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The role of substance use in adherence to HIV medication and medical appointments

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Adolescents and young adults ages 15–24 constitute half of all new cases of HIV worldwide (Joint United Nations Programme on HIV/AIDS, 2009). In the United States in 2009, more than 8,000 new cases of HIV were diagnosed in youth ages 13–24 (Centers for Disease Control and Prevention, 2011). Further, at the end of 2009, 16,743 cumulative cases of HIV were reported among New York City youth ages 13–24 (New York City Department of Health and Mental Hygiene, 2011).

Adherence to HIV medications and adherence to HIV primary care appointments are necessary for good health in this population. Quarterly medical appointments are recommended to monitor CD4+T cell count, viral load (Dietz et al., 2010), and to address

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any unmet psychosocial needs among youth. Poor medication and medical appointment adherence has been associated with lower CD4+T cell counts, higher viral loads, and other factors such as substance use among youth (Dietz et al., 2010).

Substance Use and Youth with HIV

Research suggests that substance use is prevalent among youth infected with HIV (Naar-King, Kolmodin, Parsons, & Murphy, 2010). In a sample of 350 youth with behaviorally-acquired HIV, researchers found that almost all of the youth smoked cigarettes, consumed alcohol, or used marijuana and other drugs (Rotheram-Borus et al., 2005). Research by Naar-King et al. (2010) found that alcohol and marijuana use was high among youth with behaviorally acquired HIV, but other illegal drug use was not as prevalent. Among 186 behaviorally-infected youth who had challenges with substance use, sexual risk behavior, or medication adherence, 47% used alcohol, 37% used cannabis, and 9% used other illegal drugs in the previous month (Naar-King et al., 2010). Further, sexual minority HIV-infected youth such as men who have sex with men (MSM) may have had more problematic substance use than HIV-infected heterosexual youth (Naar-King et al., 2010). Research by VanDevanter et al. (2011) also demonstrated that substance use was prevalent in MSM with behaviorally-acquired HIV and was associated with increased sexual risk behaviors.

Substance Use and Adherence

Research by Murphy et al. (2005) on 231 youth with behaviorally-acquired HIV noted that medication adherence could be compromised by alcohol and other drug use. Research by Hosek, Harper, and Domanico (2005) also showed marijuana use to be a barrier for HIV medication adherence among youth. Further, a study of 104 perinatally- and behaviorally-infected youth demonstrated that illegal drug use was associated with medication non-adherence (Chandwani et al., 2012).

With respect to appointment adherence, research by Outlaw et al. (2010) on 82 racial and ethnic minority youth infected with HIV, the majority of whom were behaviorally infected, showed that alcohol use was the strongest predictor of suboptimal HIV appointment adherence. Research also showed that marijuana use was associated with more missed HIV appointments in behaviorally-infected youth (Dietz et al., 2010).

Our in-depth qualitative study explored the context of alcohol and illegal drug use and its impact on adherence to HIV medication and medical care among adolescent males infected with HIV. Understanding these risks has important implications for designing appropriately tailored substance abuse treatment interventions for youth infected with HIV. These interventions could provide youth with the crucial skills to balance HIV medication and appointment adherence with substance use in social settings.

Methods

Study Design and Participants

The qualitative data presented here were collected as part of a large, primarily qualitative study designed to examine the life experiences of African American and Latino youth with

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behaviorally-acquired HIV. The parent study (*n* = 59) included youth recruited by study staff or clinical staff at five adolescent HIV specialty clinics in the New York City metropolitan area. All recruitment sites provided comprehensive youth-focused HIV primary care, including mental health services and ancillary social services. Eligibility criteria for the parent study included (a) 13 to 24 years of age, (b) infected with HIV (verified by the referring clinic), (c) cognitively competent to participate, and (d) acquired HIV infection from unprotected sex or injection drug use.

Participants were recruited and interviewed between June 2004 and February 2007. There were no differences in participant response rates or demographic characteristics comparing those recruited by clinic staff or study staff (Siegel, Lekas, Olson, & VanDevanter, 2010). No refusals were reported; however, a few youth who agreed to participate dropped out of care and did not complete the interview. The study was approved by Institutional Review Boards at Columbia University and New York University and the referring clinics; it received a Federal Certificate of Confidentiality.

Data Collection and Measures

The study was primarily qualitative with a brief quantitative survey that used audio computer-assisted self-interviews (ACASI) to gather demographic and behavioral data. Sexual behavior and substance use survey questions were taken from the Youth Risk Behavior Survey. In-depth, semi-structured, focused qualitative interviews captured data on the individual's life prior to HIV diagnosis, as well as the individual's experience of living with HIV infection. A qualitative focused interview guide was used to structure the interview. The guide covered topics related to the study aims, adaptive tasks, and coping strategies related to HIV diagnosis. Interviewers were public health graduate students with prior interviewing experience. Participants were compensated $50 for their time and were offered $8 in transportation vouchers.

Data Analysis

Quantitative data were analyzed using Stata Statistical Software Release 9.0. All qualitative interviews were audio-taped and transcribed verbatim. Content analysis was used to develop a coding scheme and the constant comparison approach was used to analyze the data. Following the development of the coding scheme, inter-rater reliability was tested by parallel coding 12 of 59 transcripts (Kappa .85). Following discussion of coding inconsistencies, subsequent transcripts were divided and independently coded by the two coders (AD and TBP). ATLAS.ti® version 4.2, qualitative data software, was used to organize the transcripts and to assist with analysis. See Siegel et al. (2010) for additional description of the analytic strategy. In addition, the research team developed participant profiles that summarized demographic characteristics and provided a brief overview of their experiences living with HIV infection.

Results

The sample for our study included biological males whose gender identity was also male (*n* = 28). Table 1 shows participant demographics. The mean age at the time of the interview

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was 21 years. The mean age at diagnosis was 19 years. Less than half of the youth reported prior use of antiretroviral therapy (ART; 46.4%). The majority of the sample self-identified as African American or Black (64.3%), and 35.7% identified as Hispanic or Latino. More than half of the participants had not yet completed high school or obtained a General Educational Development credential (GED; 53.6%). The majority were not employed (64.3%). The majority of youth reported lifetime use of alcohol (89.3%) and illegal drugs (78.6%), and previous 30-day alcohol use (64.3%) and illegal drug use (64.3%).

In the qualitative interviews, youth did not differentiate between alcohol and illegal drug use as uniquely separate and distinct behaviors, thus alcohol and illegal drug use are combined in Table 2. Many youth decreased alcohol or illegal drug use post-diagnosis (39.3%); 35.7% had consistent pre- and post-diagnosis use. It should also be noted that decreases in substance use included both reductions in use and cessation. A small number of youth increased alcohol and illegal drug use post-diagnosis (7.1%). One youth (3.6%) reported alcohol or illegal drug use immediately post-diagnosis without reports of other use before or after diagnosis. Four (14.3%) youth reported no alcohol or illegal drug use.

The cases presented below are illustrations of substance use-related adherence barriers and facilitating factors in youth infected with HIV. The qualitative analysis revealed two primary themes: (a) Substance use increased missed medication doses in purposive and unintended ways, and (b) HIV-related health concerns decreased substance use for many participants.

Substance Use Increased Missed Medication Doses in Purposive and Unintended Ways

Participant 1, a 24-year-old African American heterosexual young man, who was diagnosed with HIV when he was 16 years old, described heavy alcohol use and a family history of drug abuse. After diagnosis, he increased his alcohol use considerably and reported episodes of binge drinking. He also reported being a heavy cigarette smoker. He described purposefully missing medication doses because of alcohol use. He also reported forgetting to take his medication after drinking alcohol with friends (unintended missed medication doses resulting from substance use). He did not bring his medication when socializing because he read about side effects from alcohol use when taking HIV medication. In addition he did not like the size of the pills, the taste of the medication, and side effects such as cramping, diarrhea, and nausea. The last time he took his HIV medication was 3 weeks prior to the interview and only at the prompting of his mother. The participant reported that at one point he stopped taking his medication for 6 to 8 months, in which time his viral load increased and his CD4+T cell count was reduced. He was concerned about getting pneumonia and this prompted him to resume the medication regimen. He had been on eight different medications and was resistant to several. He did not report any medical appointment adherence barriers. When Participant 1 was asked about alcohol use, he commented:

> Well actually it’s like you’re not supposed to drink anyway if you’re taking the medication. That’s one thing. Second thing, if you drink before taking the medication the nauseous of the medication – if you try to take the medicine after you already drank that could be a problem because you could get violently sick. I’m also – if you’re hanging outside and you didn’t bring it with you and you’re

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> drinking, first you're probably 'gonna lose track of time, because there's times I've hung out at like 12 noon and didn't come back till 4 in the morning, you know.

Participant 1 continued to explain the circumstances that caused him to not bring his medication when socializing. When Participant 1 was with friends, he drank to excess or was away from home when he was supposed to take his medication, and thus missed medication doses. He reported making no attempts to bring his medication with him when socializing with friends. He did not cite stigma as an adherence concern because he said that everyone knew about his status and he was not ashamed of his status. He described heavy alcohol use as (a) an unintended barrier to medication adherence, and (b) purposefully not taking his medication because of alcohol-induced sickness.

> Especially for this last month it's been like, you know – especially when I get my money I automatically hang out on the first. Um, you know. But I can hang out for 2 or 3 or 4 days in a row, it's like – because first of all if I drink too much and have a hangover I'm definitely not 'gonna want to take the medicine. I'm already feeling sick but then it's like if I 'gotta go back out again I always drink first before going out and then when I'm downtown it's like – it's like you don't really 'gotta pay for beer down there, it's just there. Some of the people buying 40s, 40s, 40s, 40s, that's all that's there, so. I don't know, it's like a repeater process so it's like you know especially for the first like I said when I get my money them days – like a lot of every days I try sometimes to get the morning dose – it's usually the night dose I don't get because I'm out.

Participant 2 also described missing medication doses because of alcohol use. This participant was an 18-year-old African American man who described himself as gay but who had also had sex with women. He was diagnosed when he was 16 years old and was immediately put on HIV medication. Participant 2 described many medication side effects and said that taking medication was stressful. He reported no medical appointment adherence difficulties. He reported a childhood history of alcohol use, but said he had decreased alcohol use post-diagnosis. He reported increased cigarette use postdiagnosis. When asked about possible barriers to medication adherence, the participant indicated that while rare, alcohol use had been a barrier in taking his medication.

> The only time I would say that I won't take the pill – if I know I've been drinking that day I don't want to take the pill and put it on top of the alcohol, so I won't take it.

Participant 2 did not indicate that he had been told by a health care provider not to take his medication when drinking alcohol.

Participant 3 was a 19-year-old African American gay man who was diagnosed when he was 18 years old. He reported a history of pre-diagnosis heavy alcohol use. He had been on several medication regimens and liked his current regimen because the pills and pill containers were smaller and more discrete. He reported that there had been instances when he went on a planned "drug holiday" because he was in an environment where it was difficult for him to take his medications discretely. In addition, he reported that he had skipped his medications when he was drinking heavily because he was afraid of mixing the

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alcohol and medication. Participant 3 reported drinking alcohol in isolation in order to cope with HIV-related stress and also socially with peers. When asked if there were any instances when he did not take his medication consistently, he described not taking his medication when he had been drinking alcohol. When asked why he decided to stop taking his medication when drinking, the participant stated that there was a warning label on the medication bottle that taking the medication when drinking alcohol was not recommended. He was unsure of any specific side effects associated with drinking alcohol and the medication; however, he had decreased his alcohol use from every weekend to 2 to 3 times a month because of the medication warning. The participant had not discussed the warning label or the alcohol-related barriers to medication adherence with his medical provider.

HIV-Related Health Concerns Decreased Substance Use for Many Participants

Some youth in our study believed substance use was a barrier to good health and therefore reduced alcohol and drug use post-diagnosis. Participant 3, who reported alcohol use as a barrier to medication adherence, also reported considerable reductions in alcohol and cigarette use post-diagnosis because his doctor mentioned alcohol could potentially negatively impact his health.

> I slowed down [on alcohol] once I found out about my status. And like I smoked cigarettes - and I even calmed that down. You know the doctor say it's not good. What do the alcohol do? - your blood? Something – I can't remember exactly what he said but I know it's not good. It's not good. I just calmed down.

Discussion

The data showed that many youth decreased alcohol or illegal drug use post diagnosis. This was an important finding given that substance use among HIV-infected youth is associated with decreased medication and appointment adherence (MacDonell, Naar-King, Huszti, & Belzer, 2013). Among the youth who reported substance use-related medication adherence challenges, none reported substance use as a barrier to medical appointment adherence, although other studies have reported that alcohol use is associated with poor appointment adherence among HIV-infected youth (Dietz et al., 2010; Outlaw et al., 2010).

Most of the substance using youth in the sample did not view substance use as a barrier to medication adherence. However, for those who did report substance use as a barrier to medication adherence, alcohol use was a significant barrier. For the youth citing alcohol use as a primary barrier to medication adherence, most often alcohol use occurred in social settings. Further, a reoccurring theme among substance using youth in our sample was the idea of refraining from taking medication when drinking alcohol due to beliefs of toxic medication-alcohol interactions. Further, youth who decreased substance use post-diagnosis reported that substance use was detrimental to good health.

Youth in our sample may have difficulty balancing potential substance use and medication interactions, particularly in social settings. The youth did not make clear distinctions between the reasons for missed medication doses: planned purposeful missed doses and unintended missed doses because of alcohol incapacitation or forgetting to bring medication

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when socializing. However, it was apparent that several substance use-related mechanisms were barriers to medication adherence. Providers and caregivers can help youth understand the consequences of missing medication doses, as well as the consequences of substance use. Providers should be urged to (a) discuss substance use and medication adherence (without prior prompting by the youth), (b) help youth develop strategies to maximize medication adherence in social substance use settings, (c) make referrals to substance abuse treatment, and (d) discuss physical health consequences of substance use, particularly because some youth reported decreasing alcohol use because of HIV infection.

Alcohol and marijuana use are prevalent among youth with HIV (Naar-King et al., 2010). Substance use among youth is highly influenced by peers; thus, use may seem more normative among drug using peer networks (Oetting & Beauvais, 1986). It was unclear from these findings if youth conformed to the substance using behaviors of their peers (socialization) or if youth selected peers based on common substance using beliefs (selection). What was clear, however, was that youth in our study who used alcohol with peers in social settings reported more difficulty with medication adherence than those who did not use alcohol. Utilizing peer networks by training youth to educate their peers about the negative aspects of substance use may also be helpful.

Limitations

The findings of this study must be interpreted within the context of several limitations. There were discrepancies in reports of substance use in the quantitative and qualitative data. Some youth reported no use in the quantitative data but gave detailed accounts of use during the qualitative interview. Similarly, some youth reported no use in the qualitative interview but disclosed multiple drugs of use in the computer-based portion of the interview.

Despite these differences, substance use in this population appeared to be a barrier to medication adherence. Our qualitative study was not intended to provide generalizable results to all youth infected with HIV. However, the results highlight important health issues relevant to all youth infected with HIV. It should be noted that all of the youth in the study were connected to comprehensive HIV medical care and social services. Youth not connected to care may be different from youth in this study. All data were self-reported and subject to social desirability.

Conclusions

Despite limitations, our study provides insight into the substance using behaviors and associated adherence barriers among male youth infected with HIV. The findings have important implications for comprehensive HIV medical care, substance abuse interventions for this population, and implications for improving HIV medication adherence. Integrating periodic substance use screening into comprehensive HIV care would be beneficial. Establishing partnerships between HIV health care providers and substance abuse prevention and treatment professionals in order to design context specific substance abuse prevention interventions for HIV-infected youth could help to address medication adherence barriers associated with difficulties balancing the desire to socialize and the need to take HIV medication.

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Table 1

Participant Demographic Characteristics, Quantitative Data

Characteristics	*N* = 28	% (unless otherwise noted)
Mean Age at time of interview[a] (*SD*)[b] [Range][c]	28	20.8 years (2.3) [17–24]
Mean Age at diagnosis (*SD*)[Range]	28	18.9 years (2.2) [16–24]
Has Ever been on ART	13	46.4%
Race/Ethnicity		
Black/African American Non-Hispanic/Latino	18	64.3%
Hispanic/Latino	10	35.7%
Educational Attainment at time of interview		
Less than HS/Some HS	15	53.6%
HS Diploma/GED	6	21.4%
Some College/Associates Degree	7	25.0%
Employment Status at time of interview		
Full-time	4	14.3%
Part-time	6	21.4%
Not employed	18	64.3%
Lifetime alcohol use	25	89.3%
Previous 30-day alcohol use	18	64.3%
Lifetime illegal drug use	22	78.6%
Previous 30-day illegal drug use	18	64.3%

[a]Mean

[b]Standard Deviation

[c]Range

Note. SD = standard deviation; ART = antiretroviral therapy; HS = High School; GED = General Educational Development

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Table 2

Alcohol and Illegal Drug Use Among Youth with HIV, Qualitative Data

Pre-and Post-Diagnosis Consistent Use	Decreased Use Post-Diagnosis	Increased Use Post-Diagnosis	Use Immediately Following Diagnosis Only[a]	No Reported Use
10	11	2	1	4

[a]Only youth reporting use immediately following diagnosis and report no additional use.