Youth in Transition: Life Skills Among Perinatally HIV-Infected and HIV-Exposed Adolescents

Sarah L. Pearlstein,1 BA, Claude A. Mellins,1 PhD, Curtis Dolezal,1 PhD, Katherine S. Elkington,2 PhD, E. Karina Santamaria,1 MPH, Cheng-Shiun Leu,1 PhD, Jennifer E. Cruz,2 PhD, and Elaine J. Abrams,3 MD

1HIV Center for Clinical and Behavioral Studies, New York State Psychiatric Institute and Columbia University, 2Special Needs Clinic, New York Presbyterian Hospital/Columbia University Medical Center, and 3ICAP, Mailman School of Public Health and College of Physicians and Surgeons, Columbia University

All correspondence concerning this article should be addressed to Claude Ann Mellins, PhD, New York State Psychiatric Institute and Columbia University, 1051 Riverside Drive, Box 15, New York, NY 10032, USA. E-mail: cam14@columbia.edu

Received May 10, 2013; revisions received September 4, 2013; accepted September 5, 2013

Objective To examine mastery of life skills necessary for independent adulthood among perinatally HIV-infected (PHIV+) and perinatally HIV-exposed but uninfected (PHIV−) youth. Methods Participants were recruited from four medical centers in New York City as part of a longitudinal study. Data for this article came from interviews of 150 PHIV+ and 95 PHIV− youth (age 13–24 years) and their caregivers. Life skills mastery was assessed using the Ansell-Casey Life Skills Assessment (ACLSA). Results PHIV+ youth had lower daily living skill mastery than PHIV− youth according to both youth and caregivers, and lower self-care mastery according to caregiver report. No HIV-status group differences were found in social relationships scores, but PHIV− youth had higher scores than an ACLSA benchmark sample. Conclusions PHIV+ youth may need supportive services in daily living and self-care needs to transition into adulthood. Normal-to-high functioning in social relationships may be important for learning to live independently.

Key words adolescence; life skills; pediatric HIV; young adult transition.

Introduction

Adolescents living with perinatal-HIV infection (PHIV+) face a unique set of challenges to navigating the years of transition to adulthood. As advances in medical management improve, children who are PHIV+ increasingly survive into adolescence and adulthood in the United States and globally (Centers for Disease Control and Prevention [CDC], 2013; Joint United Nations Programme on HIV/AIDS [UNAIDS], 2012). The question of what promotes a successful transition to independent living in this emerging population is now critically important to the families and providers who support them (Wiener, Kohrt, Battles, & Pao, 2011).

Research has indicated that PHIV+ youth comprise a population at risk for poor developmental outcomes, including impaired cognitive function and emotional and behavioral problems (Mellins & Malee, 2013; Smith et al., 2006; Wiener & Mellins, 2012). Many have experienced family disruption and changes in caregivers owing to parental substance use, illness, or death (Kang, Mellins, Dolezal, Elkington, & Abrams, 2011). They are frequently raised by a single parent, a biological relative, or an adoptive or foster parent (Bachanas et al., 2001; Malee et al., 2011). The vast majority of PHIV+ youth have grown up in impoverished communities affected by violence, substance abuse, neighborhood disintegration, and multiple stressful life events, including significant trauma (Kang et al., 2011).

Yet, despite the serious vulnerabilities associated with being PHIV+, some evidence suggests that these youth display resilience in critical areas. For example, several
studies have found relatively low rates of substance use in PHIV+ youth compared with national norms (Elkington, Bauermeister, Brackis-Cott, Dolezal, & Mellins, 2009; Mellins, 2013; Williams et al., 2010), and other studies report relatively late onset of sexual behaviors in PHIV+ youth (e.g., Bauermeister, Elkington, Robbins, Kang, & Mellins, 2012). Furthermore, although PHIV+ youth experience high rates of psychiatric disorders compared with national youth samples, several studies have found no differences in rates of psychopathology in PHIV+ youth compared with youth who were perinatally exposed to HIV but uninfected (PHIV−), or to HIV− youth with HIV+ family members (Gadow et al., 2010, 2012; Mellins et al., 2012). These findings suggest that PHIV+ youth may have coping mechanisms that help them transition through adolescence at least as successfully as demographically comparable uninfected peers.

One factor that may be a crucial determinant of successful transition into adulthood is the degree to which youth have acquired necessary life skills. Unfortunately, the majority of studies on PHIV+ youth have focused exclusively on risk outcomes (e.g., psychiatric disorders, unprotected sexual behavior) (Mellins & Malee, 2013). Few, if any, studies to date have focused on adaptive behaviors such as daily living skills, self-care behaviors and social skills, which have been important in other populations for independent living (Nollan, Pecora, Nurius, & Whittaker, 2002b). Understanding life skills among PHIV+ youth could be critical to informing future interventions to promote adaptive functioning in adulthood, not only for PHIV+ youth, but also for a host of other at-risk youth populations, including those with other chronic health conditions.

A number of factors may predict youth acquisition of transition skills. Variables of interest include mental health and cognitive abilities, since these have wide-ranging impact on functioning and have been identified as problem areas for PHIV+ youth in previous studies (Mellins & Malee, 2013; Smith et al., 2006). Additionally, because caregivers may play an important role in teaching life skills, caregiver characteristics could be important predictors of youth life skill mastery. These include whether the primary caregiver is a biological or an adoptive parent and the HIV status of caregivers, which may affect caregiver motivation and need for youth independence and thus the promotion of youth transition life skills.

To date, there are few measures to assess life skill mastery. Of those available, the Ansell-Casey Life Skills Assessment (ACLSA) is one of the few developed for vulnerable populations and for a wide age range (i.e., adolescence through early adulthood). In addition, the ACLSA is unique because “benchmark” data are available from similarly vulnerable youth from around the United States. We administered the ACLSA during structured interviews with youth and their caregivers as part of Project Child and Adolescent Self-Awareness and Health (CASAH), a relatively large cohort study of PHIV+ and PHIV− youth living in one of the US epicenters of the pediatric HIV epidemic, New York City (CDC, 2013). Given the psychosocial factors (described above) that place PHIV+ youth at risk for difficulty transitioning to adulthood, it is important to use comparison groups from similar vulnerable backgrounds. PHIV− youth have similar sociodemographic traits, including perinatal exposure to HIV, without actually being infected. This provides an opportunity to explore the unique contribution of perinatal HIV infection.

Using the ACLSA, we investigate life skills in the domains of daily living, self-care, and social relationships, with the following aims: (1) to describe the adult transition skills of PHIV+ and PHIV− youth; (2) to explore the potential demographic and psychosocial correlates of transition skills, including HIV status, academic functioning, and mental health; and (3) to consider data on life skills from this population in relation to findings from populations of uninfected youth. To fulfill our third aim, we compared life skills in the CASAH sample with the ACLSA benchmark sample of youth around the country who come from other vulnerable populations. Although there is no ideal comparison group for HIV-affected youth, given the complex backgrounds and factors that influence behavior, we made this comparison to lend perspective to the scores that CASAH youth attained.

We hypothesized that growing up with HIV infection would compound other life stressors and thus that PHIV+ youth would achieve fewer transition skills than PHIV− youth in all three areas of life skills under investigation. Given the high rates of mental illness and cognitive delays found in both PHIV+ and PHIV− youth in previous studies (Gadow et al., 2010, 2012; Mellins et al., 2009; Smith et al., 2006), we also hypothesized that better mental health and academic functioning would be associated with better transition skills.

**Methods**

**Participants and Procedures**

Data came from the second follow-up interview of a longitudinal study of PHIV+ and PHIV− youth, Project CASAH (Mellins et al., 2009). Participants were initially recruited from four NYC medical centers that provide primary and tertiary care to HIV-affected families. Inclusion criteria at baseline were (1) youth aged 9–16 years with perinatal
exposure to HIV (as confirmed by medical charts), (2) cognitive capacity to complete interviews, (3) English or Spanish speaking, and (4) caregiver with legal ability to sign consent for youth participation. Among 443 eligible participants, 11% refused contact and 6% could not be contacted by the clinics. A total of 367 (83%) caregiver–youth dyads were approached, 340 enrolled (206 PHIV+ and 134 PHIV−) and 325 (196 PHIV+ and 129 PHIV−) completed the full baseline interview. For the first follow-up interview (follow-up 1; FU1), 280 (86%) families (166 PHIV+ and 114 PHIV−) were enrolled, with a mean time interval of 18 months between baseline and FU1.

In the fifth year of CASAH, additional funding that was not initially planned was secured to continue to follow the CASAH cohort, re-recruiting families and engaging them in additional interviews (CASAH-2). All participants in CASAH were eligible to be contacted, and attempts were made by phone, mail, or through their pediatric HIV-care clinics. Participants were eligible for the second follow-up interview (follow-up 2; FU2) if they were (1) at least 13 years old and (2) it had been at least 1 year since they had completed their last CASAH interview.

As of August 2012, 312 (91%) of the 340 families enrolled at baseline had been contacted for FU2. Among the 312, 12 refused to participate, 2 had relocated outside New York State, 3 youth were incarcerated, and 38 could not be interviewed thus far due to participants’ scheduling conflicts, multiple cancellations, or caregiver changes. Among the 254 youth and/or caregivers who completed FU2, 245 had complete data on key variables for the current analyses (150 PHIV+ and 95 PHIV−). There has been no difference in attrition thus far owing to HIV status.

Data for this set of analyses came from caregiver and youth interviews from FU2, when the ACLSA was first administered. At FU2, youth ranged in age from 13–24 years. Caregivers and youth were interviewed separately but simultaneously by trained bachelor- and masters-level interviewers in English or Spanish. Institutional review board approval was obtained from all sites; caregivers provided written consent for themselves and youth. Youth provided written assent (or consent, if ≥18 years of age). Compensation for time and transportation was provided.

Assessments

Life Skills

The ACLSA is a self-report assessment of behaviors and abilities that are viewed as critical to meeting adult transition goals and living a healthy life (Nollan & Downs, 2000). It was originally developed to measure the capacity of youth raised in foster care to function independently once they have left the foster care system. Reliability and validity of the ACLSA have been established and presented in the ACLSA and Life Skills Guidebook Manual (Nollan, Horn, Downs, & Pecora, 2002a). We collected data from three domains of the ACLSA: daily living (e.g., “I can fix meals for myself on my own,” “I follow the basic fire prevention and safety rules for where I live”), self-care (e.g., “I can explain how to prevent pregnancy,” “I can describe two strategies for responsible drinking”), and social relationships (e.g., “I show appreciation for things others do for me,” “I am part of a group, besides my family, that cares about me”).

The ACLSA has separate versions for different age groups; most items are common across levels, but a few vary to reflect developmentally appropriate skills. Each version assesses the same domains. We used versions of the ACLSA that corresponded to three age ranges: 11–14 years, 15–18 years, and ≥19 years. Both youth and their caregivers reported on youth skills. For this investigation, the interviewer read each item aloud to the youth or caregiver who rated the items on a three-point scale, reporting whether each behavior was (1) not like the youth, (2) somewhat like the youth, or (3) very much like the youth. Following ACLSA procedures, we calculated mastery scores by totaling the percentage of items rated 3, “very much like the youth” for each domain. These scores reflect mastery of developmentally appropriate skills at the targeted age ranges (Nollan et al., 2002a) such that 50% skill mastery at one age is comparable with 50% mastery at another. Thus, mastery scores of different aged youth can be grouped together and mean scores can be calculated.

In addition to comparing mastery scores of PHIV+ and PHIV− youth, we also compared them to benchmark data, collected between January 2005 and March 2006 for >23,000 youth and 6,000 caregivers (ACLSA, 2006). Data were available on youth of the same ages as those in CASAH; the sample was ethnically diverse, with most of the youth in foster care. The sample also included some youth in the juvenile justice system, some homeless youth, and some in mental health settings. Currently, there are no normative data for the ACLSA. However, the ACLSA benchmark sample helps to place in context the mastery scores that CASAH youth attained, by providing a comparison group of different vulnerable youth populations.

Demographics

Demographics included youth and caregiver age, gender, ethnicity, and HIV status; caregiver education and relationship to the youth (e.g., biological vs. adoptive parent or relative); income; and youth placement changes.
Psychiatric Functioning

Youth psychiatric disorder was assessed using the Diagnostic Interview Schedule for Children (DISC-IV; generic parent and child versions; Shaffer et al., 1996), one of the most extensively used and well-validated structured diagnostic instruments to assess the most common diagnoses defined by the American Psychiatric Association’s Diagnostic and Statistical Manual of Mental Disorders (DSM) system (APA, 1994). We focused on the most common DSM-IV child/adolescent diagnoses including anxiety, mood, disruptive behavior, and substance abuse disorders (Hudziak, Copeland, Stanger, & Wadsworth, 2004; Lewinsohn, Shankman, Gau, & Klein, 2004). Youth and their caregivers were interviewed about the youths’ symptoms (presence or absence) in the past year. Previous work has found consistent discrepancies between youth and caregiver reports, with both showing partial validity (Achenbach, McConaughy, & Howell, 1987; Bird et al., 1998; Piacentini, Cohen, & Cohen, 1992). When both are considered, more valid outcomes are created and thus, based on the recommendations of the Bird et al. (1998) and Piacentini et al. (1992), criteria for a disorder were considered met if indicated by either the youth or the caregiver.

Cognitive Function

The Peabody Picture Vocabulary Test (PPVT-IV) is a widely used test of verbal ability, specifically receptive language of children and adults (Dunn & Dunn, 2007). The examiner reads a word aloud, and the youth chooses which of four pictures best illustrates the word; the process is repeated until the youth’s skill level has been determined. This measure has excellent psychometric properties, including reliability and validity and has been associated with overall cognitive function (Dunn & Dunn, 2007). Youth were also asked whether they had ever been in any kind of remedial education (yes/no), including remedial English, math, a special program for the educationally handicapped, and/or a dropout prevention program.

Data Analysis

ACLSA scores were calculated separately from the adolescent and the caregiver reports. Intraclass correlations were calculated to determine the degree of association between the scores from the two sources. PHIV+ and PHIV− youth were compared on various sample description variables using chi-square tests for categorical and t-tests for continuous variables (Table I). The bivariate association between ACLSA scores and study variables were assessed using t-tests for two-group comparisons and correlations for continuous variables (Tables II and III). Owing to the exploratory nature of these analyses and the limited data to date, no adjustment for multiple comparisons was done, and all associations at the .05 level are noted.

Multivariate regression analyses were conducted to determine the association between ACLSA scores and youth HIV status, after adjusting for youth age and gender, as well as history of a remedial education class, PPVT scores, and whether they had a psychiatric diagnosis, given the potential impact of cognitive and psychiatric function on daily living skills (Table IV). We did not include as covariates variables that were not associated with any ACLSA scores in bivariate analyses (e.g. race/ethnicity; see Results), nor did we include as covariates caregiver HIV status and caregiver relationship to youth, because there was significant overlap between these variables and youth HIV status. This overlap has been described in previous publications from CASAH as well as noted in other cohort studies (Malee et al., 2011; Mellins et al., 2009). In brief, given the study requirement that all children were born to an HIV+ mother, 100% of biological mothers were HIV+ by study definition. There were few fathers in the sample and thus the majority of biological parents were HIV+ mothers. Second, significantly fewer PHIV+ than PHIV− youth were living with their biological mother. Likely, HIV transmission occurred more often among sicker mothers, who were more likely to pass away early on in the US HIV epidemic owing to more limited treatment. Thus, only youth HIV status, the primary study variable, was included in multivariate analyses. Finally, we compared mean mastery scores for our sample (separately by HIV status) with a large benchmark norms sample. T-tests were used to compare the two groups on continuous ACLSA scores.

Results

Participant Description

A description of the sample is shown in Table I, separately by youth HIV status with few significant group differences. Half of the sample was female and almost all were African American or Latino. PHIV+ youth were significantly older than PHIV− youth [17.7 vs. 16.2; t = -4.33(243), p < .001]. PHIV+ youth were more likely to have attended a remedial education class and to have lower PPVT scores than PHIV− youth, although only the PPVT comparison was statistically significant [t = 3.22(241), p = .001]. The proportion having a DISC psychiatric diagnosis was similar for PHIV+ and PHIV− youth (43% vs. 46%, ns).

Youth–Caregiver Association/Concordance

Intraclass correlations on the ACLSA showed a weak association between scores based on the youth and caregiver reports. In daily living skills the intraclass correlation was
The lack of concordance between caregivers and youth is similar to previous studies that have measured life skills using the ACLSA (Casey et al., 2010). The decision was made, therefore, to analyze youth and caregiver results separately and not combine in a total score.

HIV Status Differences

Daily Living
PHIV− youth had significantly higher daily living scores than PHIV+ youth, according to both the youth and the caregiver reports \( t = 2.6(238), p = .010 \) and \( t = 2.3(164), p = .022 \), respectively (see Tables II and III). PHIV− youth reported mastering 53% of the daily living items, compared with 43% reported by PHIV+ youth.

Self-Care
There was no significant HIV status group difference on self-care according to youth report; PHIV− youth reported mastering 38% of the items compared with 54% for the PHIV+ youth. However, there were significant HIV status group differences in caregiver reports of youth self-care. Caregivers reported that PHIV− youth mastered 70% of
the self-care items, compared with 57% of the PHIV+ youth \[ t = 2.6(172), p = .010 \].

**Social Relationships**

There were no significant differences in average scores on social relationships scales according to either youth or caregivers. According to youth report, on average 64% of the social relationships items were mastered by PHIV– youth, compared with 61% for PHIV+ youth. According to the caregiver reports, PHIV– youth mastered an average of 67% of the social relationships items, compared with 59% for the PHIV+ youth.

### Other Sociodemographic Comparisons for the Entire Sample Combined

#### Daily Living

Based on youth report, significantly higher daily living scores were found among youth who were younger \( r = -0.308, p < .001 \), those who had not attended a remedial education class \( t = 2.9(238), p = .004 \), and those with an HIV+ caregiver \( t = -2.6(231), p = .011 \). Based on caregiver report, higher daily living scores were found among youth who were younger \( r = -0.163, p = .036 \) and female \( t = -2.6(164), p = .010 \), those without a
psychiatric diagnosis \( t = 2.1(155), p = .033 \), those who had an HIV+ caregiver \( t = -3.2(161), p = .002 \), and those whose caregiver was a biological parent \( t = -2.1(164), p = .035 \).

Self-Care
Based on youth report, self-care scores were significantly associated with older youth age \( r = .207, p = .001 \) and higher PPVT scores \( r = .305, p < .001 \). No associations were found between self-care and any sociodemographic variables based on caregiver report.

Social Relationships
Higher social relationships scores were found among youth without a psychiatric diagnosis according to both the youth and caregiver reports \( t = 3.5(173), p = .001 \). No other significant associations were found between ACLSA scores and any of the demographic or psychosocial variables in this area.

Multivariate Analyses
Multivariate regression results are shown in Table IV. After adjusting for youth age, gender, history of remedial education, PPVT scores and DISC diagnosis, youth HIV status was not significantly associated with mastery scores derived from youth report on any ACLSA subscale. From caregiver report data, youth HIV status remained significantly associated with daily living \( b = -10.4, SE = 4.7, p = .029 \) and self-care scores \( b = -11.9, SE = 5.5, p = .032 \), with PHIV+ youth scoring higher. Social relationships scores were not associated with HIV status, according to either youth or caregiver report, after adjusting for the same covariates.

Comparison to ACLSA Benchmark Sample
Table V shows the mastery scores of the current sample compared with the youth in the benchmark sample. All scores are presented separately by age (13–15 years and 16–18 years) for us to compare our findings with ACLSA benchmark data, which were only reported by specific age groups on the ACLSA Web site. Based on youth reports, both PHIV+ and PHIV− youth who were ≤15 years old scored significantly lower than youth in the benchmark sample in daily living and self-care. For older participants, both PHIV+ and PHIV− youth scored significantly higher than the benchmark sample on daily living, and PHIV+ participants scored significantly lower on self-care skills. Based on the caregiver reports, almost all of the comparisons were statistically significant, with CASAH participants scoring significantly higher than the benchmark sample in all three domains, regardless of youth HIV status.

Discussion
This study is the first that we know of that examines the adaptive skills necessary for transition to independent adulthood in a population of youth with perinatal HIV infection. Overall, and consistent with our primary hypothesis, we find that daily living and self-care skills may be areas of weakness for PHIV+ adolescents, indicating that interventions are needed in these domains. However, contrary to our primary hypothesis, the PHIV+ youth in our sample displayed potential strength in the area of social relationships, suggesting an area of resilience.

In the daily living skills domain (e.g., “I can fix meals for myself on my own”), even after adjusting for demographic and psychosocial factors, PHIV+ youth scored significantly lower than PHIV− youth, according to caregivers. This finding is of concern because daily living items largely assess knowledge of nutrition and meal preparation, which is particularly important for those coping with chronic illness. Evidence demonstrates that proper nutrition can play an important role in slowing the disease course in perinatal HIV (Campa et al., 1999) and other illnesses (e.g., cystic fibrosis: Borowitz, Baker, & Stallings, 2002; chronic hemodialysis: Ikizler, Wingard, Harvell, Shyr, & Hakim, 1999). The current data suggest an important need for providers to focus on nutrition, education, and healthy meal planning in their work with...
patients as the youth transition to adulthood to improve prognosis in this population.

On self-care scores, PHIV+ youth also scored significantly lower than PHIV− youth, according to caregiver report only. One possible explanation for the lower daily living and self-care scores is that caregivers may perceive PHIV+ youth as being less capable of self-care because of their health, leading them to report their PHIV+ youth’s skills as being less well developed than they truly are. Caregivers may also afford PHIV+ youth special care and protection owing to their illness, which could inadvertently hamper their youths’ life skills. This phenomenon has been reported in other populations of chronically ill youth. For example, Holmbeck et al. (2002) found that the parents of preadolescents with spina bifida tended to be more overprotective than the parents of their peers, which was correlated with negative outcomes in the youth, such as diminished autonomy in making decisions. Youth with PHIV infection and other chronic health conditions may be sheltered from the adult transition process for longer periods. As PHIV+ youth continue to reach older stages of adulthood, additional research is required to illuminate whether this delay is necessary or if it creates problems in adult function.

An alternative explanation for an HIV status difference in daily living and self-care skills is HIV-related impairment in cognitive functioning that may influence ability to care for oneself (e.g., Nichols et al., 2012; Smith et al., 2006). In this study, PHIV+ youth had lower scores on the PPVT, a measure of receptive language that is highly associated with overall cognitive functioning (Dunn & Dunn, 2007), and were more likely to have been in a remedial education class than PHIV− youth. Based on youth reports and corresponding with our hypotheses, lower scores on the PPVT were associated with lower self-care scores, and attending a remedial education class was associated with lower daily living scores. Thus, HIV-related effects on cognitive functioning may be implicated in the weaker life skills found in PHIV+ youth.

Although mastery of skills in daily living and self-care differed based on HIV status, social relationships scores were similar across the groups of PHIV+ and PHIV− youth. Social skills may be an area in which PHIV+ youth display resilience despite the heightened risks associated with being PHIV+, including stigma, elevated occurrence of psychiatric conditions, and more frequent enrollment in remedial education. Despite these risks, both groups of HIV-affected (PHIV+ and PHIV−) youth in the CASAH sample had greater mastery of social relationships compared with a national sample of youth from foster care and other vulnerable populations (see Table V).

One possible explanation is that the stress of living with HIV or of having a family member who is HIV+ may motivate youth to cultivate the skills necessary to develop a strong network of social support. Social support networks serve as a critical buffer against life stressors (Cohen & Wills, 1985) and may promote successful transition to adulthood.

As in previous studies (Mellins et al., 2009; Mellins & Malee, 2013), both PHIV+ and PHIV− youth had high rates of psychiatric disorders. Consistent with our hypothesis, youth without psychiatric disorders had better mastery of daily living skills according to caregivers, and had better social relationship skills according to both caregivers and youth. In multivariate regressions, the caregiver-reported difference in social relationship skills remained significant. However, the other associations, which were modest to begin with, failed to reach statistical significance after adjusting for various demographic variables, possibly owing to lack of power. These findings suggest that mental health is relevant to life skills, but there may be complex relationships between mental health and other variables like age, gender, and cognitive function. Future studies with larger sample sizes are needed to disentangle this interaction and clarify how mental health impacts life skills in PHIV+ youth and other chronically ill youth populations.

Youth with HIV+ caregivers had significantly higher mastery scores for daily living skills than those with HIV− caregivers, according to both youth and caregiver report. This may be because families of HIV-exposed youth with HIV+ caregivers may receive more supportive services than those with HIV− caregivers, which may allow them to teach life skills more effectively. Alternatively, because HIV+ caregivers have had to confront their own health problems, they may be more motivated to help their youth master life skills, or they may be better equipped to do so. However, due to the overlap between caregiver HIV status, caregiver type, and youth HIV status discussed above, it is difficult to determine the cause of this finding.

Concordance between youth ratings of their own life skills and caregiver ratings of the youths’ life skills was relatively low. Similarly low concordance has been observed in other studies using the ACLSA (Casey et al., 2010) as well as in studies measuring psychiatric disorder (Jensen et al., 1999) and substance use (Delaney-Black et al., 2010). The widespread disagreement between the information that youth and their caregivers report is a finding worth focusing on in future research. For example, it would be useful to investigate the validity of both reports at various ages, so that researchers can gain a clearer understanding of which source of information is more accurate at which developmental time point. If caregivers provide the more accurate
data, then the finding in this study that youth did not report any significant differences in life skills (after adjusting for demographic factors) may imply that PHIV+ youth lack insight into their skill deficits and do not know to seek support. Previous research with the ACLSA has suggested that youth do tend to overestimate their skills (Casey et al., 2010). Thus, providers may need to work with PHIV+ youth on transition skills over longer periods to help youth gauge their own skill mastery and engage in activities to improve adult transition. Providers may also need to help parents provide more autonomy to their children as they age.

It may be useful to examine levels of concordance as a potential predictor of youth outcomes. At least one study (Howard, Cross, Li, & Huang, 1999) has reported a relationship between parent–youth concordance and youth psychosocial functioning. Concordance between caregivers and youth may reflect quality of communication and level of involvement. It may even elucidate the extent to which caregivers are engaging youth in skills-based teaching about the transition to adulthood. Therefore, youth–caregiver concordance rates could be a key variable of interest for future interventions seeking to promote the mastery of youth life skills. Clearly, when parents and youth have a similar understanding of youth needs, parents may be better equipped to provide guidance and youth may be more receptive to receiving help moving forward.

A possible limitation of our study is the use of the ACLSA. We selected the ACLSA because it was one of the only tools available to measure life skills for adult transition. It has been widely used and validated (Nollan et al., 2002a), and many states use it to gauge preparedness to transition out of the foster care system (Heart Foundation, 2011). However, it has not been used extensively in other areas and there are no normative data available. The ACLSA benchmark scores are useful because they come from populations that are demographically similar to the CASAH cohort. However, because these populations were also at risk, it is difficult to understand whether the scores from CASAH indicate deficits, strengths, or normative function. These issues highlight the need for additional tools to assess life skills that are conducive to research as well as to monitoring clinical progress in vulnerable populations.

In summary, given the dramatic number of youth growing up HIV+ who will soon enter young adulthood worldwide (UNAIDS, 2012), the findings presented here provide a window into a new and critical area for promoting the wellbeing of PHIV+ youth: life skills needed for successful transition to independent living. Overall, the PHIV+ youth in our study are on par with PHIV− youth and even appear to compare favorably with other at-risk populations. However, findings across these populations, particularly among PHIV+ youth, identify some deficits in life skills and suggest important opportunities for intervention. Specifically, the data suggest a need for providers to work with PHIV+ youth and their caregivers to promote daily living and self-care skills enhancement, as well as age-appropriate opportunities for autonomy. PHIV+ youth have additional challenges to meet, beyond those typically required in adolescence, which include navigating romantic and social partnerships despite having a stigmatizing medical condition, adapting to changes in medical care, and managing their chronic illness. These are challenges that they may have difficulty meeting independently. For example, a large number of studies have investigated the specific self-care behavior of adhering to antiretroviral treatment and found increasing rates of non-adherence in PHIV+ youth as they age (Mellins, 2013; Usitalo et al., 2013). These findings are consistent with our results and further underscore the importance of ensuring that PHIV+ youth gain the skills to maneuver the additional complexities embedded in their transition to independent living.

Furthermore, these findings build on a body of previous research (e.g., Gadow et al., 2010; Malee et al., 2011) supporting the need for mental health services in PHIV-affected youth, as both PHIV+ and PHIV− youth in this study presented with high rates of psychiatric disorder (43–46%). For PHIV+ youth, families are often overwhelmed by health care appointments for multiple family members, and therefore, the integration of mental health services into primary health care settings may be crucial to improve access and acceptance of additional services (Havens & Mellins, 2008). Such integrative treatment would provide the opportunity to address not only psychiatric disorders but also skills deficits that may impair overall health, including poor adherence to antiretroviral treatment. Implementing interventions to support daily living and self-care skills alongside mental health treatment and within primary care settings may be an optimal strategy for promoting overall well-being in these youth as they continue along the developmental pathway to adulthood.

**Acknowledgments**

We wish to thank the youth and their caregivers who participated in this study.

**Funding**

This research was supported by a grant from the National Institute of Mental Health (grant number R01MH069133 to C.A.M.). The HIV Center for Clinical and Behavioral
Studies is supported by a center grant from the National Institute of Mental Health (P30MH43520). Katherine S. Elkington’s effort on this project was supported by a Career Development Award from the National Institute of Mental Health (grant number K01MH089832).

Conflicts of interest: None declared.

References


