Health Protective Behaviors among Young People Living with HIV/AIDS

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Abstract

Young people living with HIV/AIDS (YPLH) in the post-HAART era have the potential to manage their HIV as a chronic illness rather than as an almost inevitable terminal disease. However, little is known about behaviors YPLH can engage in to promote or protect health beyond taking anti-retroviral (ARV) medicines. The current study fills an important gap in existing research by identifying correlates of Health Protective Behaviors (HPB) within an urban sample of YPLH. Participants (n=134) were recruited from two pediatric clinics serving adolescents living with HIV who met the following criteria: HIV-infected and aware of their status, 13-24 years old, residing in the Washington, DC metropolitan area, currently prescribed ARV or due to begin ARV within 3 months, and able to understand and sign a written consent form. Each participant was interviewed via Audio computer-assisted self-interview (ACASI) and reported the percentage of possible time they engaged in six HPB during the prior month using a 10-point scale (e.g., 5=50%). Results indicate that most patients engaged in the measured health protective behaviors more than half the time, although patients 18 and older engaged in all HPB less frequently than their younger counterparts. Patients with adherence > 90% were far more likely to engage in HPB than those with poorer adherence. The age differences in HPB highlight a need for broader scaffolding in the transition to independent living and adult health care. Given the relationship between adherence and HPB, the establishment and maintenance of healthy lifestyle practices early in adolescence can translate into positive long-term health outcomes.

Keywords: HIV; Youth; Health behaviors; Adherence

Abbreviations: HIV: Human immunodeficiency virus; YPLH: Young people living with HIV/AIDS; HAART: Highly Active Anti-Retroviral Treatment; ARV: Anti-Retroviral; HPB: Health Protective Behaviors; ACASI: Audio Computer-Assisted Self-Interview; ANOVA: One-way Analysis of Variance

Introduction

Development of the multi-drug combination therapy known as HAART (highly active anti-retroviral treatment) profoundly changed how HIV was treated in the mid-1990s. In a span of less than 10 years, the death rate from HIV/AIDS declined by 50-80% [1] with numerous studies crediting the adoption of antiretroviral (ARV) medication for the marked and sustained reductions in AIDS-related morbidity and mortality rates [2-6]. HIV positive children and adolescents in the post-HAART era now have the potential to manage this disease as a chronic illness rather than as an almost inevitable terminal disease.

For good reason, much of the focus on secondary prevention for young people living with HIV (YPLH) has been directed at improving adherence rates to ARV treatment, given recent reports of the relationship between community viral load (i.e., average viral load within a population) and transmission rates [7]. However, adherence in YPLH has proven suboptimal, with adherence averaging 50% in YPLH within a population) and transmission rates [7]. However, adherence in YPLH has proven suboptimal, with adherence averaging 50% in YPLH [19]. These visits also provide important opportunities for providers to treat infections, extend reproductive and primary care, and address psychosocial concerns. Despite the significant consequences of not taking medications as prescribed, adequate adherence to ARV (anti-retroviral) medications (>95%) is especially challenging for YPLH.

Health Protective Behaviors

The foremost health protective behavior for people living with HIV is adherence to medication and medical appointment attendance. A critical component of HIV treatment, regardless of age, is attending quarterly medical appointments to monitor viral load [19]. These visits also provide important opportunities for providers to treat infections, extend reproductive and primary care, and address psychosocial concerns. Despite the significant consequences of not taking medications as prescribed, adequate adherence to ARV (anti-retroviral) medications (>95%) is especially challenging for YPLH.
because of their developmental status (e.g., inconsistent daily routine, not understanding the need to take medication when one feels well) [20, 21].

Living a healthy lifestyle also includes maintaining a healthy diet, exercising routinely, and getting adequate sleep. Diet and nutrition have been extensively studied in the larger HIV positive population, and a well-balanced diet (e.g., high in protein, fruits, vegetables and complex carbohydrates) as well as vitamin supplements have been proven effective for countering nutritional deficiencies and weight loss [22]. On the other hand, there is evidence that overweight/obesity is of concern among YPLH, particularly among those who have lipodystrophy, are living on their own, and/or have lower CD4+ T-cell counts, because of high frequency of sedentary activity (i.e., TV watching) and poor diet quality [23].

While research on physical activity among people living with HIV is more limited, the evidence suggests exercise programs can improve aerobic fitness without having negative effects on immune functioning [22,24]. In contrast to the detrimental effects of a sedentary lifestyle, aerobic exercise (~180 minutes/week) has been shown to improve physiological functioning (e.g., increase cardiorespiratory capacity) and lower cholesterol, as well as reduce symptoms of depression and anxiety [25]. Furthermore, actigraphy measurements of time spent exercising has been associated with reduced viral load [26].

Sleep also appears to be affected by HIV status. In a study of children (6-18 years old), those with HIV experienced poorer sleep quality (more wake after sleep onset) and took more naps than healthy matched peers. Such sleep disturbances may lower immunity among YPLH [27]. Elevated rates of fatigue and insomnia among HIV-positive adults [28,29] are linked to suppressed immune functioning [30]. In a small-scale study of adults with HIV on combination antiretroviral therapy, psychological distress was associated with poorer sleep quality which in turn was associated with lower T-cytotoxic/suppressor (CD3+CD8+) cell counts [31].

The current study fills an important gap in existing research by identifying correlates of HPB within a sample of YPLH attending adolescent HIV/AIDS clinics in Washington, DC. Guided by the Health Promotion Model [32], which postulates three sets of health behavior determinants (i.e., individual characteristics and experiences; behavior specific cognitions and affect; and situational/interpersonal influences), we focused this examination on differences in rates of HPB by individual demographic characteristics (i.e., age, gender, mode of transmission). Research on healthy adolescents suggests such behavior declines with age, and that there are some gender differences, particularly in terms of exercise [33,34]. We will also consider HIV characteristics (transmission mode, viral load) because these may limit youths' ability to engage in HPB (e.g., sicker youth may not feel well enough to engage in such activities), influence perceptions of self-efficacy (e.g., those with higher viral load may not believe HPB are as beneficial), and may be related to social support for HPB (i.e., perinatally-infected YPLH may have stronger ties to their healthcare providers and support from family) [35]. The results of this study will help demonstrate the importance of understanding and promoting HPB in this population.

Methods

Study site

The study was conducted at the Children's National Medical Center (CNMC) in Washington, DC. Participants were recruited between October 2009 and June 2010 from two pediatric clinics serving adolescents living with HIV from the geographic areas surrounding the District of Columbia, including Maryland and northern Virginia. One clinic is a sub-specialty clinic while the other is based on a primary care model clinic serving adolescents.

In terms of standard care related to HPB in these clinics, all providers review appropriate health promotional behaviors with patients as designated in a comprehensive health inventory which is incorporated in the electronic medical record. This inventory includes questions and counseling prompts on diet, exercise, safety, sleep, and risk behaviors. Additionally, each patient is assessed for nutritional needs at least once a year. Nutritionists meet with “low” risk/need patients every six months, “moderate” need patients every three months, and “high” need patients weekly/monthly. Along with setting individualized nutritional goals, the nutritionist may also counsel patients on exercise and physical activity goals. At subsequent visits, clinic nurses and physicians reinforce the recommendations of the nutritionist.

Study procedures

Each participant was interviewed on five occasions over the course of 12 months; only baseline data is reported here. The study protocol was reviewed and approved by the CNMC Institutional Review Board. The study received a waiver of parental consent from the IRB because adolescents receiving care for HIV at these clinics are able to consent for themselves due to the nature of their condition. Efforts to ensure understanding of the consent form included the completion of an Assessment of Understanding and a brief verbal survey regarding key points of the consent form. Research staff provided additional clarification of the consent form as needed.

Participants were introduced to the study and the study staff by their health care provider, either a nurse practitioner or their HIV specialist. Each individual was screened by the study personnel to meet the following inclusion criteria: HIV-infected and aware of their status, 13-24 years old, residing in the Washington, DC metropolitan area (or a temporary displaced resident), receiving care at the Burgess Adolescent Clinic or the Special Immunology Clinic, currently prescribed ARV medication or due to begin ARVs within three months of enrollment in the study, able to understand and sign a written consent form. Individuals who had acute or severe mental illness or less than borderline intellectual functioning per a clinician's assessment or full scale IQ scale <65 were not included.

After participants gave informed consent, audio computer-assisted self-interview (ACASI) surveys were administered in a private consultation room on a password protected laptop computer. The computer program reads each question and response options to the participant, listening via headphones, who then enters the chosen response via the keyboard. Prior to completing the survey questions, participants practiced on 5 sample questions, and trained research staff members were available in the room to answer any questions. Following the completion of each study visit, participants received compensation for their time (Baseline, 12 month visits- $30; 3, 6, 9 month visits- $20).

Measures

Demographic characteristics were collected via ACASI during the baseline study visit. Participants reported their gender (male, female, transgendered), age, ethnicity (Hispanic, not Hispanic) and race (American Indian or Alaskan native, Asian, Black or African American, Hawaiian or Pacific Islander, White, other), which was recoded as Black/African American vs. Other as the majority of the patients (91%) were Black/African American.
Research staff completed medical chart reviews at baseline to ascertain transmission mode (i.e., perinatal, behavioral, unknown) and viral load (tested within 11 days of ACASI).

Health protective behaviors were measured using six questions administered via ACASI. Participants reported the percentage of [possible] time they engaged in each behavior during the prior month using a 10-point scale (e.g., 5=50%). The specific behaviors included: "taking an HIV medication"; "taking other medicines or vitamins/supplements"; "keeping medical or health appointments"; "eating well-balanced meals complete with fruit and vegetables"; "sleeping at least 8 hours at night," and "exercising for at least 30 minutes at least three times per week." The minimum of ninety minutes of exercise per week was based on research citing the benefits of this level of aerobic training for adult patients living with HIV [36,37].

Data Analysis

First, descriptive statistics (e.g., means, standard deviations, frequencies) were calculated for all variables, and there was no evidence of skew or kurtosis requiring statistical transformation. One-way Analysis of Variance (ANOVA) was then used to examine the associations between HIV-related behaviors (ARV medication adherence >90%) and other HPB. ANOVAs were also conducted to test for differences in self-reported rates of HPB across age, gender, HIV transmission mode and viral load categories. Finally, seven multivariate linear regressions were conducted to test the independent associations of demographic and HIV characteristics with each of the HPB.

Results

Table I provides descriptive statistics characterizing this sample. The majority of adolescents participating in this study were over 15 years old (n=112, 84%), male (n=78, 58%), African American (n=122, 91%), and had contracted HIV perinatally (n=7, 72%). These demographic characteristics are representative of the larger population YPLH in Washington, DC [38]. Half of participants (n=66, 49%) had viral loads <500 copies/mL. The vast majority had prescriptions for ARV medications (n=124, 93%).

In the past month, this sample, on average, reported attending scheduled healthcare visits 75% of the time, taking their ARV medications 57% of the time, more frequently took other medicines/vitamins/supplements, kept medical appointments, ate a well-balanced diet 64% of the time, getting 8 hours of nighttime sleep 61% of the time and engaging in regular exercise 55% of the time, on average.

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Table II shows that participants who adhered to their ARV medication 90% of the time, more frequently took other medicines/vitamins/supplements, kept medical appointments, ate a well-balanced diet, and got regular exercise compared to those who were less adherent. ARV medication adherence was not significantly associated with frequency of sleeping 8 hours/night.

The unadjusted associations shown in Table III indicate that
Discussion

In this sample of urban, predominately African American YPLH,
we found that most patients engaged in the measured health protective
behaviors more than half the time. They were particularly diligent about
attending medical appointments (75%) and well within the reported range
of adherence to ARV medication regimens, well within the reported range
of viral load increases; however this could seem likely that neglecting to engage in certain HPB such as taking
ARV medications and exercise. It seems likely that neglecting to engage in certain HPB such as taking
ARV medications precedes viral load increases; however this could not be deduced from our cross-sectional analysis. It may also be the

Table 4: Unadjusted variation in health protective behavior by HIV characteristics.

<table>
<thead>
<tr>
<th>Health Protective Behaviors (M, SD)</th>
<th>Perinatal</th>
<th>Behavioral</th>
<th>F</th>
<th>&lt;500</th>
<th>500-10,000</th>
<th>&gt;10,000</th>
<th>F</th>
</tr>
</thead>
<tbody>
<tr>
<td>Total score (sum)</td>
<td>6.25 (1.62)</td>
<td>5.37 (2.52)</td>
<td>2.86</td>
<td>6.42 (1.97)</td>
<td>5.50 (1.93)</td>
<td>5.78 (1.70)</td>
<td>2.85</td>
</tr>
<tr>
<td>Taking ARV medications</td>
<td>5.8 (3.49)</td>
<td>5.73 (3.59)</td>
<td>.92</td>
<td>6.34 (3.65)</td>
<td>5.50 (3.13)</td>
<td>4.63 (3.44)</td>
<td>2.67</td>
</tr>
<tr>
<td>Taking other medicines/vitamins/supplements</td>
<td>5.19 (3.43)</td>
<td>4.71 (3.68)</td>
<td>.91</td>
<td>5.53 (3.58)</td>
<td>4.60 (3.31)</td>
<td>4.73 (3.73)</td>
<td>1.01</td>
</tr>
<tr>
<td>Keeping medical/health appointments</td>
<td>7.79 (2.15)</td>
<td>6.62 (3.38)</td>
<td>2.87</td>
<td>7.63 (2.66)</td>
<td>6.83 (2.63)</td>
<td>7.76 (2.14)</td>
<td>1.25</td>
</tr>
<tr>
<td>Eating well-balanced meals</td>
<td>6.65 (2.09)</td>
<td>5.85 (2.90)</td>
<td>1.47</td>
<td>6.69 (2.16)</td>
<td>5.77 (2.79)</td>
<td>6.75 (2.08)</td>
<td>1.92</td>
</tr>
<tr>
<td>Regular exercise</td>
<td>5.63 (3.11)</td>
<td>4.94 (3.25)</td>
<td>.71</td>
<td>6.23 (2.91)</td>
<td>4.93 (3.10)</td>
<td>4.70 (3.24)</td>
<td>3.55*</td>
</tr>
<tr>
<td>Sleeping 8 hours/night</td>
<td>6.48 (2.39)</td>
<td>5.15 (3.06)</td>
<td>3.27*</td>
<td>6.31 (2.60)</td>
<td>5.37 (2.85)</td>
<td>6.78 (2.11)</td>
<td>2.46</td>
</tr>
</tbody>
</table>

* p < .05

Table 5: Adjusted effects of age, gender, and transmission mode on health protective behaviors.

<table>
<thead>
<tr>
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compared to those who were 15-17 years old, participants who were
18-23 years old took other medications/vitamins/supplements, kept
scheduled medical appointments, ate a well-balanced diet and got
regular exercise less frequently. Also, males exercised significantly more
often than females. The ANOVA results shown in Table IV indicate that
participants with viral loads <500 copies/mL exercised most frequently,
and those with higher viral loads (>10,000 copies/mL) compared
to those with viral loads <500 copies/mL. A similar association with
viral load was found for taking ARV medications; those with lower viral
loads were reported taking their medications more frequently.

The multivariate linear regression models shown in Table V indicate
significant unique and differential effects of most of the independent
variables; there was no evidence of collinearity according to tolerance
and variance inflation factor statistics. Age was the strongest and most
significant predictor of HPB. Compared to older participants, youth 15-
17 years old reported taking other medicines/vitamins/supplements,
keeping medical appointments, and eating a well-balanced diet more
frequently. Both gender and viral load were predictors of participation in exercise. Females engaged in exercising significantly less often than
males, as did those with high viral load (>10,000 copies/mL) compared
to those with viral loads <500 copies/mL. A similar association with
viral load was found for taking ARV medications; those with lower viral
loads were reported taking their medications more frequently.

Discussion

In this sample of urban, predominately African American YPLH,
case that those with higher viral loads are more symptomatic and thus do not feel well enough to exercise or were abiding by their doctor's recommendations not to participate in strenuous physical activities [26]. Although there was a trend toward lower HPB among behaviorally-infected patients in unadjusted models, the differences may not have reached statistical significance due to the small proportion of behaviorally-compared to perinatally-infected youth.

The most consistent correlate of HPB in our sample was patient age. In particular, patients who were no longer minors (i.e., 18 and over) engaged in all behaviors less frequently than their younger counterparts. This pattern was significant for taking other medicines/vitamins/supplements, keeping medical appointments and eating a well-balanced diet, even when controlling for transmission mode, which is closely associated with age (i.e., perinatally-infected youth are younger than behaviorally-infected).

We purport that the lower engagement in HPB among older YPLH may be due to a number of changing environmental factors that accompany their transition into adulthood and independence. For instance, patients living apart from their caregivers may receive less assistance from family members preparing meals, reminding them to take other medicines, or helping coordinate/schedule healthcare appointments [35]. Youth in this age group are also more likely to be unstably housed [40] and have limited employment opportunities, stressors that consume their energy and divert attention away from participation in HPB. They are also likely to be behaviorally infected youth who have been shown to have higher depression rates, more exposure to violence and substance abuses [41–43].

The age difference in HPB may also reflect the focus of care providers in the infectious disease clinic from which participants were recruited. In this clinic, for example, providers are typically most concerned with adherence to ARV regimens. They use vitamins as a mechanism for establishing a habit of daily pill taking before starting ARV medication regimens, but as they get older YPLH may discontinue taking the vitamins/supplements because they do not understand that these remain a beneficial component of their healthcare alongside ARV medications. As patients become older adolescents, the clinical focus often shifts to include more of an emphasis on reducing risk factors (e.g., substance abuse, unsafe sex) than on promoting behaviors that can sustain positive health outcomes. While both issues are clinically relevant for YPLH, longer clinical appointments may be necessary to address these issues equally.

Interestingly, data from this study revealed no significant differences by transmission mode, once age was controlled. This finding is contrary to other research that found significant differences in adherence related behavior when distinguishing a cohort of YPLH by mode of transmission [44]. With few existing studies that compare health behaviors between those with perinatally and behaviorally acquired HIV infection; this is an area of research that deserves more attention.

On the whole, findings regarding age differences in HPB may highlight a need for broader scaffolding in the transition to independent living and adult health care [20]. Providers and caregivers could encourage HPB in older adolescents and young adults by emphasizing their value, particularly with regard to exercise reducing viral load, and facilitating routines for and helping to address environmental barriers to taking other medicines/vitamins/supplements, keeping medical appointments and eating well-balanced meals. When working with younger HIV-positive patients, providers should view their time as an opportunity to promote healthy living above and beyond taking ARV medicines as a lifetime goal. Our clinical experiences working with YPLH suggest that in spite of their diagnosis, they want to be treated like their non-infected peers. Perhaps by encouraging HPB in general, providers can reduce stigma concerns raised by secondary prevention initiatives targeting people living with HIV [45]. The establishment and maintenance of healthy lifestyle practices early in adolescence should translate into positive long-term health outcomes, especially given the relationship between general HPB and adherence to ARV treatment. Thus, it is important to help YPLH think in a future-oriented manner, possibly by highlighted how HPB will promote achievement of life goals/milestones. 

Limitations and future directions

Several limitations should be considered when interpreting these results. First, behavioral data were self-reported and therefore subject to self-enhancement bias [46], although the use of ACASI may minimize this effect [47]. Future research would benefit by broadening the HPB variables examined to include behaviors such as stress management, dental check-ups, and exercise to include aerobic and muscle and bone strengthening activities as well as asking about HPB (e.g., exercise, diet) in relation to professional recommendations/guidelines to facilitate comparisons across studies. Additional demographic variables might include SES, education, poverty, sexual orientation and substance use supplemented by information on self-efficacy (i.e., behavior specific cognitions and affect) and social support and living arrangements (i.e., situational/interpersonal influences). Secondly, while this investigation reports only cross-sectional data, this is only a constraint on the conclusions that can be drawn about the direction of associations between HPB and viral load. The other independent variables are static or, in the case of age, only change in one direction. This study represents a first step in a new line of research on HPB among YPLH, thus it was prudent to examine cross-sectional correlations to develop hypotheses for future longitudinal investigations. Longitudinal data looking at individual change over time will be useful for determining whether age is associated with a reduction in HPB as opposed to our findings being explained by other differences between age cohorts. Finally, our findings are not generalizable to other inner-city, minority populations as this sample was predominantly African American and perinatally infected.

Conclusion

The notion of protecting young people from harm through a combination of risk reduction and the promotion of protective factors evolved from research on resiliency that dates back to the 1970's [48,49]. We now know that a foundation for healthy lifestyle choices and behaviors in adulthood begins in childhood and adolescence [50]. Results presented in this study argue for the need to further investigate the role of HPB at an early age in YPLH that extend beyond taking ARV medicines. Promoting all aspects of a healthy lifestyle may be important for these youth in several ways. Since social factors and stigma are identified as strong barriers to medication adherence in urban YPLH [51], this may help normalize their situation and make them feel more similar to their non-infected peers who should also be engaging in the same health behaviors. Patients may also see exercise and taking control of eating as empowering ways to enhance their self-efficacy and motivation, important psychosocial factors influencing adherence in high-risk YPLH [52]. Since this investigation has identified that HPB decline as patients reach adulthood, pediatric HIV providers may have the opportunity to promote a healthy lifestyle while patients are still young and reinforce this message as they age. Older adolescents and
young adults who are encouraged to practice healthy lifestyles could benefit from strategies that help them address environmental barriers as well as strengthen their cognitive beliefs about their ability to make healthy choices and engage in HPB [49]. Strengthening these cognitions may reduce youth perceptions that healthy behaviors are difficult to perform as life demands increase leading to improved adherence that is sustainable into adult care. Recognition of the relationship between lifestyle patterns and risk behaviors can lead to the development and testing of interventions that improve health outcomes in YPLH.

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