Predictors of Medication Adherence in High Risk Youth of Color Living with HIV

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Objective. To test predictors of medication adherence in high-risk racial or ethnic minority youth living with HIV (YLH) using a conceptual model of social cognitive predictors including a continuous measure of motivational readiness. Methods. Youth were participants in a multi-site clinical trial examining the efficacy of a motivational intervention. Racial-minority YLH (primarily African American) who were prescribed antiretroviral medication were included (N = 104). Data were collected using computer-assisted personal interviewing method via an Internet-based application and questionnaires. Results. Using path analysis with bootstrapping, most youth reported suboptimal adherence, which predicted higher viral load. Higher motivational readiness predicted optimal adherence, and higher social support predicted readiness. Decisional balance was indirectly related to adherence. Conclusions. The model provided a plausible framework for understanding adherence in this population. Culturally competent interventions focused on readiness and social support may be helpful for improving adherence in YLH.

Key words. Adherence; adolescents; HIV; minority populations; young adults.

Adolescents and young adults have one of the fastest growing rates of new HIV infection (Centers for Disease Control and Prevention [CDC], 2007). The rates of new and existing infections continue to be disproportionately higher in youth of color, particularly among African American and Latino adolescents and young adults (CDC, 2008). Recent advances in antiretroviral medications have allowed for dramatic improvements in life expectancy and health outcomes for youth living with HIV (YLH; Watson & Farley, 1999). However, these medications are only effective with near perfect rates (i.e., 90–95%) of adherence to the regimen. Suboptimal adherence to medication can lead to further complications such as infections and drug resistance (Mullen et al., 2002), and is associated with higher viral loads. The few studies of adherence to HIV medication regimens in adolescents and young adults suggest suboptimal adherence (59% in Murphy, Wilson, Durako, Muenz, & Belzer, 2001; 63% in Naar-King et al., 2006).

Studies of the factors related to medication adherence among YLH are limited, and studies specifically focused on medication adherence in racial or ethnic minority YLH are even more limited (Belzer, Fuchs, Luftman, & Tucker, 1999; Murphy et al., 2001). Murphy et al. (2001) conducted the REACH study, the first large-scale disease progression study of behaviorally infected YLH. In this sample, only 41% of youth reported full adherence to highly active antiretroviral therapy (HAART). Youth depression was strongly associated with nonadherence; however, there was no relationship between social support and adherence. In a study of much smaller scale, Belzer et al. (1999) found that 61% of YLH reported >90% adherence in the last 90 days. Youth who perceived that medications would improve and prolong their lives were more likely to be adherent.

In general, health behavior change during late adolescence and early adulthood has received little attention compared to other periods of lifespan development...
(e.g., childhood, early and middle adolescence, and adulthood). This lack of attention is problematic given that adolescence and early adulthood are developmental periods marked by experimentation and risk taking (Elkind, 1998). Emerging adults of color face unique challenges due to societal stereotypes regarding the competencies of racial or ethnic minority youth (Arnett, 2003). The transition into adulthood can be even more difficult for youth with chronic medical conditions, as many have to negotiate a transition of care as their parents become decreasingly involved and they shift from pediatric/adolescent medicine to adult-care settings (Weissberg-Bencell, Wolpert & Anderson, 2007).

In the few quantitative studies specifically focused on YLH, frequent substance use, advanced stage of HIV infection, younger age, life stressors (Murphy et al., 2005), psychological symptoms (Hosek, Harper, & Domanico, 2005; Naar-King et al., 2006; Williams et al., 2006), low self-efficacy (Naar-King et al., 2006), and perceptions of the effects of HIV medications (Belzer et al., 1999) have been linked to poor medication adherence. Conceptual models of adherence in YLH that are empirically tested are needed to understand the interrelationships among these factors. Researchers have called for theoretically driven and scientifically sound empirical adherence studies in pediatric psychology to integrate research and practice (Riekert & Drotar, 2000). These studies should address a range of risk and resiliency factors among specific groups of youth living with chronic illnesses (such as racial or ethnic minority YLH) in order to best inform future interventions (Harper & Hosek, 2003).

The Transtheoretical Model (TTM; Prochaska et al., 1994) has been suggested as a plausible framework for understanding medication adherence (Riekert & Drotar, 2000), though it has not been tested in pediatric/adolescent medicine populations to date. The TTM posits that motivational readiness to change behavior, or a continuum of an individual’s perception of how ready he/she is to change, precedes actual behavior change. While originally conceptualized as stages of change, critiques of the stage model (e.g., Littel & Girvin, 2002) suggest a more continuous conceptualization of motivational readiness (Migneault, Adams, & Read, 2005). Beyond motivational readiness, there are cognitive factors from the TTM that may be applicable to understanding adherence behavior. Cognitive factors that relate to increases in motivational readiness in the TTM include self-efficacy (confidence and avoiding temptation) and decisional balance (weighing the pros and the cons of behavior change). The purpose of the present study is to test a conceptual model of adherence behavior in YLH using variables from the TTM and from existing research on YLH.

We hypothesized that motivational readiness to adhere to medication regimens would be associated with better adherence. Higher self-efficacy and higher decisional balance scores (with pros of adherence outweighing cons) would predict increased motivational readiness and better adherence. Low social support and high levels of psychological symptoms were expected to relate to lower self-efficacy, lower decisional balance (cons of adherence outweighing pros), and suboptimal adherence. Higher decisional balance was expected to be associated with higher self-efficacy. Substance use was also assessed because of the high prevalence among YLH and its relationship to adherence in one study (Murphy et al., 2005). High rate of substance use was expected to be related to poorer adherence. Finally, optimal adherence was expected to predict lower viral load, the marker of disease progression most immediately impacted by adherence to HIV medications (Murphy et al., 2001).

Methods
Participants
Youth were participants in “Healthy Choices,” a randomized, multi-site clinical trial examining the efficacy of a motivational intervention aimed at reducing risk and promoting healthy behaviors in YLH. Inclusion criteria included HIV-positive status, aged 16–24 years, and ability to complete questionnaires in English. Because the study targeted high-risk HIV-positive youth, they had to have engaged in at least one of the three problem behaviors: a sexual risk problem (at least one unprotected sex act in the previous month); an alcohol or illicit drug use problem based on an adolescent medicine screener (CRAFFT; Knight et al., 1999); or a medication adherence problem (self-report of <90% adherence in the last month). Youth with an active thought disorder were excluded due to an inability to complete questionnaires. Youth who were currently involved in behavioral research (assessment or intervention) targeting adherence, sexual risk, or alcohol and/or drug substance abuse or who were involved in a substance abuse treatment program were also excluded from the study.

Youth were recruited from five study sites across the USA. All five sites offered comprehensive, multidisciplinary care including social work and case management services and access to mental health services. The Adolescent Trials Network (ATN) sites were located in Fort Lauderdale, FL; Philadelphia, PA; Baltimore, MD; and Los Angeles, CA. Additionally, a non-ATN site was located in Detroit,
Michigan. The sites were chosen to represent a regional cross-section of the population to promote the ability to test the effectiveness of the intervention and assure transportability. Indeed, the sample demographics were consistent with the national HIV/AIDS epidemic (CDC, 2008).

Only racial or ethnic minority youth (self-identified as African American, Latino, or mixed race) that were prescribed the HIV antiretroviral medication (N = 104 of 186) were included in the present study. Demographic information overall and by site is presented in Table I. Total 85% of youth self-identified as African American, 14% Latino, and 1% mixed race. From the sample 65% identified themselves as heterosexual, 11% as bisexual, 23% as gay, and 1% as other. Sexual orientation was treated as a dichotomous variable (gay, bisexual, or other vs. heterosexual) for subsequent analyses.

**Procedure**

The protocol was approved by each site’s institutional review board and 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. All participants were screened to confirm seropositivity or provided documented test results from a prior HIV screening. Informed consent was obtained from all participants, and a waiver of parental permission was obtained for youth aged 16 and 17 years. This waiver was approved by each site’s IRB board as part of the consent packet. Interviewers collected participant data using a computer-assisted personal interviewing (CAPI) method via an Internet-based application. Responses to CAPI questions were entered into the computer by the research interviewer. Upon completion of the baseline interview, the participants received $30 for their time. Food, childcare, and transportation to and from visits were also available for participants at no cost.

**Measures**

**Adherence to Medications**

Adherence was assessed using a visual analog scale from 0 to 100 (Giordano et al., 2004). Participants indicated the percent of time they took HIV medications, the percent of time they took HIV medications as directed (e.g., food restrictions), and how often they took all doses as prescribed for the day. Responses to these questions were averaged to form a composite percent adherence score for the past month. Adherence as assessed by this measure has been strongly correlated to plasma HIV RNA levels in prior studies (Naar-King et al., 2006).

**Viral Load**

Viral load (in HIV copies/ml of blood) was tested at the initial clinic visit unless a recent (within 1 month) test result was available from the participant. Because of a highly skewed distribution, viral load was log transformed.

**Decisional Balance**

To understand the decision-making process, attitudes toward adherence were measured using a 22-item measure that includes perceived pros and cons of adhering to HIV medications. This measure was based on the Decisional Balance Inventory (Velicer, DiClemente, Prochaska, & Brandenburg, 1985) and adapted for pros and cons of taking HIV medication (Parsons, Rosof & Mustanski, 2007). Respondents are given a number of reasons for taking or not taking their HIV medications and asked to rate the importance of each from 1 (“not at all important”) to 5 (“extremely important”). Higher decisional balance scores indicate more importance placed on reasons to take medications as prescribed. Cronbach’s $\alpha$ was .89 for this measure in the present sample.

**Self-efficacy**

Youth completed a 25-item instrument consisting of a combination of a temptation measure (22 items, reverse-coded) and a confidence measure (3 items). The temptation measure asks participants to use a 5-point Likert Scale to rate how confident they are that they could take their HIV medications on time under 11 circumstances (e.g., on vacation; out at night). The measure also asks about their temptation to miss their HIV medications under those same 11 circumstances. The measure was shown to have strong reliability and validity
in previous studies of HIV medication adherence (e.g., Parsons, Rosof, & Mustanski, 2008), and had excellent reliability in the current study with Cronbach’s \( \alpha = .92 \). The confidence measure assessed confidence to take medications as prescribed on a 5-point scale. The measure showed adequate reliability \( (\alpha = .81) \). Cronbach’s \( \alpha \) for the combined self-efficacy measure was .88.

**Motivational Readiness to Adhere to Medications**
The adherence to medications item from Rollnick’s Readiness Ruler (Stott, Rollnick, Rees, & Pill, 1995) was used to assess motivation for adherence. Respondents rated how ready they are to take HIV medications as prescribed on a scale from 1 (‘‘not ready’’) to 10 (‘‘ready to change or already changed’’). This measure has been recommended for use by clinicians to determine readiness to change in HIV care (CDC, 1993), and has been used for other behaviors in YLH (S. Naar-King, J. Parsons, D. Murphy, R. Harris, & K. Kolmodin, manuscript submitted for publication).

**Symptoms of Emotional Distress**
The Brief Symptom Inventory (BSI) measures nine primary symptom dimensions of physical and mental status combined to form the Global Severity Index (GSI; Derogatis & Spencer, 1982). The BSI asks respondents to rate how much they are distressed by a series of issues (e.g., lack of appetite, thoughts of ending your life) based on a 5-point response scale ranging from 1 (‘‘not at all’’) to 5 (‘‘extremely’’). Internal consistency for the BSI–GSI was excellent with Cronbach’s \( \alpha = .98 \).

**Social Support for Taking Medications**
A single item asking about social support specific to medication adherence (“There are people in my life that are supportive about taking HIV medication”) was rated on a 5-point Likert Scale from “strongly agree” to “strongly disagree”. This item was used because social support specific for reducing risk behaviors has been shown to be related to risk behaviors more than has general social support (Naar-King et al., 2006).

**Substance Use**
Actual alcohol and illicit drug use in the past 30 days was assessed using the Timeline Follow-Back (TLFB) procedure. A calendar assists participants in recalling when they used a particular substance and the amount used on each occasion. The TLFB procedure has demonstrated excellent psychometric properties in a number of studies (Carney, Tennen, Affleck, del Boca, & Kranzler, 1998) including correlation with urine drug screens (Fals-Stewart et al., 2000). Number of standard drinks (8 ounces beer, 4 ounces of wine, or 1 ounce hard liquor) and number of illicit drug use episodes were used for analysis.

**Data Analysis**
Descriptive statistics and bivariate analyses assessed simple associations between variables. Chi-square and t-tests were used to assess demographic differences across variables. Path analysis with bootstrapping was conducted (AMOS v7.0; Arbuckle, 2006) to examine the relations between the variables in the model and adherence to HIV medication. Path analysis rather than latent variable modeling was used because of the relatively small sample size. While SEM is often utilized with large samples \( (N > 200) \), bootstrap analyses allow model testing with small samples by utilizing the actual data to estimate standard error (Bollen & Stine, 1993). There is evidence that bootstrapping increases the power of the statistical results and is a particularly useful technique when sample sizes are small (Shrout & Bolger, 2002). Our sample size of 104 is reasonable for estimation of model effects (Kline, 1998), but certainly caution should be used in interpreting results due to the relatively small sample size.

In the path model, we tested whether social support, self-efficacy, and decisional balance predicted motivational readiness. We also tested if the associations between these three variables and our outcome variables, adherence and viral load, were mediated by motivational readiness. In addition to standardized root mean square residual (SRMR), comparative fit index (CFI) and root mean square error of approximation (RMSEA), and the Tucker-Lewis index (TLI) were used as fit indices as they are less sensitive to small sample size \( (n < 200) \) than other indices (Fan, Thompson, & Wang, 1999).

**Results**
**Descriptive Analyses and Bivariate Correlations**
 Seventy-nine percent of youth \( (N = 82) \) reported taking their prescribed antiretroviral therapy medications <90% of the time in the last month. Viral load ranged from 0 (below detection) to 750,000 copies/ml \( (M = 65,316.89, SD = 144,005.58) \) and a median of 8,500 copies/ml. Substance use did not vary by adherence status \( [\chi^2(1, n = 91) = 1.65, p > .10] \) and was excluded from subsequent analyses. Decisional balance scores ranged from \(-4.0\) to \(40.0, M = 18.07 (11.48)\). Average self-efficacy score was 7.91 (1.51; range 4.12–10.00). Motivational readiness ranged from 1.0 to 10.0, \( M = 8.44 (1.82) \). Social support ranged from 1.0 to 5.0 with \( M = 4.35 (0.99) \). Youth BSI scores averaged 56.82 (15.44; range 25.0–80.0). There were no significant differences between
biological males and females on any variable. Youth who identified as gay, bisexual, or other than heterosexual scored higher than heterosexuals on the BSI GSI, \(t(102) = -3.60, p < .01\). Sample demographics across the different study sites are detailed in Table I.

Motivational readiness (.21, \(p < .05\)) and viral load \((- .53, p < .01\)) were significantly correlated with adherence. Higher motivational readiness \((- .27, p < .01\)) and optimal adherence \((- .53, p < .01\)) were strongly associated with lower viral load. There were also a number of significant correlations among predictor variables. Youth BSI was not associated with any outcome or proposed predictor variable and was not included in the model.

**Path Analysis**

Both direct and indirect relations were evaluated using standardized regression weights. Model testing involved consideration of the hypothesized model (Figure 1) followed by modifications to improve parsimony. The hypothesized model resulted in an adequate fit, \(\chi^2(5, 104) = 9.41, p = .094, \text{RMSEA} = .093, \text{CFI} = .939, \text{SRMR} = .051, \text{TLI} = .816\), but a number of paths were not significant. A reduced model was estimated with non-significant paths \((p > .10\) deleted from the originally hypothesized model. Figure 2 shows the final model. Table II details the progression from the hypothesized model to the final, most parsimonious model. The final model had an acceptable fit with the data \(\chi^2 = 12.42; \text{df} = 9; p = .19; \text{CFI} = .95; \text{TLI} = .92; \text{RMSEA} = .06; \text{SRMR} = .07\). The model accounted for approximately 29% of the variance in viral load.

The reduced model demonstrated a number of significant associations among variables. Direct effects are detailed in Table III. Indirect effect significance levels were

![Figure 1. Hypothesized path model of adherence.](image)

**Table II. Progression of the Path Model**

<table>
<thead>
<tr>
<th>Step</th>
<th>Path removed</th>
<th>(\chi^2)</th>
<th>(p)</th>
<th>df</th>
<th>CFI</th>
<th>TLI</th>
<th>RMSEA</th>
<th>SRMR</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>–</td>
<td>9.4</td>
<td>.09</td>
<td>5</td>
<td>.94</td>
<td>.82</td>
<td>.09</td>
<td>.05</td>
</tr>
<tr>
<td>2</td>
<td>Social support (\rightarrow) self-efficacy</td>
<td>9.5</td>
<td>.15</td>
<td>6</td>
<td>.95</td>
<td>.88</td>
<td>.08</td>
<td>.05</td>
</tr>
<tr>
<td>3</td>
<td>Self-efficacy (\rightarrow) adherence</td>
<td>9.7</td>
<td>.21</td>
<td>7</td>
<td>.96</td>
<td>.92</td>
<td>.06</td>
<td>.05</td>
</tr>
<tr>
<td>4</td>
<td>Social support (\rightarrow) decisional balance</td>
<td>10.2</td>
<td>.25</td>
<td>8</td>
<td>.97</td>
<td>.94</td>
<td>.05</td>
<td>.06</td>
</tr>
<tr>
<td>5 (Final)</td>
<td>Decisional balance (\rightarrow) adherence</td>
<td>12.4</td>
<td>.19</td>
<td>9</td>
<td>.95</td>
<td>.92</td>
<td>.06</td>
<td>.07</td>
</tr>
</tbody>
</table>

**Table III. Final Path Model (Bootstrapping Results)**

<table>
<thead>
<tr>
<th>Path</th>
<th>Standardized (B)</th>
<th>Unstandardized (B)</th>
<th>SE</th>
<th>Bias(^a)</th>
<th>(p)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Social support (\rightarrow) motivational readiness</td>
<td>0.26</td>
<td>0.48</td>
<td>0.16</td>
<td>-0.01</td>
<td>.003</td>
</tr>
<tr>
<td>Decisional balance (\rightarrow) self-efficacy</td>
<td>0.36</td>
<td>0.05</td>
<td>0.01</td>
<td>0.001</td>
<td>&lt;.01</td>
</tr>
<tr>
<td>Decisional balance (\rightarrow) motivational readiness</td>
<td>0.18</td>
<td>0.03</td>
<td>0.02</td>
<td>0.001</td>
<td>.06</td>
</tr>
<tr>
<td>Self-efficacy (\rightarrow) motivational readiness</td>
<td>0.22</td>
<td>0.26</td>
<td>0.12</td>
<td>-0.004</td>
<td>.02</td>
</tr>
<tr>
<td>Motivational readiness (\rightarrow) adherence</td>
<td>0.21</td>
<td>4.36</td>
<td>2.01</td>
<td>-0.005</td>
<td>.03</td>
</tr>
<tr>
<td>Adherence (\rightarrow) viral load</td>
<td>-0.53</td>
<td>-0.03</td>
<td>0.004</td>
<td>0.001</td>
<td>&lt;.01</td>
</tr>
</tbody>
</table>

\(^a\)Bias refers to the difference between the average of estimates obtained from bootstrap samples and the estimate obtained from the original sample.
obtained through bootstrapping. As expected, optimal adherence predicted lower viral load. Higher motivational readiness significantly predicted optimal adherence to medications. Motivational readiness also has a significant indirect effect on viral load (−.11, p < .05). Higher self-efficacy was associated with higher motivational readiness. There was a trend towards higher decisional balance predicting higher motivational readiness (p = .06). Decisional balance was also significantly related to self-efficacy, and it had significant indirect effects on both adherence (.05, p < .05) and viral load (−.03, p < .05). In turn, higher levels of social support predicted higher motivational readiness. Social support also had trend-level indirect effects on adherence (.05, p = .07) and viral load (−.03, p = .07).

**Discussion**

The current study was among the first to explore predictors of adherence to medications in a multi-site sample of racial or ethnic-minority YLH. Youth in this study were in emerging adulthood, a developmental period often characterized by high rates of risk-taking behavior. The present study illustrated that risk-taking may extend to health behaviors. YLH reported suboptimal medication adherence despite the benefits of taking antiretroviral medications and the potential complications of not following the medication regimen. Our results support the link between self-reported adherence and health outcome in this population, as youth report of adherence was strongly associated with higher viral load.

Our conceptual model of adherence was a good fit for the data and provided a plausible framework for understanding adherence behavior in youth of color living with HIV. Our model may also guide the development of adherence interventions. Youth who reported higher motivational readiness were likely to have optimal adherence and lower viral load. Decisional balance was related to motivational readiness at trend-level. Social support to take medications was also included in the model. While it was not associated with self-efficacy or decisional balance, it was associated with the construct directly related to adherence, motivational readiness. Future research further assessing decisional balance and self-efficacy as well as other change processes would improve our understanding of the utility of this model for understanding adherence behavior.

Contrary to expectations, psychological symptoms were not associated with medication adherence, viral load, or any of the predictors included in the model. Previous research has found links between depression or psychological symptoms and decreased adherence (Hosek et al., 2005; Murphy et al., 2001). Perhaps we did not see associations with psychological symptoms because of our restricted range, as almost half the youth had clinical levels of symptoms. The REACH sample had lower rates of psychological symptoms (as measured by depression), but used a different measure of psychological symptoms (CES-D). Unlike our project, REACH did not include perinatally infected youth or youth older than 18 years, and had a majority female participants.

Similarly, while the REACH study found a relationship between substance use and adherence, our study did not. High rates of substance use have been found in the general population of YLH (Etzel, Lightfoot, Rotheram-Borus, & Swendeman, 2002). This may indicate that although substance use is a risky behavior, by itself it does not significantly influence medication adherence. Rather, underlying motivation and factors that influence motivation have the most impact on medication adherence and health outcomes. However, the presence of multiple risk factors, such as psychological symptoms and
substance use, could potentially have a cumulative impact on medication adherence (e.g., Koinis-Mitchell et al., 2007).

Although this study represents one of the first investigations of medication adherence in high-risk youth of color living with HIV, there are several limitations. This sample may be at higher risk than the broader population of YLH as they were recruited based on risky behaviors, and this may have influenced our findings regarding depression and substance use and their lack of association with adherence. This study was also conducted with a small clinic-based convenience sample, and may not represent community samples. The model should be tested using a larger sample size. Another limitation includes the reliance on self-report measures, particularly for adherence and substance use. An additional limitation is that social support was measured using a single-item, and given the complexity of this construct the findings regarding social support should be viewed with caution. Finally, longitudinal data are necessary to truly predict and understand adherence in this population.

Future research should continue to explore adherence to medications in youth of color living with HIV. Interventions to improve adherence and decrease health risks should be designed using culturally sensitive and developmentally specific frameworks, and address the range of factors that may compromise the health and well being of racial or ethnic minority YLH. Specific recommendations that have been offered for how to address issues of culture in primary and secondary HIV risk reduction programs (Harper, 2007) may also be applicable to adherence programs for racial or ethnic minority YLH. Our model provides a feasible framework for understanding adherence in older adolescents and young adults of color with other chronic medical conditions. Future research could further explore these factors beyond our at-risk group of racial or ethnic minority youth living with HIV and in the broader population of youth with chronic medical conditions.

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