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Adherence to Scheduled Appointments among HIV-Infected Female Youth in Five US Cities

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Abstract

Objective—Identify factors associated with appointment-keeping among HIV-infected adolescents and young adults.

Methods—HIV-infected adolescent and young adult females in five US cities were followed for a period of 18 months to examine adherence to scheduled clinic visits with their HIV care provider. Psychosocial and behavioral factors that have been shown in other populations to influence appointment adherence were measured at baseline and follow-up visits using an ACASI questionnaire. These factors included mood disorder, depressive symptoms, social network support, health care satisfaction, disease acceptance, HIV stigma, alcohol use, and marijuana use. CD4 count and prescription of ART medication were also monitored to understand the influence of health status on appointment-keeping.

Results—Participants included 178 youth with a mean age of 20.6 years. Forty-two percent had clinically significant depressive symptoms, 10% had a diagnosable mood disorder, 37% reported marijuana use in the last 90 days, and 47% reported alcohol use. Overall, participants attended 67.3% of their scheduled visits. Controlling for age and health status, marijuana use was the only variable that was associated with appointment-keeping behavior.

Conclusions—Considering the importance of appointment-keeping for maintaining personal health and preventing further transmission, screening HIV-infected adolescents for marijuana use could help alert providers of this specific barrier to visit compliance.

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INTRODUCTION

HIV/AIDS is the leading cause of death in young African American women 25–34 years old (Centers for Disease Control and Prevention [CDC], 2007). Many of these women became infected as adolescents and young adults. Efforts to reduce HIV-related morbidity and mortality in adolescents and young adult women require that they adhere to scheduled appointments. Regular attendance at scheduled medical appointments is necessary for medical treatment, behavioral interventions, and monitoring of CD4 counts and viral load levels. Individuals who miss medical appointments are more likely to have poorer HIV health status, including lower CD4 counts and higher viral loads. (1)

Little is known about appointment keeping behavior among HIV infected adolescent and young adult women. Studies examining appointment-keeping among adults with HIV infection report a substantial proportion of missed medical care appointments, with rates ranging from 12–36%. (2–4) One study of HIV-infected adolescents found that they missed 33% of their scheduled appointments over a six month period.(5) However these data were collected through a retrospective chart review and may not be reliable or valid. Prospective studies on adolescent and young adult women's adherence to scheduled appointments are needed.

Factors associated with missed appointments among HIV-infected adult patients include illicit drug use, HIV stigma, mental health disorders, less perceived social support, younger age, and less severe illness. (6;7) Dissatisfaction with the health care provider and transportation issues have also been linked to missed appointments.(8–10) However, few studies have examined determinants of appointment keeping in HIV infected adolescent and young adult women.

The objectives of this prospective study were to determine percentage of scheduled HIV care visits attended by HIV infected adolescent and young adult women in several cities around the US and to determine the effects of substance use, satisfaction with health care services, social network support, and mental health on appointment keeping.

METHODS

Participants

HIV-infected female adolescents aged 13–24 were recruited from five sites in the Adolescent Trials Network (ATN), New York City (Montefiore Medical Center, Adolescent AIDS Program), Miami (University of Miami/Jackson Memorial Medical Center), New Orleans (Tulane Medical Center), Chicago (Stroger Hospital of Cook County), and Los Angeles (Los Angeles Children's Hospital and University of Southern California). Eligibility criteria required that patients be engaged in HIV-related care at the recruitment site and that they were not infected through blood transfusion or vertical transmission.

Procedures

Approval for the study protocol was granted from each institution's human subjects review board. Adolescents interested in participating provided written informed consent. At some sites, parental consent was also required from participants younger than 18 years. Participants were followed for a period of 18 months. The recruitment period lasted from January 2003 through November 2004, and data collection was finished in May 2006.

Surveys were conducted at the clinical sites using an audio computer-assisted self-interview (ACASI) questionnaire at baseline, 6 months, 12 months, and 18 months. Baseline interviews took 2–3 hours to complete, and follow-up visits lasted 1–2 hours. Participants were compensated \$25–\$50 per study visit, varying by study site.

Measures

The primary outcome variable was appointment-keeping, defined by the number of clinic visits attended. These data were collected weekly using records maintained by clinic staff. Rescheduled appointments were not considered missed appointments as long as the participants attended the visit at the rescheduled date.

We collected demographic information at the baseline visit as well as data on psychosocial, perceptual, and behavioral predictors that had previously shown possible associations with missed appointments among different HIV+ populations. The alpha values listed below are for the current study population.

Mood disorder—was tested using the computerized version of the NIMH Diagnostic Interview Schedule for Children (DISC). The DISC covers five major categories of mental disorders: anxiety, mood, behavior, substance use, and other. Since previous research has focused on a possible association between depression and missed visits, we only considered the four mood disorders (major depression, mania, hypomania, dysthymia) in this paper. A binary variable was created and coded as “1” if the participant’s DISC score indicated any of the four mood disorders.

Depressive symptoms in the last week—were measured using the Center for Epidemiologic Studies Depression Scale (CES-D).⁽¹¹⁾ It is a 20-item self-report symptom rating scale developed at the NIMH to measure depressive symptoms in community surveys. Participants with a score over 16 were coded as experiencing depressive symptoms. ⁽¹¹⁾

Social network support—was measured using the adult version of the Social Provision Scale. ^(5;12) This questionnaire uses a 24-question, 4-point Likert scale ($\alpha = 0.91$) to assess six aspects of perceived social support, including attachment, social integration, reassurance of worth, guidance, reliable alliance, and opportunity for nurturance. We combined all aspects measured to obtain one measure of overall perceived social support. The total score from this scale ranges from 24 to 96 (maximum support).

Health care satisfaction—was measured using the Client Satisfaction Survey developed by The Measurement Group. ⁽¹³⁾ The 11 questions ($\alpha = 0.88$) assessed the participants’ opinion of the quality of services provided by their HIV care provider. Scores range from 11–45 with higher scores representing less satisfaction.

Acceptance of own HIV infection—was measured using a 6-item subscale of the Illness Cognition Questionnaire ^(5;14) ($\alpha = 0.92$) used to assess an individual’s perception of their capacity to accept and cope with their illness. Items include statements such as “I have learned to live with my illness” and “I can cope effectively with my illness.” Participants responded using a 4-point Likert scale. Scores range from 6–24 with higher scores indicating greater acceptance of HIV disease.

HIV stigma—was measured using two subscales from the HIV Stigma Scale ⁽¹⁵⁾ to create a 21 item questionnaire. The disclosure and negative self-image subscales were used as a representative sample to limit participant burden. Participants were asked for their degree of agreement with statements such as “People’s attitudes make me feel worse about myself” and “I never feel the need to hide the fact that I have HIV.” After reverse scoring appropriate items, we summed the disclosure and negative self-image scale to obtain a global measure of internalized stigma, Cronbach’s α for this summed scale was 0.90. Scores range from 21 to 84 with higher scores indicating higher perceived stigma.

Marijuana and alcohol use—was assessed by asking how often they had used alcohol or marijuana over the 90 days preceding the visit as part of the computerized questionnaire. Responses include 0 times, once a month or less, more than once a month but less than once a week, one or more times a week but not every day and every day. These responses were categorized into 3 groups by combining once a month or less with more than once a month but less than once a week, combining one or more times a week but not every day with every day and leaving 0 times as reference group. Two dummy variables were then assigned in the analysis for comparison to reference group. Participants also provided a urine sample at their baseline visit as a validation measure for recent marijuana use.

The CES-D and the questions on alcohol and marijuana use were repeated at each of the three follow-up visits (6-month, 12-month, and 18-month). The measures of health care satisfaction, cognition, social network support, and mood disorder were only repeated at the 12-month visit. Data on HIV stigma was only collected at the baseline visit.

In order to examine health status as a possible confounder for other predictors of appointment adherence, we used CD4 count and ART prescription as indicators of a participant's health condition. CD4 count was coded as a continuous variable, and ART medication status was coded as a binary variable. Since data on alcohol and depressive symptoms were collected at each six month visit, we calculated the mean CD4 count in each six-month period. We created four health status groups: CD4 $\geq$ 350 and not on ART medication (most healthy), CD4 < 350 and not on ART, CD4 $\geq$ 350 and on ART and CD4 < 350 and on ART (least healthy). The cut-off of 350 for CD4 count was used because this is the point at which providers are recommended to offer antiretroviral therapy.

Analyses

Hierarchical linear modeling was used to evaluate the effect of predictors on the number of scheduled appointments attended, our measure of appointment keeping. Individual level (level-2) variables were participant's age and baseline measures for mood disorder, social network support, health care satisfaction, acceptance of HIV infection, and HIV stigma. Measures collected at each visit were included as level-1 variables, including number of scheduled appointments, number of scheduled appointments attended, CD4 count, prescription of ART medication, depressive symptoms, alcohol use in the last 90 days, and marijuana use in the last 90 days (self-report). Number of scheduled appointments and participant's age were the controlling variables in all the hierarchical analyses. Assumption of random intercept and random slope on the association between number of scheduled appointments attended (outcome of interest) and number of appointments scheduled were applied.

Hierarchical modeling was applied to test the hypothesis that the overall health of the cohort did not change significantly over the 18-month study.

Because of the discrete outcome with higher frequency of low event counts (highly skewed), Poisson distribution as well as the dispersion parameter was applied to model the number of scheduled appointments attended in the hierarchical structure. Given that the outcome was number of event counts, the coefficients from the hierarchical model can be interpreted as the logarithm of the ratios of event rates for each unit increase in continuous predictors including social network support, health care satisfaction, disease acceptance and HIV stigma scores. As for binary predictors such as CES-D, mood disorder, marijuana and alcohol use, the coefficients from the model can be interpreted as the logarithm of the ratios of event rates of the predictor being present compared to being absent.

A series of analyses were first conducted to identify which psychosocial, perceptual, and behavioral predictors were associated with number of scheduled appointments attended,

controlling for age and number of visits scheduled. The variables associated in the analyses at $p < .05$ were then tested in final hierarchical model, controlling for age and number of visits scheduled in order to detect independent effects of these predictors. Hierarchical modeling was conducted using HLM software (version 6.04, IL).

RESULTS

There were 178 participants enrolled in the study: 28 were recruited at the Los Angeles sites, 39 from Chicago, 29 from New York, 41 from Miami, and 41 from New Orleans. Among the 178 enrolled participants, 122 (69%) had visit data for all 3 periods. Almost half (47%) of the participants with incomplete data were from the New Orleans site where follow-up was disrupted after Hurricane Katrina. Data regarding patients who refused to participate was not collected.

As shown in Table 1, at baseline, the mean age was 20.6 years ($SD = 2.1$, range 15–24). The study population was predominantly African American (92.2%), and 20.8 % of participants were of Hispanic origin. Forty percent of participants had at least GED or were high school graduates. Additional characteristics of the cohort are presented in Table 1.

Out of 130 participants who had urine testing for marijuana, 33 (25%) tested positive. Thirty-one of those with a positive urine test had data from both the self report and urine test, and 7/31 (23%) reported no MJ use past 90 days. Among those 97 who tested negative, 7 (7%) reported they used marijuana at least once a week and 18 (19%) reported use at least once in the past 90 days. As a result of these findings and data from the REACH study that indicate that self report was more sensitive than urine screening among HIV-infected youth, (16) we used the self-report variable in the analyses.

The mean number of clinic visits that were scheduled, attended, missed and unscheduled (attended) by the participants in each 6-month period is shown in Table 2. Over the 18-month study period, HIV-infected female adolescents attended an average of 5.0 medical visits with their HIV care providers in each 6-month time period, including those that were not scheduled in advance. The percentage of scheduled visits attended remained relatively constant, between 68.9% and 65.9%.

HLM showed that the mean CD4 counts ($p = 0.48$) and participants' probability of being prescribed ART ($p = 0.62$) did not change significantly over the course of the 18 month study. This indicates that the health status of the group remained stable during the 18 months.

Table 3 shows comparisons between participants by ART and CD4 count status, using patients who were not prescribed ART and who had CD4 counts ≥ 350 as the reference group. Those participants who were prescribed ART medication were more likely to attend scheduled visits than those not prescribed ART, controlling for participants' age and number of scheduled appointments. Among participants with CD4 counts ≥ 350 , those who were prescribed ART attended 15% more of their scheduled appointments. Among participants not prescribed ART, those with CD4 counts < 350 were less likely to attend scheduled visits, but the association was not statistically significant.

Marijuana use more than once a week ($RR = 0.86$) was the only other variable associated with the number of scheduled appointments attended. Controlling for ART status and CD4 counts, participant's age, and number of scheduled appointments, marijuana use remained significant in multivariate analyses ($RR = 0.87$; 95% CI 0.80–0.99). HIV stigma subscales were not significantly associated with the outcome of interest. Those participants who reported depressive symptoms, frequent alcohol use in the last 90 days, and mood disorder at baseline

attended less of their scheduled appointments than those who did not report these attributes, but the difference was not statistically significant.

DISCUSSION

Using prospective documented visit data, rather than self-report or chart review, we found that HIV infected adolescent and young adult women attend much higher number of medical visits (10.6 visits per year) than the average adolescent, who attends 3.3 medical visits per year. (17) The percentage of scheduled appointments attended by HIV-infected adolescent girls and young women is greater than the reported percentages of less than 50% for uninfected adolescents. (18–20)

One reason for the higher appointment adherence percentages in HIV infected adolescents and young adult women might be that they have formed strong relationships with their care providers through frequent visits. O'Brien and Lazebnik (21) found that adolescent patients who scheduled more appointments had a higher attendance rate, possibly because these patients are likely to be sicker and therefore have more incentive to keep appointments. This theory is consistent with our findings—those participants prescribed ART medications were more likely to attend scheduled visits, regardless of their age. It should not be surprising that those participants who had CD4 counts > 350 and were prescribed ART had the highest compliance rates—these participants seem to be responding to and benefiting from their adherence to medical advice. Further, it is possible that the patients who chose to participate in this study were more adherent to their visits than the overall patient population at these clinics.

We also found that prescription of ART and marijuana use in the last 90 days are the only factors that showed a significant association with missed clinical visits in HIV-infected adolescent female participants. The frequency of self-reported marijuana use over the last 90 days found in this cohort was in the range found in other studies of HIV-infected adolescents. (22;23) Conducting urine toxicology before completing questionnaires on substance use may have increased truth in reporting (having the effect of a bogus pipeline), (24) therefore increasing our ability to measure an association of marijuana use with medical visit adherence.

The observed association between marijuana and missed clinical visits may or may not be a direct cause and effect relationship. In other words, marijuana may have a direct effect in that individuals intended to go to their appointment, used marijuana, and then decided not to go to their appointment (a dis-inhibition hypothesis). Or, it might be that that marijuana has an indirect effect in that when individuals use marijuana they are engaged in some other social activity that distracts them from going to their appointment (context hypothesis). The current study design does not allow us to differentiate between the two pathways. The advantage of the longitudinal design is that it allows us to rule out the role of unmeasured dispositional factors as sensation seeking or other personality traits that might create a confounded and thus spurious association between marijuana and missed clinical visits.

One limitation of this study is that some of the variables were not measured at each six month visit, and therefore baseline measures were used to predict visit adherence over the eighteen month period. It is possible that the score given at baseline for something like disease acceptance does not reflect a participant's perceptions throughout the entire period.

Comprehensive services are needed to keep HIV-infected youth in care, (25) and patients known to use marijuana should be targeted for interventions aimed at decreasing risk behaviors. (26) The clinical implication that can be drawn from this study is that screening for substance use early among HIV-positive adolescents will assist clinic staff in 1) determining whether referrals to mental health providers or drug treatment programs need to be made, and 2) provide

care providers with information about which patients may need more support to ensure that they comply with medical visits.

As HIV infection has made the transition from an acute disease to a chronic condition it is critical to further our understanding of factors which influence HIV-infected adolescents' adherence to medical care. Closer examination of psychosocial factors influencing medicine compliance (27) and appointment-keeping are required to keep youth engaged in care.

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Table 1

Baseline characteristics of participants (N=178)

Age, mean (SD)	20.6 (2.1)
Hispanic Origin, %	20.8
Race – African American, %	92.2
Married, %	8.4
GED/High School Graduate, %	39.9
Currently Working, %	27.0
Ever Been Homeless, %	29.8
CES-D score ≥ 16 , %	42.1
Mood Disorder (indicated by DISC), %	10.4
Social Network Support, mean, SD (range)	74.5, 11.3 (30–96)
Health Care Satisfaction, mean, SD (range)	14.3, 4.3 (11–31)
Illness Cognition, mean, SD (range)	18.0, 4.9 (6–24)
HIV Stigma – mean, SD (range)	58.4, 12.1 (25–84)
Marijuana Use During past 90 days, %	
Never	62.7
At least once but less than once a week	19.8
More than once a week, including every day	17.5
Alcohol Use During past 90 days, %	
Never	53.4
At least once but less than once a week	41.0
More than once a week, including every day	5.6

Table 2

Mean (standard deviation) of number of scheduled, attended, missed and unscheduled visits by six month period

	1st Six Month period	2nd Six Month period	3rd Six month period	Mean per six month period
	(N=167)	(N=147)	(N=131)	
Scheduled	6.1 (4.7)	4.9 (4.3)	4.4 (4.1)	5.2 (4.4)
Attended	4.2 (3.7)	3.3 (3.5)	2.9 (3.0)	3.5 (3.5)
Missed	1.8 (2.2)	1.6 (1.9)	1.4 (2.1)	1.6 (2.1)
% attended visits	68.9%	67.3%	65.9%	67.3%
Unscheduled – attended	1.8 (2.8)	1.3 (3.6)	1.3 (3.7)	1.5 (3.3)
Total Attended	6.0 (5.4)	4.6 (6.0)	4.2 (5.4)	5.0 (5.6)

Table 3

Health, mental health, and behavioral predictors of kept appointments over the 18 month period: Odds Ratios (95% CI)

	Model 1*	Model 2**
ART Status and CD4 Count		
ART=0 and CD4 $\geq$ 350	Reference	Reference
ART=0 and CD4 < 350	0.93 (0.80,1.09)	0.96 (0.83,1.12)
ART=1 and CD4 $\geq$ 350	1.15 (1.02,1.28)	1.12 (1.00,1.26)
ART=1 and CD4 < 350	1.06 (0.92,1.21)	1.05 (0.91,1.20)
CES-D	0.95 (0.87,1.04)	
Marijuana Use During past 90 days		
Never	Reference	Reference
At least once but less than once a week	0.90 (0.78,1.02)	0.91 (0.80,1.04)
More than once a week, including every	0.86 (0.75,0.99)	0.87 (0.76,0.99)
Alcohol Use During past 90 days		
Never	Reference	
At least once but less than once a week	0.95 (0.86,1.04)	
More than once a week, including every	0.88 (0.74,1.05)	
Mood Disorder	0.95 (0.78,1.16)	
Social Network Support	1.00 (0.99,1.01)	
Health Care Satisfaction	1.01 (0.99,1.02)	
Illness Cognition	1.00 (0.99,1.01)	
HIV Stigma	1.00 (0.99,1.00)	

* Included single predictor and controlled for number of visits scheduled and age

** Included significant predictors from Model 1 and controlled for number of visits scheduled and Age