 (11.3)	44.6 (9.6)	45.3 (10.3)	44.4 (10.3)	47.3 (9.6)	46.3 (9.5)	44.8 (10.2)
Minimum, maximum	21, 63	21, 63	21, 63	21, 63	21, 63	21, 63	21, 63	21, 63	21, 63	21, 63
Low [T-score ≤40; n (%)]	143 (32%)	39 (19%)	49 (42%)	55 (46%)	61 (38%)	82 (29%)	109 (35%)	27 (25%)	33 (29%)	107 (33%)
Average [T-score >40–59; n (%)]	253 (57%)	143 (70%)	59 (51%)	51 (43%)	90 (56%)	163 (58%)	171 (55%)	67 (63%)	71 (62%)	180 (56%)
High [T-score ≥60; n (%)]	45 (10%)	23 (11%)	8 (7%)	14 (12%)	11 (7%)	34 (12%)	31 (10%)	13 (12%)	11 (10%)	34 (11%)
Friendship										
Mean T-score (s.d.)	46.0 (12.1)	48.0 (11.9)	43.6 (11.8)	44.8 (12.4)	48.2 (11.3)	44.7 (12.4)	45.3 (12.1)	47.8 (12.4)	47.0 (11.8)	45.6 (12.3)
Minimum, maximum	16, 68	16, 68	16, 67	16, 68	16, 68	16, 68	16, 67	20, 68	20, 68	16, 67
Low [T-score ≤40; n (%)]	158 (36%)	59 (29%)	50 (43%)	49 (40%)	49 (30%)	109 (39%)	117 (37%)	33 (31%)	41 (35%)	115 (36%)
Average [T-score >40–59; n (%)]	221 (50%)	106 (51%)	56 (48%)	59 (49%)	86 (53%)	135 (48%)	153 (49%)	56 (52%)	57 (49%)	161 (50%)
High [T-score ≥60; n (%)]	64 (14%)	41 (20%)	10 (9%)	13 (11%)	27 (17%)	37 (13%)	43 (14%)	18 (17%)	18 (16%)	46 (14%)

Notes: Missing observations: emotional (n=2), instrumental (n=3), friendship (n=1), race (n=23), ethnicity (n=5). ^aWomen constitute a larger proportion of AMP Up enrollees than men due to the co-enrollment of mothers with PHIV from the PHACS SMARTT (Surveillance Monitoring for ART Toxicities) study.

Table 3 Unadjusted and Adjusted Associations Between Social Support and Viral Suppression

Social Support Measure	Unadjusted Risk Ratio (95% CI)	Adjusted Risk Ratio (95% CI)
Emotional Support		
Low (T-score ≤40)	Ref.	Ref.
Average (T-score >40–59)	1.28 (1.04, 1.58)	1.25 (1.00, 1.56)
High (T-score ≥60)	1.41 (1.09, 1.80)	1.36 (1.05, 1.76)
Instrumental Support		
Low (T-score ≤40)	Ref.	Ref.
Average (T-score >40–59)	1.44 (1.17, 1.76)	1.54 (1.23, 1.92)
High (T-score ≥60)	1.26 (0.91, 1.74)	1.33 (0.93, 1.88)
Friendship		
Low (T-score ≤40)	Ref.	Ref.
Average (T-score >40–59)	1.35 (1.10, 1.66)	1.24 (1.00, 1.54)
High (T-score ≥60)	1.19 (0.88, 1.61)	1.16 (0.84, 1.60)

Abbreviation: 95% CI, 95% confidence interval.

Effect Modification on Associations of Instrumental Social Support with Viral Suppression

The association between instrumental support and viral suppression varied substantially by care transition status. On the additive scale (Figure 1), among those in pediatric clinical care, 51.2% (adjusted proportion) of those with average/high instrumental support were virally suppressed compared to 28.9% of those with low support (aRR=1.77,

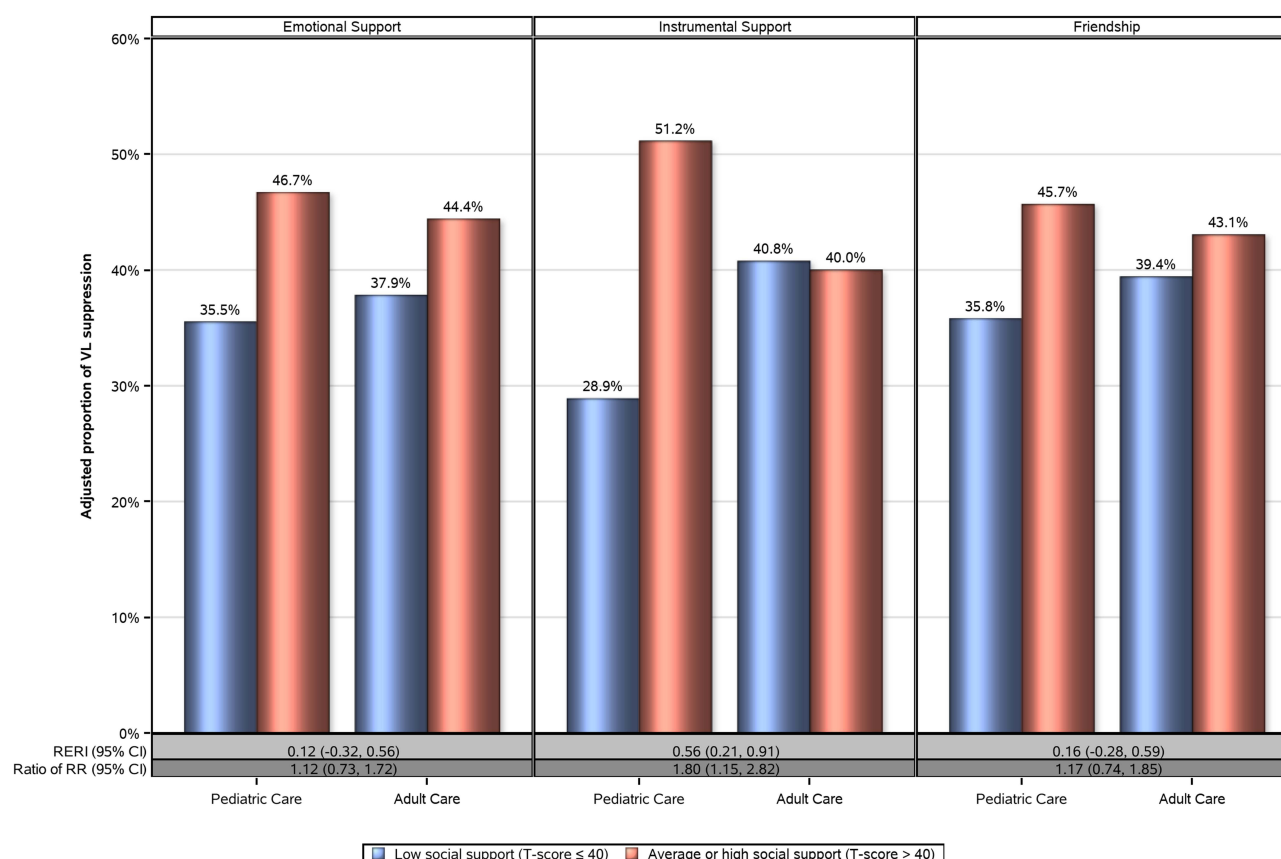


Figure 1 Effect modification by care transition status on social support. Y-axis represents adjusted proportion of viral suppression for each combination of social support and transition status strata. RR: Adjusted risk ratio of viral suppression comparing participants within each combined stratum of social support and transition status to the reference stratum (=low support + adult care). RERI (additive interaction) = (combined effect of transition status and social support) - (individual effect of transition status) - (individual effect of social support) + 1. Ratio of RR (multiplicative interaction) = (combined effect of transition status and social support) / (individual effect of transition status) * (individual effect of social support). Viral load measures assessed in the one-year period (3–15 months) following social support assessments at entry and year 3. Viral suppression was defined as all viral load measures over one-year period < 50 copies/mL. GEE Poisson regression models with exchangeable correlation structure were used to take into account repeat social support and viral load measures at entry and year 3. Separate models were fit for each social support measure, adjusting for age and medical insurance at AMP Up visit, sex, race, and ethnicity.

95% CI=1.37, 2.29). However, among those in adult clinical care, the adjusted proportion of viral suppression among those with average/high instrumental support was similar to those with low support (40.0% and 40.8% respectively; aRR=0.98, 95% CI=0.67, 1.44). The RERI (=0.56, 95% CI =0.21, 0.91) strongly indicates that on the additive scale, the estimated effect of average/high social support on viral suppression among those in pediatric care is larger than its effect among those in adult care. There was also evidence of effect modification on the multiplicative scale. The ratio of the stratum-specific risk ratios (1.80, 95% CI=1.15, 2.82) strongly indicates that the combined effect of having average/high social support and being in pediatric care is larger than the effect of having average/high social support and being in adult care. This effect modification was unchanged when restricting the analysis to young adults who were of similar age in both pre- and post-care transition groups (Figure S1). There was no effect modification evident by care transition status on the associations between either emotional social support or friendship and viral suppression, although the associations were somewhat stronger in the pre- versus post-transition period (Figures 1 and S1).

Discussion

In this large U.S.-based cohort of young adults with perinatally-acquired HIV, approximately one-third were below the average range for emotional or instrumental social support or friendship during early adulthood. Of particular concern, fewer than half of young adults had sustained viral suppression. This is consistent with previous observations of those with HIV, where viral suppression in late adolescence and young adulthood is lower than either earlier in adolescence⁹ or later in adulthood.^{43,44} Those who reported average or higher social support in their lives were more likely to have sustained viral suppression than those with low levels of support.

While low levels of all three types of social support were associated with reduced likelihood of viral suppression, the strongest association was with instrumental support, defined as the belief that there are people in one's life who can provide direct help with daily medical, household, transportation, or other tasks. For young adults who had not yet transitioned from pediatric to adult clinical care, those with low instrumental social support were less likely to have sustained viral suppression compared to those with higher levels of support. The time period spanning this transition is often an uncertain stage of life for those with lifelong chronic health conditions, with disruptions in health insurance coverage⁴⁵ and loss of child benefits.⁴⁶ Young persons with PHIV under the care of an attentive clinical team and family, and with consistent adherence to treatment and medical care appointments, can achieve and maintain viral suppression. When anticipating the transition to adult care, the young adult may begin to sense the loss of the relationship with their pediatric providers, who cared for them across childhood and adolescence. It may be challenging to consider developing a similarly supportive relationship with a new provider. This period also corresponds to that of emerging adulthood,⁴⁷ defined by new relationships and significant increases in responsibilities related to obtaining and maintaining employment, housing, and further education. The anticipation of these additional responsibilities, along with young adults' concern about losing their existing supportive relationships, may increase levels of stress and anxiety. This in turn may prompt inconsistent medication adherence, limited or absent health care participation, and eventual loss of viral suppression. Sufficient levels of social support during the pre-transition period may provide needed help in sustaining health care during this challenging period and also reduce the likelihood of anxiety and other mental health problems,⁴⁸ all serving to lessen the impact on viral suppression.

Adult-oriented clinical care for chronic health conditions may vary in the provision or linkage to other services such as mental health and sexual/reproductive health⁴⁹ for young adults affected by HIV. While many adult care programs provide comprehensive services and support, delayed or incomplete linkage to these services at the time of adult health care initiation may temporarily disrupt self-care among young adults with PHIV. This may be particularly true for persons experiencing stigma, mental health challenges, or poverty, as is often the case for young adults with PHIV,^{50,51} and may ultimately result in poor health outcomes.⁵² We might therefore expect that instrumental social support would continue to be important in maintaining viral suppression post-transition, but we did not observe this. The timing of social support may be just as important as the type or quality of support for certain outcomes. During important life transitions⁵³ or periods of heightened stress,⁵⁴ such as the period approaching transition to adult clinical care, social support might play a particularly important role. After care transition, other factors such as substance use, busier

schedules, impacts of social and health disparities, or concerns with HIV disclosure to new professional or romantic relationships, may become more consequential than social support in maintaining health care adherence and viral suppression.

Overall, there were no differences in viral suppression between those reporting average versus high social support, suggesting that it is specifically low or inadequate levels of support that are problematic. Two other studies in older adults with HIV had similar findings.^{21,55} Routine use of a brief measure of social support can be used to identify young adults with low support, particularly among those who are preparing to transition to adult clinical care. A recent review included a small number of interventions designed to increase psychosocial support among young persons with HIV.⁵⁶ None of the interventions specifically assessed viral suppression as an outcome, but several were associated with increased retention in care and ART adherence.

Young adults can also be encouraged to evaluate their current social support and taught skills to more effectively seek out support from existing networks.⁵⁷ But prior to helping young adults learn how to strengthen their networks, the causes of low support need to be addressed. Mental health or cognitive challenges, social anxiety, or structural barriers such as lack of health insurance, perceived or enacted HIV-related stigma and poverty may hinder young adults from accessing or maintaining current networks. Therefore, linkages to mental health treatment, for example, or teaching young adults how to effectively disclose HIV status in new relationships, are essential initial steps. And, new social support networks can be developed by linking young adults to peer navigators, liaisons, or social workers, individuals who can provide support not just for HIV-specific clinical care but also for mental health needs, housing support, employment, education, and reproductive health. Specifically in the period approaching the transition to adult health care, social support groups, peer mentors, and social workers can supplement or replace support from caregivers or pediatric providers that may be waning.

Strengths and Limitations

This study is based in the largest US cohort of young adults with PHIV. We used validated, standardized measures of social support and examined multiple types of perceived social support. This is one of the few prospective examinations of the relationship between social support and viral suppression,^{17,21,22} and the only one that used a validated measure of social support among young adults with HIV.

There are several limitations. We do not know whether participants were reporting support from family members, friends, or clinical providers, information which can be useful when creating strategies to enhance or expand individuals' available support networks. Sources of support might also differ pre- and post-transition and this may in part explain the differential effect of instrumental support across these different periods. We acknowledge the potential for selection bias since young adults not retained in clinical care may have had both lower social support and lower likelihood of viral suppression. We investigated this potential bias with a sensitivity analysis restricted to participants followed for years in an earlier PHACS cohort with high retention, and our results were similar. This suggests that selection bias had minimal effects on our observed results. The participants in AMP Up are a relatively highly supported group with a long history of care engagement, and many have been involved in clinical research since early childhood. Our results therefore may not be generalizable to young people without a history of supportive clinical or research care. Finally, this analysis used data collected before the COVID-19 pandemic, with its devastating effects on social support and access to medical care.^{58,59} We can only anticipate that there are more challenges to social support, mental health, and viral suppression that will warrant consideration moving forward.

Conclusion

Young adults with PHIV in the US who perceive low levels of social support in their lives are less likely to be virally suppressed. The role of instrumental social support in sustained viral suppression appears to be particularly important for young adults who have not yet transitioned to adult clinical care. The presence of sufficient and sustainable social support should be evaluated prior to the transition to adult health care and efforts should be made to support the development of autonomy and healthy relationships with adult care providers during this crucial period.

Acknowledgments

We thank the participants and families for their participation in PHACS, and the individuals and institutions involved in the conduct of PHACS. The study was supported by the *Eunice Kennedy Shriver* National Institute of Child Health and Human Development with co-funding from the National Institute on Drug Abuse, the National Institute of Allergy and Infectious Diseases, the National Institute of Mental Health, the National Institute of Neurological Disorders and Stroke, the National Institute on Deafness and Other Communication Disorders, the National Institute of Dental and Craniofacial Research, the National Cancer Institute, the National Institute on Alcohol Abuse and Alcoholism, the Office of AIDS Research, and the National Heart, Lung, and Blood Institute through cooperative agreements with the Harvard T.H. Chan School of Public Health (HD052102) (Principal Investigator: George R Seage III; Program Director: Liz Salomon) and the Tulane University School of Medicine (HD052104) (Principal Investigator: Russell Van Dyke; Co-Principal Investigator: Ellen Chadwick; Project Director: Patrick Davis). Data management services were provided by Frontier Science and Technology Research Foundation (PI: Suzanne Siminski), and regulatory services and logistical support were provided by Westat, Inc (PI: Julie Davidson).

The following institutions, clinical site investigators and staff participated in conducting PHACS AMP and AMP Up in 2019, in alphabetical order: Ann & Robert H. Lurie Children's Hospital of Chicago: Ellen Chadwick, Margaret Ann Sanders, Kathleen Malee, Yoonsun Pyun; Baylor College of Medicine: Mary Paul, Shelley Buschur, Chivon McMullen-Jackson, Lynnette Harris; Bronx Lebanon Hospital Center: Murli Purswani, Mahboobullah Mirza Baig, Alma Villegas; Children's Diagnostic & Treatment Center: Lisa- Gaye Robinson, Sandra Navarro, Patricia Garvie; Boston Children's Hospital: Sandra K. Burchett, Rebecca Pinsky, Adam R. Cassidy; Jacobi Medical Center: Andrew Wiznia, Marlene Burey, Ray Shaw; Rutgers - New Jersey Medical School: Arry Dieudonne, Linda Bettica, Juliette Johnson, Karen Surowiec; St. Christopher's Hospital for Children: Janet S. Chen, Taesha White, Mitzie Grant; St. Jude Children's Research Hospital: Katherine Knapp, Jamie Russell-Bell, Megan Wilkins, Erick Odero; San Juan Hospital Research Unit/Department of Pediatrics, San Juan Puerto Rico: Midnela Acevedo-Flores, Heida Rios, Vivian Olivera; Tulane University School of Medicine: Margarita Silio, Medea Gabriel, Patricia Sirois; University of California, San Diego: Stephen A. Spector, Megan Loughran, Veronica Figueroa, Sharon Nichols; University of Colorado Denver Health Sciences Center: Elizabeth McFarland, Carrie Chambers, Emily Barr, Mary Glidden; University of Miami: Gwendolyn Scott, Grace Alvarez, Juan Caffroni, Anai Cuadra.

Dr. Tassiopoulos had full access to all the data in the study and takes responsibility for the integrity of the data and the accuracy of the data analysis.

Note: The conclusions and opinions expressed in this article are those of the authors and do not necessarily reflect those of the National Institutes of Health or US Department of Health and Human Services.

*Dedicated to Dr. George Richard Seage III (1957-2021).

Disclosure

Dr Katherine Tassiopoulos, Ms Yanling Huo, Dr Deborah Kacanek, Dr Sharon Nichols and Dr Russell B Van Dyke report grants from the National Institutes of Health, during the conduct of the study; grants from the National Institutes of Health, outside the submitted work. Dr Kathleen Malee reports grants from the National Institutes of Health, during the conduct of the study. Dr Stephan Kohlhoff reports grants from the National Institutes of Health, during the conduct of the study; grants from Pfizer, grants from DiaSorin, outside the submitted work. The authors report no other conflicts of interest in this work.

References

1. Holt-Lunstad J, Smith TB, Layton JB. Social relationships and mortality risk: a meta-analytic review. *PLoS Med*. 2010;7(7):e1000316. doi:10.1371/journal.pmed.1000316
2. Rad GS, Bakht LA, Feizi A, Mohebi S. Importance of social support in diabetes care. *J Educ Health Promot*. 2013;2:62. doi:10.4103/2277-9531.120864
3. DiMatteo MR. Social support and patient adherence to medical treatment: a meta-analysis. *Health Psychol*. 2004;23(2):207–218. doi:10.1037/0278-6133.23.2.207

4. Gariépy G, Honkaniemi H, Quesnel-Vallée A. Social support and protection from depression: systematic review of current findings in Western countries. *Br J Psychiatry*. 2016;209(4):284–293. doi:10.1192/bjp.bp.115.169094
5. Kim SH, McDonald S, Kim S, Foster C, Fidler S. Importance of self-motivation and social support in medication adherence in HIV-infected adolescents in the United Kingdom and Ireland: a multicentre HYPNet Study. *AIDS Patient Care STDS*. 2015;29(6):354–364. doi:10.1089/apc.2014.0335
6. Power R, Koopman C, Volk J, et al. Social support, substance use, and denial in relationship to antiretroviral treatment adherence among HIV-infected persons. *AIDS Patient Care STDS*. 2003;17(5):245–252. doi:10.1089/108729103321655890
7. Haberer JE, Bwana BM, Orrell C, et al. ART adherence and viral suppression are high among most non-pregnant individuals with early-stage, asymptomatic HIV infection: an observational study from Uganda and South Africa. *J Int AIDS Soc*. 2019;22(2):e25232. doi:10.1002/jia2.25232
8. Williams PL, Storm D, Montepiedra G, et al. Predictors of adherence to antiretroviral medications in children and adolescents with HIV infection. *Pediatrics*. 2006;118(6):e1745–1757. doi:10.1542/peds.2006-0493
9. Kacanek D, Huo Y, Malee K, et al. Nonadherence and unsuppressed viral load across adolescence among US youth with perinatally acquired HIV. *AIDS*. 2019;33(12):1923–1934. doi:10.1097/QAD.0000000000002301
10. Damulira C, Mukasa MN, Byansi W, et al. Examining the relationship of social support and family cohesion on ART adherence among HIV-positive adolescents in southern Uganda: baseline findings. *Vulnerable Child Youth Stud*. 2019;14(2):181–190. doi:10.1080/17450128.2019.1576960
11. Amberbir A, Woldemichael K, Getachew S, Girma B, Deribe K. Predictors of adherence to antiretroviral therapy among HIV-infected persons: a prospective study in Southwest Ethiopia. *BMC Public Health*. 2008;8:265. doi:10.1186/1471-2458-8-265
12. Kalichman SC, DiMarco M, Austin J, Luke W, DiFonzo K. Stress, social support, and HIV-status disclosure to family and friends among HIV-positive men and women. *J Behav Med*. 2003;26(4):315–332. doi:10.1023/A:1024252926930
13. Lee S, Yamazaki M, Harris DR, Harper GW, Ellen J. Social support and human immunodeficiency virus-status disclosure to friends and family: implications for human immunodeficiency virus-positive youth. *J Adolesc Health*. 2015;57(1):73–80. doi:10.1016/j.jadohealth.2015.03.002
14. McDowell TL, Serovich JM. The effect of perceived and actual social support on the mental health of HIV-positive persons. *AIDS Care*. 2007;19(10):1223–1229. doi:10.1080/09540120701402830
15. Matsumoto S, Yamaoka K, Takahashi K, et al. Social support as a key protective factor against depression in HIV-infected patients: report from large HIV clinics in Hanoi, Vietnam. *Sci Rep*. 2017;7(1):15489. doi:10.1038/s41598-017-15768-w
16. Galvan FH, Davis EM, Banks D, Bing EG. HIV stigma and social support among African Americans. *AIDS Patient Care STDS*. 2008;22(5):423–436. doi:10.1089/apc.2007.0169
17. Simoni JM, Frick PA, Huang B. A longitudinal evaluation of a social support model of medication adherence among HIV-positive men and women on antiretroviral therapy. *Health Psychol*. 2006;25(1):74–81. doi:10.1037/0278-6133.25.1.74
18. Burgoyne RW. Exploring direction of causation between social support and clinical outcome for HIV-positive adults in the context of highly active antiretroviral therapy. *AIDS Care*. 2005;17(1):111–124. doi:10.1080/09540120412331305179
19. Knowlton A, Arnsten J, Eldred L, et al. Individual, interpersonal, and structural correlates of effective HAART use among urban active injection drug users. *J Acquir Immune Defic Syndr*. 2006;41(4):486–492. doi:10.1097/01.qai.0000186392.26334.e3
20. Knowlton AR, Arnsten JH, Gourevitch MN, et al. Microsocial environmental influences on highly active antiretroviral therapy outcomes among active injection drug users: the role of informal caregiving and household factors. *J Acquir Immune Defic Syndr*. 2007;46(Suppl 2):S110–119. doi:10.1097/QAI.0b013e31815767f8
21. Friedman MR, Coulter RW, Silvestre AJ, et al. Someone to count on: social support as an effect modifier of viral load suppression in a prospective cohort study. *AIDS Care*. 2017;29(4):469–480. doi:10.1080/09540121.2016.1211614
22. Kennedy MC, Kerr TH, Wood E, Shoveller JA, Montaner JSG, Milloy MS. Social and structural factors associated with greater time with a plasma HIV-1 RNA viral load above log₁₀(1500) copies/mL among illicit drug users. *AIDS*. 2018;32(8):1059–1067. doi:10.1097/QAD.0000000000001777
23. Scheurer D, Choudhry N, Swanton KA, Matlin O, Shrank W. Association between different types of social support and medication adherence. *Am J Manag Care*. 2012;18(12):e461–467.
24. Norberg M, Stenlund H, Lindahl B, Andersson C, Eriksson JW, Weinehall L. Work stress and low emotional support is associated with increased risk of future type 2 diabetes in women. *Diabetes Res Clin Pract*. 2007;76(3):368–377. doi:10.1016/j.diabres.2006.09.002
25. Hill M, Huff A, Chumbler N. Variation in networks and forms of support for care-seeking across the HIV care continuum in the rural Southeastern United States. *J Rural Health*. 2018;34(1):71–79. doi:10.1111/jrh.12238
26. Kafetsios K, Sideridis GD. Attachment, social support and well-being in young and older adults. *J Health Psychol*. 2006;11(6):863–875. doi:10.1177/13591053060069084
27. Maturo D, Powell A, Major-Wilson H, Sanchez K, De Santis JP, Friedman LB. Development of a protocol for transitioning adolescents with HIV infection to adult care. *J Pediatr Health Care*. 2011;25(1):16–23. doi:10.1016/j.pedhc.2009.12.005
28. Abrams EJ, Mellins CA, Bucek A, et al. Behavioral health and adult milestones in young adults with perinatal HIV infection or exposure. *Pediatrics*. 2018;142:3. doi:10.1542/peds.2018-0938
29. Kacanek D, Angelidou K, Williams PL, Chernoff M, Gadow KD, Nachman S. Psychiatric symptoms and antiretroviral nonadherence in US youth with perinatal HIV: a longitudinal study. *AIDS*. 2015;29(10):1227–1237. doi:10.1097/QAD.0000000000000697
30. Yusuf H, Agwu A. Adolescents and young adults with early acquired HIV infection in the United States: unique challenges in treatment and secondary prevention. *Expert Rev Anti Infect Ther*. 2021;19(4):457–471. doi:10.1080/14787210.2021.1829473
31. Patel K, Seage GR, Burchett SK, Hazra R, Van Dyke RB. Disparities in HIV viral suppression among adolescents and young adults by perinatal infection. *Am J Public Health*. 2019;109(7):e9. doi:10.2105/AJPH.2019.305108
32. Weijssenfeld AM, Smit C, Wit F, et al. Long-term virological treatment outcomes in adolescents and young adults with perinatally and non-perinatally acquired human immunodeficiency virus. *Open Forum Infect Dis*. 2022;9(11):ofac561. doi:10.1093/ofid/ofac561
33. Fair CD, Sullivan K, Dizney R, Stackpole A. "It's like losing a part of my family": transition expectations of adolescents living with perinatally acquired HIV and their guardians. *AIDS Patient Care STDS*. 2012;26(7):423–429. doi:10.1089/apc.2012.0041
34. Sharma N, Willen E, Garcia A, Sharma TS. Attitudes toward transitioning in youth with perinatally acquired HIV and their family caregivers. *J Assoc Nurses AIDS Care*. 2014;25(2):168–175. doi:10.1016/j.jana.2013.01.007
35. Leserman J. HIV disease progression: depression, stress, and possible mechanisms. *Biol Psychiatry*. 2003;54(3):295–306. doi:10.1016/S0006-3223(03)00323-8

36. Tassiopoulos K, Patel K, Alperen J, et al. Following young people with perinatal HIV infection from adolescence into adulthood: the protocol for PHACS AMP Up, a prospective cohort study. *BMJ Open*. 2016;6(6):e011396. doi:10.1136/bmjopen-2016-011396
37. Gershon RC, Cella D, Fox NA, Havlik RJ, Hendrie HC, Wagster MV. Assessment of neurological and behavioural function: the NIH Toolbox. *Lancet Neurol*. 2010;9(2):138–139. doi:10.1016/S1474-4422(09)70335-7
38. Cyranowski JM, Zill N, Bode R, et al. Assessing social support, companionship, and distress: national Institute of Health (NIH) toolbox adult social relationship scales. *Health Psychol*. 2013;32(3):293–301. doi:10.1037/a0028586
39. Salsman JM, Butt Z, Pilkonis PA, et al. Emotion assessment using the NIH Toolbox. *Neurology*. 2013;80(11 Suppl 3):S76–86. doi:10.1212/WNL.0b013e3182872e11
40. Babakhanyan I, McKenna BS, Casaletto KB, Nowinski CJ, Heaton RK. National institutes of health toolbox emotion battery for English- and Spanish-speaking adults: normative data and factor-based summary scores. *Patient Relat Outcome Meas*. 2018;9:115–127. doi:10.2147/PROM.S151658
41. National Institutes of Health and Northwestern University. Toolbox scoring and interpretation guide for the iPad; 2021. Available from: <https://nihtoolbox.my.site.com/s/article/nih-toolbox-scoring-and-interpretation-guide>. Accessed March 12, 2023.
42. Knol MJ, VanderWeele TJ. Recommendations for presenting analyses of effect modification and interaction. *Int J Epidemiol*. 2012;41(2):514–520. doi:10.1093/ije/dyr218
43. Mutevedzi PC, Lessells RJ, Rodger AJ, Newell ML. Association of age with mortality and virological and immunological response to antiretroviral therapy in rural South African adults. *PLoS One*. 2011;6(7):e21795. doi:10.1371/journal.pone.0021795
44. Ryscavage P, Anderson EJ, Sutton SH, Reddy S, Taiwo B. Clinical outcomes of adolescents and young adults in adult HIV care. *J Acquir Immune Defic Syndr*. 2011;58(2):193–197. doi:10.1097/QAI.0B013E31822D7564
45. Lotstein DS, Inkelas M, Hays RD, Halfon N, Brook R. Access to care for youth with special health care needs in the transition to adulthood. *J Adolesc Health*. 2008;43(1):23–29. doi:10.1016/j.jadohealth.2007.12.013
46. Callahan ST, Cooper WO. Continuity of health insurance coverage among young adults with disabilities. *Pediatrics*. 2007;119(6):1175–1180. doi:10.1542/peds.2006-1881
47. Arnett JJ, Žukauskienė R, Sugimura K. The new life stage of emerging adulthood at ages 18–29 years: implications for mental health. *Lancet Psychiatry*. 2014;1(7):569–576. doi:10.1016/S2215-0366(14)00080-7
48. Scardera S, Perret LC, Ouellet-Morin I, et al. Association of social support during adolescence with depression, anxiety, and suicidal ideation in young adults. *JAMA Network Open*. 2020;3(12):e2027491. doi:10.1001/jamanetworkopen.2020.27491
49. White PH, Cooley WC, Boudreau ADA. Supporting the health care transition from adolescence to adulthood in the medical home. *Pediatrics*. 2018;142(5). doi:10.1542/peds.2018-2587
50. Wiener LS, Kohrt BA, Battles HB, Pao M. The HIV experience: youth identified barriers for transitioning from pediatric to adult care. *J Pediatr Psychol*. 2011;36(2):141–154. doi:10.1093/jpepsy/jsp129
51. Lee S, Hazra R. Achieving 90-90-90 in paediatric HIV: adolescence as the touchstone for transition success. *J Int AIDS Soc*. 2015;18(Suppl 6):20257. doi:10.7448/IAS.18.7.20257
52. Agwu AL, Lee L, Fleishman JA, et al. Aging and loss to follow-up among youth living with human immunodeficiency virus in the HIV Research Network. *J Adolesc Health*. 2015;56(3):345–351. doi:10.1016/j.jadohealth.2014.11.009
53. Jacobson DE. Types and timing of social support. *J Health Soc Behav*. 1986;27(3):250–264. doi:10.2307/2136745
54. Helgeson V. Two important distinctions in social support: kind of support and perceived versus received. *J Appl Psychol*. 1993;23(10):825–845.
55. Chandran A, Bhondokhan F, Wilson TE, et al. Intensity of social support matters: a latent class analysis to identify levels of social support associated with optimal health outcomes among women living with HIV. *AIDS Behav*. 2021;26:243–251. doi:10.1007/s10461-021-03377-8
56. Okonji EF, Mukumbang FC, Orth Z, Vickerman-Delpont SA, Van Wyk B. Psychosocial support interventions for improved adherence and retention in ART care for young people living with HIV (10–24 years): a scoping review. *BMC Public Health*. 2020;20(1):1841. doi:10.1186/s12889-020-09717-y
57. Reblin M, Uchino BN. Social and emotional support and its implication for health. *Current Opin Psychiatry*. 2008;21(2):201–205. doi:10.1097/YCO.0b013e318282f3ad89
58. Long E, Patterson S, Maxwell K, et al. COVID-19 pandemic and its impact on social relationships and health. *J Epidemiol Community Health*. 2022;76(2):128–132. doi:10.1136/jech-2021-216690
59. Blumenthal D, Fowler EJ, Abrams M, Collins SR. COVID-19 - implications for the health care system. *N Engl J Med*. 2020;383(15):1483–1488. doi:10.1056/NEJMs2021088

Clinical Epidemiology

Dovepress

Publish your work in this journal

Clinical Epidemiology is an international, peer-reviewed, open access, online journal focusing on disease and drug epidemiology, identification of risk factors and screening procedures to develop optimal preventative initiatives and programs. Specific topics include: diagnosis, prognosis, treatment, screening, prevention, risk factor modification, systematic reviews, risk & safety of medical interventions, epidemiology & biostatistical methods, and evaluation of guidelines, translational medicine, health policies & economic evaluations. The manuscript management system is completely online and includes a very quick and fair peer-review system, which is all easy to use.

Submit your manuscript here: <https://www.dovepress.com/clinical-epidemiology-journal>