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Barriers to Medication Adherence in Behaviorally and Perinatally Infected Youth Living with HIV

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Abstract

The study explored barriers to antiretroviral medication adherence in perinatally and behaviorally HIV infected adolescents and young adults in a cross-sectional, multisite sample. The study included a subset of a convenience sample from a cross-sectional analysis. Participants were youth with HIV ages 12–24 who were prescribed HIV medication and reported missing medication in the past 7 days ($n = 484$, 28.4 % of protocol sample). The top barriers were similar for perinatally and behaviorally infected youth, but perinatally infected youth reported significantly more barriers. Forgetting, not feeling like taking medication and not wanting to be reminded of HIV infection were the most common barriers reported. Number of barriers was significantly correlated with percent of doses missed, viral load, and psychological distress for perinatally infected youth and with doses missed, psychological distress, and substance use for behaviorally infected youth. Interventions to improve adherence to HIV medications should not only address forgetfulness and choosing not to take medications, but also consider route of infection.

Keywords

Antiretroviral medication adherence; Route of infection; Barriers to adherence; Youth living with HIV; Intervention development

Introduction

Nearly half of new human immunodeficiency virus (HIV) infections are among adolescents and young adults ages 15–24 [1]. With new guidelines resulting in earlier initiation of antiretroviral treatment (ART), adolescents and young adults (hereafter called youth) are quickly becoming the largest group of initiators of ART. Youth living with HIV are at particular risk of poor adherence to ART because they are in the midst of a developmental period characterized by less inhibition, increased risk-taking, and decreased parental support

and oversight [2]. A review of over 50 studies on pediatric HIV infection confirmed that 42–80 % of youth had suboptimal medication adherence [3]. However, few studies of medication adherence have focused specifically on adolescents and young adults living with HIV; moreover, few studies have included comparable samples of perinatally and behaviorally infected youth that allow assessment of the role of route of infection.

An estimated 10,000 perinatally HIV-infected youth in the United States are now aging into adolescence and young adulthood because of the success of ART [4]. Perinatally infected youth constitute a unique population with different treatment needs than youth with behaviorally acquired HIV. Many perinatally infected youth have long treatment histories and extensive drug resistance from years of ART therapy and inconsistent treatment adherence [4–6]. Perinatally infected youth are more likely to be in advanced stages of HIV disease and have more complicated ART regimens than their behaviorally infected peers. Perinatally infected youth also often face greater obstacles to functional autonomy because of physical or developmental disability resulting from long term infection with HIV and ART and greater dependency on family than behaviorally infected youth of similar age [5, 6]. In Rudy et al. [7] 25.5 % of perinatally infected youth identified themselves as non-adherent to HIV medication. Given these challenges, studies focused on medication adherence may need to consider route of infection and specifically assess similarities and differences underlying adherence in perinatally and behaviorally infected youth.

Since adequate medication adherence is necessary to achieve favorable health outcomes [8], it is important to understand the obstacles youth face in adhering to HIV medication regimens. Several studies have explored barriers to medication adherence in behaviorally infected youth or in mixed samples (behaviorally and perinatally infected youth). The REACH study [9] assessed self-reported barriers to HIV medication adherence in behaviorally-infected adolescents. In REACH, the most common reasons reported for nonadherence were forgetting, not having medication with them, and changes in daily routine [9]. MacDonell et al. [10] assessed perceptions of youths' temptation to miss taking HIV medications in various situations (e.g., when medication causes physical side effects, when there is fear of disclosure of HIV status) in a predominately behaviorally infected sample (83.3 % behaviorally infected). Youth reported that experiencing physical symptoms and side effects of the medication would tempt them to miss their HIV medications. However, these situations were not actually associated with poor medication adherence. Instead, lack of social support for taking medications, needing a break from taking medications, and not seeing a need for medications/perception of being able to stay healthy without HIV medications were associated with poor medication adherence. Rudy et al. [7] explored medication adherence in a cross-sectional sample of perinatally infected adolescents and young adults (ages 12–24). In this study, structural barriers including problems related to job or school and problems caring for children, and total number of structural barriers were associated with medication adherence.

The current study expands existing research by exploring self-reported barriers to HIV medication adherence in both behaviorally and perinatally infected adolescents and young adults who have demonstrated poor medication adherence. The study directly compared barriers to medication adherence within the largest multisite sample of youth living with HIV in the United States to date, using a comparable sample of perinatally and behaviorally infected youth. It is important to understand differences and similarities in barriers to adherence by route of infection to determine the need for tailored adherence interventions. We hypothesized that perinatally and behaviorally infected youth would differ in what they considered barriers to medication adherence. In addition, we anticipated that the association between reported barriers to adherence and other factors such as adherence, psychological distress, and viral load would vary by route of infection.

Methods

Participants

The study utilized data from a cross-sectional, multisite study conducted across 15 Adolescent Medicine Trials Units (AMTUs) in the United States participating in the Adolescent Trials Network (ATN). Data were collected as part of a cross-sectional study aimed at describing risk behaviors for HIV transmission (e.g., substance use) and protective factors (e.g., social support) in a large, nationwide sample of adolescents and young adults living with HIV in the U.S. The present study was based on secondary analysis of a sub-sample of this larger convenience sample. Participants were HIV-positive (perinatally or behaviorally infected) youth who were in care (new or existing patient) at an AMTU and/or its affiliate or partnering clinic. All youth had at least one clinic visit during the 1 year enrollment period of the study. Youth who participated were aged 12–24 years and aware of their HIV-positive status. Exclusion criteria included serious psychiatric symptoms, and appearing visibly distraught (e.g., violent behavior) or intoxicated at the time of consent/assent or data collection.

Protocol and Study Samples

The study utilized a subset of the full study sample and included those youth who were taking medication to treat HIV and had suboptimal medication adherence. The full study sample consisted of 1,707 participants. Of these, 993 (58.2 %) were currently taking medications to treat HIV ($N = 368$, 84.0 % of perinatally infected; $N = 548$, 48.8 % of behaviorally infected youth). Participants who were prescribed HIV medication and reported missing at least one dose of medication in the past 7 days and/or last weekend were included in the present study ($n = 484$, 28.4 % of the full sample; $n = 217$, 59.6 % of perinatally infected sample; and $n = 236$, 43.4 % of behaviorally infected sample). Thirty-one (6.4 %) of the study sample were unsure about their route of infection or had missing data so could not be categorized as behaviorally or perinatally infected.

Procedures

The protocol was approved by each study site's Institutional Review Board (IRB). A certificate of confidentiality was obtained from the National Institutes of Health. Participants were approached during a regularly scheduled clinic visit or during supportive activities. HIV infection was confirmed through documented test results from earlier HIV screening. Informed consent was obtained from all participants, as well as an IRB-approved waiver of parental/legal guardian permission for youth under age 18. Data collection occurred either immediately following consent, or within 2 weeks of obtaining consent if it could not occur during a single visit. Participant data were collected through biomedical chart extraction and/or laboratory evaluation and by using Audio Computer Assisted Self Interview (ACASI) technology via an Internet-based application. The participant was given headphones and a laptop computer in a private area. An AMTU staff member assisted with ACASI tutorials and was present in case a participant required a break. If the ACASI program was discontinued before completion, the participant's incomplete data were deleted. The participant could return within 2 weeks in order to re-enroll and retake the survey from the beginning. Participants received compensation for their time and transportation, as determined by the local IRB, for their participation.

Measures

Biomedical Information—Biomedical information was obtained through medical chart abstraction, including CDC Classification for HIV Disease, antiretroviral exposure history for the past 2 years, and the most recent HIV-1 viral load obtained within 6 months prior to

entry. Participants that do not have documentation of HIV-1 viral load measurement obtained within the previous 6 months had blood collected for this evaluation ($n = 12$, 2.5 %).

Route of Infection—Participants were asked “How do you think you got HIV?” in a multiple choice question format as part of the demographic questionnaire. Responses were coded into behavioral or perinatal route of infection. Responses of “I don’t know” or “other” were treated as missing data ($n = 33$, 6.8 %).

Medication Adherence—Participants were asked to estimate how many doses of HIV medication they had missed in the last 7 days. “Dose” was defined as the quantity of pills or medicines prescribed to be taken at one particular time. Participants were also asked the total number of doses per day of their HIV medication they were currently prescribed. Percentage of doses of HIV medication missed in the last 7 days was calculated as number of doses missed divided by weekly dosage.

Barriers to Medication Adherence—Participants completed a 19-item checklist of barriers to adherence medication measure adapted from a measure developed for the REACH study [9]. Youth were instructed “If you missed taking any pills over the last 7 days, what were some of the reasons (Please answer “yes” to anything that made it hard to take each and every dose of medication)”. Every barrier selected was assigned 1 point for a maximum possible score of 19. It is important to note that the barriers measure was only administered to those participants who reported missing medication in the last 7 days and/or last weekend.

Psychological Symptoms—Psychological symptoms were assessed by the Brief Symptom Inventory (BSI) [11]. The BSI yields nine primary symptom scales and global indices and has norms for adolescents and adults. The reliability, validity, and utility of the BSI instrument have been tested in more than 400 research studies. In the present study, the global severity index (GSI) T-score was used in analyses as both a continuous and dichotomous variable. A score of ≥ 63 on the GSI and/or any two dimensions was used as the clinical cut-off for psychological distress. The instrument developers did not specify a clinical cut-off, but advise that using the reference group of adult non-patients a T-score of ≥ 63 on the GSI and/or any two dimensions would merit further mental health evaluation [11].

Substance Use—The CRAFFT (Car, Relax, Alone, Forget, Friends, and Trouble) was used to assess the consequences of alcohol and/or marijuana use by adolescents and young adults [12]. This 6-item measure was designed for clinical settings. Scores of 2 or greater are suggestive of problem substance use, abuse or dependence. In the present study, the CRAFFT was included as both a continuous and dichotomous variable with scores of 2 or above considered problem substance use.

Data Analysis

Descriptive statistics were used to explore demographic variables in the full subsample and across groups by route of infection (perinatally infected vs. behaviorally infected). Independent samples t tests and χ^2 tests were conducted to assess differences by route of infection. Number of barriers to medication adherence was assessed for the full sub-sample and separately by route of infection. Bivariate correlations between number of barriers and other key variables were conducted by route of infection. Finally, the most frequently endorsed barriers to medication adherence were described for the full subsample and by route of infection, and χ^2 tests were used to compare percentages across groups. As

expected, viral load was highly skewed, so a logarithmic ($\log_{10}$) transformation was performed and used in subsequent analyses. All analyses were conducted using SPSS 19.0.

Results

Sample Characteristics

Table 1 details demographic variables for the full sub-sample and by route of HIV infection (behaviorally vs. perinatally infected). Participants ranged in age from 12 to 24 years (M (Mean) = 19.9 years, SD = 2.9). 21.5 % (n = 104) of the sample identified as having Hispanic or Latino heritage. Youth were asked how they identified beyond Hispanic/Latino ethnicity and 64.9 % self-identified as African American (n = 314), followed by Mixed Race (n = 63, 13.0 %), and White (n = 54, 11.2 %). A majority (58.5 %) were male (2.5 % transgender) and 57.4 percent of participants (n = 278) identified as heterosexual. Viral load ranged from below detection to 1,809,370 copies/ml, M = 23,638.28 (SD = 123,952.09). Median (Mdn) viral load was 95.00 with 50 % of viral load counts between 40.0 and 3565.0. Percent of doses of HIV medication missed in the last 7 days ranged from 0 to 100 % with M = 27.42 % (SD = 26.08). Problematic substance use ranged from 0 to 6, M = 2.37 (SD = 1.83), with 58.5 % at or above problem level use. Finally, 14.0 % of the sample was at or above the clinical cut-off for psychological distress.

Sample Characteristics by Route of HIV Infection

Two-hundred and seventeen participants (44.8 %) reported that they were perinatally infected, 236 (48.8 %) were behaviorally infected, and 31 (6.4 %) were unsure about their route of infection or had missing data. Among those behaviorally infected, most believed they acquired HIV through sexual behavior (97.5 %). Behaviorally infected participants were significantly older than perinatally infected participants, $t(449) = -16.03$, p .00. A larger percentage of behaviorally infected than perinatally infected participants were male ($X^2(1, 441) = 37.19$, p .00) and identified as a sexual minority (were other than heterosexual), $X^2(1, 453) = 169.50$, p .00. A significantly greater percentage of behaviorally infected participants had problem level substance use as indicated by the CRAFFT ($X^2(1, 439) = 34.98$, p .00) and were at or above the clinical cut-off for mental distress on the BSI ($X^2(1, 453) = 5.81$, p .05) than those perinatally infected. Participants who acquired HIV perinatally had a higher median viral load, Mdn = 244.00 copies/ml with 50 % between 48.0 and 6689.5 copies/ml (43.3 % were below detection at 500 copies/ml), while those behaviorally infected had a lower median viral load, Mdn = 50.00 copies/ml with 50 % between 20.0 and 1261.0 copies/ml (69.5 % were below detection). A significantly greater percentage of behaviorally infected participants had viral load below detection, $X^2(1, 452) = 8.36$, p .01. Perinatally infected participants had significantly higher viral load than those who were behaviorally infected, $t(450) = 3.48$, p .001. There was not a significant difference by route of infection for percent of doses of HIV medication missed in the last 7 days, $t(448) = -1.44$, p = .15. Percent of doses missed was significantly and positively correlated with viral load for both perinatally (r = .16, p .05) and behaviorally infected (r = .36, p .00) participants.

Number of Barriers to Medication Adherence

The number of barriers to medication adherence ranged from 0 to 19, M = 3.29 (SD = 2.53). Number of barriers varied significantly by route of transmission of HIV. Participants who were perinatally infected endorsed a mean of 3.68 (SD = 2.62) barriers while those who were behaviorally infected reported M = 2.97 (SD = 2.49) barriers, $t(436) = 2.88$, p .01. For perinatally infected participants, number of barriers was significantly correlated with percent of doses of medication missed in the last 7 days (r = .27, p .00), viral load (r = .27, p .00), and psychological distress (r = .38, p .00), but not with substance use (r = .10, p .00).

= .17). For behaviorally infected participants, number of barriers was significantly correlated with percent of doses missed ($r = .35, p = .00$), psychological distress ($r = .25, p = .00$), and substance use ($r = .14, p = .05$), but not with viral load ($r = .12, p = .08$).

Top Barriers to Medication Adherence

Table 2 shows the descriptive statistics for all possible barriers to medication adherence in descending order from most to least often endorsed for the full study sample and by route of infection. “Forgot” (73.6 %) was the most common reason for missing a dose of medications, followed by “Didn’t feel like it/needed a break,” (30.0 %) “Taking it reminds me of HIV,” (28.9 %) “Made me sick to my stomach/tasted bad,” (20.5 %) and “Ran out of prescription” (20.5 %).

The top barriers endorsed were similar for perinatally and behaviorally infected youth. Participants who were infected perinatally most frequently endorsed “Forgot” (75.1 %), followed by “Didn’t feel like taking it, needed a break” (39.2 %), “Taking it reminds me of HIV” (35.5 %), and “Made me sick to my stomach/tasted bad” (27.6 %). Participants who were infected behaviorally most often selected “Forgot” (72.9 %), “Didn’t feel like taking it/needed a break” (22.0 %), “Taking it reminds me of HIV” (21.6 %), “Ran out of prescription” (21.2 %), and “Worried that someone will find out about my HIV” (19.9 %). Though the top 3 barriers (“Forgot”, “Taking it reminds me of HIV”, “Didn’t feel like taking it”) were the same across groups, the frequency with which they were endorsed varied by route of infection for some items. The percentage of participants who endorsed “Forgot” did not vary significantly across groups (72.9 % of perinatal vs. 75.1 % of behavioral), but the percentage of participants who endorsed “Didn’t feel like taking it/needed a break” differed significantly by route of infection (22.0 % of behavioral vs. 39.2 % of perinatal), $X^2(1, N = 449) = 15.84, p = .00$. The percentage of participants who endorsed “Taking it reminds me of my HIV” also differed significantly by route of infection (21.6 % of behavioral vs. 35.5 % of perinatal), $X^2(1, N = 452) = 10.95, p = .001$. Though not among the top items endorsed, several other barriers were significantly different by route of infection. The percentage of participants endorsing the items “Made me sick to my stomach/tasted bad” ($X^2(1, n = 448) = 11.96, p = .001$) “Didn’t think I need the pills anymore, I can stay healthy without them” ($X^2(1, n = 448) = 9.56, p = .01$) “Nowhere to keep the pills at school or work” ($X^2(1, n = 452) = 3.93, p = .05$) “Don’t understand why I have to take the pills” ($X^2(1, n = 451) = 5.33, p = .05$) and “I keep getting sick even when I do take the pills” ($X^2(1, n = 451) = 8.57, p = .01$) were significantly different by route of infection. Perinatally infected youth endorsed all of these barriers more frequently than behaviorally infected youth.

Discussion

This study was among the first to explore barriers to medication adherence in a multi-site sample of perinatally and behaviorally infected youth living with HIV. Sampling procedures were successful in obtaining comparable numbers of non-adherent perinatally and behaviorally infected youth.

Barriers Across All Participants

In the current study, forgetting was overwhelmingly the most commonly endorsed barrier to adherence for both perinatally and behaviorally infected youth. Research has consistently found forgetting among the top reasons for poor adherence behavior in youth living with HIV [9, 10]. The second and third most frequently endorsed barriers in the present study (not feeling like taking it/needing a break and medication reminds of HIV) represent a conscious decision and specific reason not to take medication rather than simple forgetting. Though beyond the scope of the current study, it is possible that participants sometimes

reported that they “forgot” to take medications when, in reality, they made a decision not to take medications or had another reason for not taking medications. “I forgot” may sometimes represent a dismissive or evasive response for not taking medications rather than actual forgetting. This may be particularly relevant to youth with HIV given the developmental challenges, most notably asserting independence and increasing autonomy from caregivers and authority figures, faced during the transition to adulthood. Given that “forgetting” represents such a large proportion of the identified barriers, it is important to better understand what this barrier actually means to participants. Future research should explore “forgetting” to take HIV medications using emerging methodologies such as Ecological Momentary Assessment (EMA) [13], a set of methods used to collect data in a participant’s environment in “real time”. Other methodologies to consider include neuropsychological assessment and qualitative research. For instance, interventions targeting prospective memory (“remembering to remember”) may be important to address “forgetting” medications [14].

Consistent with previous research [8], youth with better medication adherence tended to have lower viral loads, regardless of route of infection. In addition, for both perinatally and behaviorally infected youth, higher total number of barriers was related to poorer medication adherence. Higher total number of barriers was also associated with higher psychological distress for both perinatally and behaviorally infected youth. This suggests that successful interventions should focus on youth with mental health symptoms as well as those reporting high numbers of barriers, regardless of route of infection.

Barriers for Perinatally Infected Youth

In the present study, perinatally infected youth reported significantly more barriers overall than behaviorally infected youth. In addition, only perinatally infected participants included feeling sick to the stomach/feeling bad among their top barriers. Perinatally infected youth tend to have longer histories of experience with the challenges of taking complex drug regimens and with the routine of chronic HIV medical care. Perinatally infected youth may also be more likely to be prescribed more complicated and less tolerable (i.e., more associated side effects) medication because many of these youth have accumulated significant HIV resistance, often making the antiretroviral regimens necessary for complete viral suppression more complex. Multiple studies have found links between physical symptoms or side effects associated with medications and medication adherence in adults and youth [10, 15, 16]. It is also important to note that for many perinatally infected youth, missing a dose of HIV medication may have a greater impact on medication efficacy than behaviorally infected youth because they are prescribed less potent medication regimens due to acquired resistance to HIV medication.

Multiple barriers were associated with viral load in perinatally infected youth only, though both perinatally and behaviorally infected youth had significant associations between adherence and viral load. It is possible perinatally infected youth are more likely to miss medications in the face of perceived barriers whereas behaviorally infected youth are more likely to persist. This may be due to the fact that perinatally infected youth tend to have more complicated ART regimens than behaviorally infected youth. In addition, research suggests that adherence may worsen in some patients over time after initiating ART [17].

Barriers for Behaviorally Infected Youth

Behaviorally infected participants were more likely than perinatally infected youth to be worried about stigma, or that someone would find out about HIV. Behaviorally infected youth may be adjusting to life living with HIV and dealing with issues related to fear of disclosure, stigma of living with HIV, and coping with new medication regimens. Research

has found strong links between stigma and depression, putting youth more at risk of poor treatment adherence [18, 19]. Interventions targeting stigma and fear of disclosure in youth living with HIV may help decrease barriers to healthy treatment adherence, particularly for youth who acquired HIV through behavioral means.

Importantly, a greater number of total barriers to medication adherence was associated with more substance use in behaviorally infected youth, but not in perinatally infected youth. This may be due to the higher rates of problem level use in this population [20]. Interventions for behaviorally infected youth may need to specifically focus on substance use as a key barrier to adequate medication adherence.

Study Limitations

Our findings are intended to be descriptive and should be replicated. Another limitation is that this study was conducted with a clinic-based convenience sample and may not represent community samples. In addition, we rely on participant retrospective self-report for measures of medication adherence, psychological health, substance use, route of infection, and barriers to adherence. It is important to note that patients may overestimate their medication adherence in self-report measures [21]. Future research might use alternative, “real time” methods such as Ecological Momentary Assessment (EMA) [13, 22] to assess medication adherence [23], barriers to adherence, and contextual variables such as mood and social support. Another limitation of this study is that we did not directly assess participants’ individual medication regimen histories, and we did not have access to caregiver data. Finally, our sample of behaviorally infected youth living with HIV was predominately male and gay/bisexual. While this is generally representative of the demographics of the current HIV/AIDS epidemic, it may make generalization difficult and confound comparison by route of infection.

Implications for Intervention

Results of this study support recent recommendations for medication strategies offered by the Panel on Antiretroviral Guidelines for Adults and Adolescents (Department of Health and Human Service) [24]. The Panel recommends that effective medication regimens should be simple (fewest doses per day and lowest number of pills), conform to patient and family routines, be palatable, and have the fewest side effects possible. Interventions to improve adherence to HIV medications should also consider route of infection, particularly differences in treatment histories and barriers to adherence. Importantly, more resources may need to be devoted to medication adherence interventions specifically targeting perinatally infected youth. Perinatally infected youth, who may have longer treatment histories marked by inconsistent adherence, reported more barriers overall and had higher viral loads. Unlike behaviorally infected youth, they endorsed physical symptoms as a barrier to adherence, so interventions should focus on physical side effects of medication in order to be effective. Interventions could also focus on increasing motivation in the face of unavoidable side effects, improving communication with providers to address side effects, and strategies to manage side effects such as relaxation and mindfulness [25]. In contrast, behaviorally infected youth endorsed fear of disclosure as a barrier, and substance use was related to barriers in this group only. Interventions addressing the development of adherence strategies in the face of fears about stigma and disclosure as well as those addressing multiple behavior change such as substance abuse and non-adherence [20] may be useful for behaviorally infected youth.

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References

1. Joint United Nations Programme on HIV/AIDS. Report on the global AIDS epidemic; Mexico City. International AIDS Conference; Aug. 2008
2. Arnett, JJ. Emerging adulthood: the winding road from the late teens through the twenties. New York: Oxford University Press; 2004.
3. Simoni JM, Montgomery A, Martin E, New M, Demas PA, Rana S. Adherence to Antiretroviral Therapy for pediatric HIV infection: a qualitative systematic review with recommendations for research and clinical management. *Pediatrics*. 2007; 119:e1371–83. [PubMed: 17533177]
4. Hazra R, Siberry GK, Mofenson LM. Growing up with HIV: children, adolescents, and young adults with perinatally acquired HIV infection. *Annu Rev Med*. 2010; 61:169–85. [PubMed: 19622036]
5. Koenig LJ, Nesheim S, Abramowitz S. Adolescents with perinatally acquired HIV: emerging behavioral and health needs for long-term survivors. *Curr Opin Obstet Gynecol*. 2011; 23(5):321–7. [PubMed: 21836510]
6. Foster C, Fidler S. Adolescents with perinatally acquired HIV-1 Infection. *Eur Infect Dis*. 2011; 5(1):10–6.
7. Rudy B, Murphy D, Harris R, Muenz L, Ellen J. Prevalence and interactions of patient-related risks for nonadherence to antiretroviral therapy among perinatally infected youth in the United States. *AIDS Patient Care STDs*. 2010; 24(2):97–104. [PubMed: 20059354]
8. Bangsberg DR, Perry S, Charlebois ED, et al. Non-adherence to highly active antiretroviral therapy predicts progression to AIDS. *AIDS*. 2001; 15:1181–3. [PubMed: 11416722]
9. Murphy DA, Sarr M, Durako SJ, Moscicki AB, Wilson CM, Muenz LR. Barriers to HAART adherence among Human Immunodeficiency Virus-infected adolescents. *Arch Pediatr Adolesc Med*. 2003; 157:249–55. [PubMed: 12622674]
10. MacDonell KE, Naar-King S, Murphy DA, Parsons JT, Huszti H. Situational temptation for HIV medication adherence in high-risk youth. *AIDS Patient Care STDs*. 2011; 25(1):47–52. [PubMed: 21162691]
11. Derogatis, LR.; Spencer, PM. The brief symptom inventory (BSI): administration, and procedures manual-I. Baltimore, MD: Clinical Psychometric Research;
12. Knight JR, Shriner LA, Bravender TJ, Farrell M, Vander Bilt J, Shafer HJ. A new brief screen for adolescent substance abuse. *Arch Pediatr Adolesc Med*. 1999; 53:591–6. [PubMed: 10357299]

13. Shiffman S, Stone AA, Hufford MR. Ecological momentary assessment. *Ann Rev Clin Psychol.* 2008; 4:1–32. [PubMed: 18509902]
14. Woods PW, Moran LM, Carey CL, Dawson MS, Iudicello JE, Gibson S, Grant I, Atkinson JH. the HIV Neurobehavioral Research Center (HNRC) Group. Prospective memory in HIV infection: Is “remembering to remember” a unique predictor of self-reported medication management? *Arch Clin Neuropsychol.* 2008; 23(3):257–70. [PubMed: 18243645]
15. Gonzalez JS, Penedo FJ, Llabre MM, Duran RE, Antoni MH, Schneiderman N, Horne R. Physical symptoms, beliefs about medications, negative mood, and long-term HIV medication adherence. *Ann Behav Med.* 2007; 34(1):46–55. [PubMed: 17688396]
16. Ammassari A, Murri R, Pezzotti P, et al. Self-reported symptoms and medication side effects influence adherence to highly active antiretroviral therapy in persons with HIV-infection. *J Acquir Immune Defic Syndr.* 2001; 28:445–9. [PubMed: 11744832]
17. Roux P, Kouanfack C, Cohen J, Marcellin F, Boyer S, Delaporte E, Carrieri P, Laurent C, Spire B. the Strata ANRS 12110/ESTHER Study Group. Adherence to antiretroviral treatment in HIV-positive patients in the Cameroon context: Promoting the use of medication reminder methods. *J AIDS.* 2011; 57(6S):S40–S43.
18. Tanney MR, Naar-King S, MacDonell K. Depression and stigma in high-risk youth living with HIV: a multi-site study. *J Pediatr Health Care.* in press.
19. Rintamaki LS, Davis TC, Skripkauskas S, Bennett CL, Wolf MS. Social stigma concerns and HIV medication adherence. *AIDS Patient Care STDs.* 2006; 20(5):359–68. [PubMed: 16706710]
20. Naar-King S, Kolmodin K, Parsons JT, Murphy DA. the ATN Protocol Team. Psychosocial factors and substance use in high risk youth living with HIV: a multisite study. *AIDS Care.* 2010; 22(4): 475–82. [PubMed: 20146112]
21. British HIV Association/Medical Society for the Study of Venereal Diseases (MSSVD). [February 12, 2012] Guidelines on provision of adherence support to individuals receiving antiretroviral therapy. 2002. <http://www.aidsmap.com/cms1032065>
22. Stone A, Shiffman S. Ecological momentary assessment (EMA) in behavioral medicine. *Ann Behav Med.* 1994; 16(3):199–202.
23. Haberer J, Kahane J, Kigozi I, Emenyonu N, Hunt P, Martin J, Bangsberg D. Real-time adherence monitoring for HIV antiretroviral therapy. *AIDS Behav.* 2010; 14:1340–6. [PubMed: 20809380]
24. Panel on Antiretroviral Guidelines for Adults and Adolescents. Guidelines for the use of antiretroviral agents in HIV-1-infected adults and adolescents. Department of Health and Human Services; Oct 14. 2011 p. 1-167. <http://aidsinfo.nih.gov/contentfiles/AdultandAdolescentGL.pdf>
25. Duncan LG, Moskowitz JT, Neilands TB, Dilworth SE, Hecht FM, Johnson MO. Mindfulness-based stress reduction for HIV treatment side effects: a randomized, wait-list controlled trial. *J Pain Symptom Manage.* 2012; 43(2):161–71. [PubMed: 21925831]

Table 1

Demographics of study subsample and by route of infection

Variable	Full subsample (N = 484)		Route of infection	
			Perinatal (n = 217)	Behavioral (n = 236)
	Range	M (SD)	Range	M (SD)
Age ^a	12–24	19.89 (2.93)	12–24	18.08 (2.64)
Viral load (log10) ^a	0–6.26	2.32 (1.58)	0–6.26	2.58 (1.53)
% doses missed	0–100 %	27.42 (26.08)	0–100 %	25.60 (25.01)
Substance use (CRAFT) ^a	0–6	2.37 (1.83)	0–6	1.87 (1.79)
Psychological distress (BSI GSI T Score) ^a	42.30–74.29	49.74 (6.02)	42.30–66.14	48.88 (5.36)
	n	Percentage	n	Percentage
Hispanic/Latino	104	21.5	48	22.1
African American	314	64.9 %	133	61.3 %
Mixed Race	63	13.0	31	14.3
Caucasian	54	11.2	30	13.8
Male ^a	283	58.5	98	45.2
Heterosexual ^a	278	57.4	193	88.9
Problem-level substance use ^a	283	58.5	96	44.2
Problem-level psychological distress ^a	68	14.0	23	10.6

^aSignificantly different by route of infection, *p* .05

Table 2

Barriers to medication adherence for full study sample and by route of infection

Barrier	Full subsample (% , N)	Perinatally infected (% , N)	Behaviorally infected (% , N)
Forgot	73.6, 356	75.1, 163	72.9, 172
Didn't feel like taking it, needed a break ^a	30.0, 145	39.2, 85	22.0, 52
Taking it reminds of HIV, want to forget ^a	28.9, 140	35.5, 77	21.6, 51
Made me sick to my stomach/tasted bad ^a	20.5, 99	27.6, 60	14.4, 34
Ran out of prescription	20.5, 99	17.5, 38	21.2, 50
Worried that someone would find out about HIV	16.3, 79	16.1, 35	19.9, 40
Got in the way of my daily schedule	15.5, 75	17.5, 38	14.4, 34
Family and/or friends don't help me remember	15.1, 73	17.5, 38	12.3, 29
Got another illness, wasn't feeling well	12.4, 60	14.7, 32	10.6, 25
Change in living situation, moved	10.7, 52	8.8, 19	12.7, 30
Can't get pill at drug store	11.2, 54	9.2, 20	12.7, 30
Get sick even when I take the pills ^a	10.2, 49	14.7, 32	6.4, 15
Don't understand why have to take the pills[4]	8.5, 41	11.5, 25	5.5, 13
Nowhere to keep pills at school or work ^b	8.3, 40	11.1, 24	5.9, 14
Didn't think I need the pills anymore ^a	7.6, 37	12.0, 26	4.2, 10
Did not have health insurance	6.4, 31	6.0, 13	6.8, 16
Got a headache, other physical symptom	6.0, 29	6.0, 13	6.8, 16
Family or friends say I shouldn't take them	1.7, 8	1.4, 3	2.1, 5
Other	23.3, 113	22.6, 49	24.2, 57

^aPercentage of participants endorsing significantly different by route of infection, $p < .01$ ^bPercentage of participants endorsing significantly different by route of infection, $p < .05$