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Correlates of Missed Clinic Visits among Youth Living with HIV

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Abstract

Youth living with HIV (YLH) face significant problems with regularly attending their medical appointments. Poor attendance, consequently, predicts viral non-suppression and other negative HIV-related outcomes. To identify targets of intervention, this cross-sectional study examined correlates of past-year missed clinic visits among a diverse sample of YLH (ages 12 to 24; $N=2125$) from HIV clinics in the United States and Puerto Rico. Our results revealed that 36% of YLH reported missing two or more visits in the past year. Several factors were associated with missed clinic visits in our multivariate logistic regression model based on adjusted odds ratios (AORs). Among sociodemographic characteristics and HIV disclosure status, females (AOR = 1.63, compared to males), Black YLH or YLH of mixed racial heritage (AORs = 1.76, 1.71, respectively, compared to White YLH), YLH with an unknown route of infection (AOR = 1.86, compared to YLH with perinatal infection), and YLH endorsing HIV disclosure (AOR = 1.37, compared to YLH not endorsing disclosure) were at greater risk for missed visits. In addition, number of times YLH moved residences was associated with missed visits (AOR = 1.07). Among behavioral health risks, YLH who endorsed marijuana use (AOR = 1.42), frequent other drug use (AOR = 1.60), or a history of incarceration (AOR = 1.27) had greater odds of missed visits than youth not endorsing these health risks. Finally, two social-cognitive factors emerged as protective against missed visits: adherence self-efficacy (AOR = .28) and adherence social support (AOR = .88). We conclude by discussing the ways in which providers and clinics working with YLH can improve this population's retention outcomes by recognizing youth-specific individual, social, and structural barriers to treatment engagement.

Introduction

More than one in five new HIV infections in the United States (US) occurs in a young person aged 13 to 24 years (CDC, 2015). Fortunately, with proper care, youth living with

HIV (YLH) can expect to lead long and relatively healthy lives (Marcus et al., 2016). Adherence to antiretroviral therapy (ART) also has the benefit of preventing new infections through viral suppression and sexual risk reduction. However, taking ART daily and regularly accessing healthcare services are difficult tasks. More than other age groups, YLH demonstrate poor treatment adherence and low rates of viral suppression (Zanoni & Mayer, 2014). YLH are particularly challenged with missing medical appointments (Horberg et al., 2013). Whereas research has paid attention to this behavior among adults (Horberg et al., 2013; Kipp et al., 2017; Traeger, O’Cleirigh, Skeer, Mayer, & Safren, 2012; Zinski et al., 2015), less is known about youth retention. Specifically, few studies have examined youths’ clinic attendance and its possible correlates (Harper et al., 2013; Kahana et al., 2015; Kahana et al., 2016). The current study therefore explores these associations in order to prioritize areas for intervention and guide clinical practice.

One simple yet informative indicator of retention is the number of medical appointments HIV patients miss over a period of time. While many ways to assess retention in care exist, this indicator is as effective as others at identifying individuals at risk for poor health outcomes (Mugavero et al., 2012). Among adults, missed visits has been associated with viral non-suppression (Mugavero et al., 2012; Zinski et al., 2015), low CD4 count (Horberg et al., 2013), AIDS-defining illnesses (Park et al., 2007), and mortality (Horberg et al., 2013; Mugavero et al., 2009; Park et al., 2007). Among youth, missed visits has been linked to decreased ART adherence (Ernesto et al., 2012). In addition, researchers found that YLH who do not attend a recommended number of medical appointments in a year are at heightened risk for being lost to follow-up (Agwu et al., 2015). Finally, a prior investigation with the current sample observed that YLH who missed two or more visits in the past year had lower odds of being on ART and achieving viral suppression (Kahana et al., 2015).

Studies from the adult literature have identified factors correlated with missed clinic visits. Social Action Theory (Ewart, 1991), a model previously used to explain ART adherence (Johnson et al., 2003), may be a useful framework for understanding who is at risk for retention problems. According to the theory, patients’ sociodemographic background and behavioral health characteristics contribute to a context which influences retention behavior. At the same time, retention-related social and cognitive resources are associated with the degree to which patients can adhere to care within this context. Indeed, research with adults has found associations between missed clinic visits and patients’ sociodemographic characteristics (Horberg et al., 2013; Traeger et al., 2012), behavioral health problems (Kipp et al., 2017; Traeger et al., 2012), and social-cognitive resources (Traeger et al., 2012). When applied to retention, the Social Action Theory model also proposes a cyclical process; that is, patients who attend their appointments gain motivation and self-efficacy which further strengthens their ability to keep future appointments.

Consistent with the theory, youth who miss clinic visits are likely to be experiencing a broad range of other behavioral health problems which impact their psychosocial functioning and make it difficult for them to consistently keep appointments. At the same, the more visits youth miss, the fewer opportunities exist for healthcare providers to screen for health risks and provide youth with treatment referrals. Despite experiencing barriers to care, it is possible that some youth are still able to demonstrate good retention due to a high degree of

social-cognitive resources including the adherence self-efficacy, readiness, and social support needed to routinely attend appointments. Accessing social resources also involves HIV disclosure, an event known to enhance adherence outcomes (Elopre et al., 2015).

We sought to determine which sociodemographic factors identify YLH at risk for missed clinic visits as well as the social-cognitive resources that protect against this behavior. We also examined behavioral health risks hypothesized to be positively associated with missed visits. Our investigation will extend a prior study with the current sample. Kahana and colleagues (2016) explored structural determinants (i.e., geographic-level variables) of youths' ART uptake and adherence to care and found that YLH residing in economically disadvantaged areas were at increased risk for missed visits while controlling for individual differences (Kahana et al., 2016); however, their study did not explore a broader range of patient characteristics as well as factors potentially protective of missed visits. Given that our study is cross-sectional and our theoretical model assumes bidirectional effects, we examine these possible psychosocial correlates of missed clinic visits without hypothesizing a causal direction.

Method

Participants

Participants ($N = 2125$) were recruited between December 2009 to January 2012 from 20 adolescent medical clinics serving YLH across the U.S. and Puerto Rico. Sites included Boston, Baltimore, Chicago, Denver, Fort Lauderdale, Houston, Los Angeles, Miami, Memphis, New Orleans, New York City, San Francisco, Tampa, Washington, DC, and San Juan, Puerto Rico. Eligible youth had to be: (1) aged 12 to 24 years; (2) living with HIV; (3) aware of their HIV status; (4) in care at an Adolescent Trials Network for HIV/AIDS Interventions (ATN) treatment unit or affiliate; and (5) able to understand English or Spanish. Participants were recruited to participate in a cross-sectional health survey. Study staff approached eligible youth while they were attending a medical appointment and described the study in detail including its procedures. Informed consent was obtained from youth interested in participation. If needed, parental consent and youth assent were obtained. In most cases, however, IRBs waived parental consent. Eighteen of the 20 recruitment sites, which enrolled 91% of participants, provided recruitment screening data. Of those 18 sites, 95% of YLH approached were eligible and 91% of eligible YLH agreed to participate (Brown, Whiteley, Harper, Nichols, & Nieves, 2015). Recruited youth were representative of clinic populations.

Procedures

Study staff met with participants within two weeks of obtaining informed consent/assent to administer to them an audio computer assisted self-interview (ACASI). The ACASI assessed sociodemographics, social-cognitive resources, behavioral health risks, and healthcare utilization. The assessment took 45–90 min to complete. Participants were compensated for their time and transportation in accordance with site-specific IRB guidelines (range = \$20 to \$150; mean [M] = \$56, median = \$50). Other details on procedures can be found elsewhere (Brown et al., 2015; Kahana et al., 2015).

Measures

Sociodemographics and HIV disclosure status.—YLH were assessed for gender identity, sex assigned at birth (to determine transgender gender identity), age, race, ethnicity, sexual orientation, route of HIV infection, education, school status, past 30-day income, employment status, and housing. They were also asked if they had ever disclosed their HIV status to someone.

Social-cognitive resources.—Participants reported on their social-cognitive resources related to HIV care. One item based on Rollnick's Readiness Ruler (Stott, Rollnick, Rees, & Pill, 1995) assessed motivational *appointment readiness* on a 1 (not ready) to 10 (completely ready) scale which asked: "How ready are you to get to medical appointments (at least 4 times a year)?" Three items with responses ranging from 1 ("very sure I cannot") to 4 ("very sure I can") measured degree of self-efficacy to attend appointments with items such as "How sure are you that you can keep doctor and other health care appointments even if you were very tempted not to?" Cronbach's α for the *appointment self-efficacy* scale was .79. Two items used in previous ATN studies (MacDonell, Naar-King, Murphy, Parsons, & Harper, 2009) assessed adherence social support with responses to two statements, "There are people in my life that are supportive about (1) keeping medical appointments and (2) taking HIV medication." Response options ranged from 1 (strongly disagree) to 5 (strongly agree). Alpha for the two-item *adherence support* measure was .80. Finally, *provider support* was assessed with five items related to perceived social support from a healthcare provider. Each item has a response ranging from 1 (strongly disagree) to 5 (strongly agree). A sample item is "I feel understood by my care provider." Alpha for this scale was .87.

Behavioral health risks.—Three indicators of *mental health* were used. Psychological distress was assessed with the 53-item Brief Symptom Inventory (BSI) (Derogatis, 1993). The measure produces a Global Severity Index (GSI) which combines several mental health symptoms. Previous studies have used this index to measure general psychological distress (Reid, Richards, Loughran, & Mulvey, 2017). Items follow a five-point response ranging from 'not at all' to 'extremely'. To calculate the GSI, a mean item-level score was used with higher scores corresponding to more distress. We also report on the percent of youth meeting the cut-off for clinically significant symptoms (T-score ≥ 63). In addition, YLH were asked if they had thought of attempting suicide or had attempted suicide in the past year. Two measures were used to assess *substance use*: the CRAFFT (Knight, Sherritt, Shrier, Harris, & Chang, 2002) and the ASSIST (WHO Group, 2002). A score of two or more on the CRAFFT is indicative of problematic substance use risk. We used ASSIST items to assess use of alcohol, marijuana, and other drugs (e.g., cocaine). Participants were also asked about their recent (past three months) sexual behavior. We assessed three *sexual risk behaviors*: unprotected (condomless) anal or vaginal sex, unprotected anal or vaginal sex with an HIV-negative or HIV status unknown partner, and unprotected sex while using substances. In terms of *legal involvement*, participants were asked if they had ever been incarcerated.

Missed clinic visits.—One item assessed number of missed clinic visits by asking participants, "How many doctor's appointments have you missed in the past year?"

Consistent with past investigations (Kahana et al., 2016), this variable was dichotomized (0 = one missed visit, 1 = two missed visits).

Plan of Analysis—First, we conducted a series of bivariate logistic regressions to explore associations between participant factors (sociodemographics, HIV disclosure status, social-cognitive resources, mental health, substance use, and legal involvement) and number of missed clinic visits. Next, participant factors significantly associated with missed clinic visits at the bivariate level ($p < .05$) were included in a single multivariate model to determine which factors had the strongest independent association with missed clinic visits. We used multiple imputation with imputed data derived from the pooled results of five separate imputed datasets to account for missing data. Missing data was low on most variables (1%) with the exception of past 30-day income (19%). Analyses were conducted in SPSS 22.0.

Results

Sample Characteristics (Table 1)

Sociodemographics and social-cognitive resources.—Most youth identified as male or female. More youth were young adults or older adolescents compared to younger adolescents. The sample primarily identified their race as Black and non-Hispanic/Latino. Almost half of the youth reported their sexual orientation as straight with the rest identified as a sexual minority. Youth acquired HIV primarily through behavioral or perinatal infection with a small number of youth unsure of how they were infected. A third of participants had not completed high school and approximately half were not currently attending school. Most were unemployed and almost a third had no past 30-day income. About half still lived with their parents. They moved residences in the past year on average 1.79 times. Most of the sample indicated disclosing their HIV status. Finally, youth generally reported a high degree of social-cognitive resources.

Behavioral health risks.—Psychological distress among youth as measured by the GSI was $M = .98$, $SD = .79$, with 18% of YLH above the cut-off for clinically significant symptoms. Fifteen percent of youth reported suicidal ideation and 6% had attempted suicide in the past year. Substance use was high among YLH with many reporting frequent use. Indeed, over half of the sample met the CRAFFT cut-off for risky use. Almost a third of young people indicated engaging in unprotected sex in the past three months with fewer reporting sex with a partner who did not know their HIV status or were HIV-negative, and sex while under the influence of substances. Finally, one in three youth reported past incarceration.

Missed clinic visits.—A total of 787 participants (36%) missed two or more clinic visits in the past year and 1425 (64%) missed one or no visits.

Associations between Participants Characteristics and Missed Clinic Visits

The final multivariate regression model included only variables significant at the bivariate level (Table 1). When multiple variables from similar behavioral health risks (e.g., any

alcohol use and frequent alcohol use) were significant, the one with the largest effect was chosen. In this model, female youth, Black youth or youth of a mixed racial background, and youth with an unknown route of infection, were at higher risk for missed visits compared to their demographic counterparts. Number of times moved and HIV disclosure also remained significantly associated with missed visits. Of the social-cognitive resources, only appointment self-efficacy and adherence support were significantly related to missed visits. Among behavioral health risks, youth who endorsed any marijuana use, frequent other drug use, or a history of incarceration had greater odds of missed visits compared to youth not endorsing these health risks.

Discussion

YLH are burdened by a life-long commitment to HIV treatment. Guided by Social Action Theory, our study examined factors related to the number of clinic visits youth miss in the past year, a behavior known to predict poor health functioning. Many of our findings were consistent with the adult literature and associations were in the expected directions; however, one was unique to youth (gender differences) and another was counter to our theoretical model (HIV disclosure). Overall, missing two or more visits had associations with a range of behavioral health risks while social-cognitive factors had protective associations with missed visits.

Given their significance as independent correlates of missed visits, the behavioral health risks of marijuana use, frequent other drug use, and incarceration deserve attention. Two noteworthy etiological implications stemming from cyclically related pathways to optimal retention may underlie these associations. First, consistent with Social Action Theory and studies with adults (Kipp et al., 2017; Traeger et al., 2012), substance use and legal involvement could be present and even co-occurring in youth who are in stressful circumstances characterized by poverty and unsafe communities. Thus, these YLH may be already facing barriers to retention, and engaging in problem behavior, perhaps because of being exposed to such conditions, further limits their ability to attend to treatment demands. Second, because we know from adult studies that missed visits are associated with health problems over time, it can be assumed that receiving HIV care is an opportunity to link patients with behavioral health services, which in turn, leads to better clinic attendance.

Sociodemographic characteristics distinguished youth based on missed visits in our multivariate model. Unlike adult studies (Horberg et al., 2013), we observed that young females had a greater risk for missed visits than young males. We know from previous reports that our female youth sample have worse mental health than males (Brown et al., 2015), making treatment engagement difficult. Moreover, female youth in our sample could live in higher risk settings which act as a barrier to retention, a finding reflected in Kahana et al.'s (2016) investigation. Our results also highlight racial disparities existing along the HIV care cascade (Simoni et al., 2012) and mirror research conducted with adults (Zinski et al., 2015)—even in the presence of other pertinent correlates, Black youth and youth of mixed racial heritage were over 70% more likely to miss visits than White youth. In addition, youth who were unaware of how they were infected had greater odds for missed visits which could be attributed to their possible treatment naivety. Finally, housing stability, likely via its

impact on young people's ability to access and form relationships with local clinics, was related to missed visits.

One demographic factor that was not significant in our multivariate model but should be considered is age. Bivariate analyses revealed that there was a trend towards older youth having an increased likelihood of missed visits than younger youth. Younger YLH may have greater support and structure via the family environment in comparison to older adolescents and young adults who are increasingly tasked with healthcare self-management. Another significant bivariate finding supports this notion: YLH who reported residing with their parents had a lower likelihood of missed clinic visits compared to YLH who did not reside with their parents.

Surprisingly, HIV disclosure was related to a greater likelihood of missed visits. Most studies with adults find that disclosure leads to better treatment outcomes including retention in care (Elopre et al., 2015). This protective association is consistent with Social Action Theory, as disclosure can spur social support. For some youth, however, disclosure could lead to peer or family rejection, which ultimately hinders accessing support.

Our findings have implications for clinicians. Most significantly, we demonstrated how a one-item measure of retention, easily incorporated into screening practices, can identify youth who may be experiencing a host of behavioral health problems. The wide range of patient characteristics related to missed visits underscores how interventions to improve retention should be holistic. With adults, strategies which target adherence and substance use, or adherence and depression, show promise in increasing retention (Ingersoll et al., 2015; Safren et al., 2009). With youth, similar interventions focused on cognitive and behavioral processes are effective (Naar-King, Parsons, Murphy, Kolmodin, & Harris, 2010), consistent with the protective association we observed between appointment self-efficacy and missed visits. However, youth-specific interventions are rare. Moreover, given the strong relation in our sample between adherence support and missed visits, they could be enhanced with a greater focus on social context. This a critical consideration for transitional age older adolescents and young adults, who rely less on their families, form increasingly close peer and partner relationships, and are expected to move from pediatric or adolescent clinics to adult HIV services. Finally, a holistic approach should address sociostructural barriers to care. This might involve training providers on the social determinants of health (Klein et al., 2011), such as housing and legal involvement, to facilitate resource referrals.

Limitations

A few study limitations should be noted. Our cross-sectional design precludes causal inferences related to the effects observed. Our measures are also self-report and vulnerable to a social desirability bias, although the ACASI minimizes the chances for this bias to occur. In addition, we only used one measure of retention. Finally, caution should be made when generalizing our findings to YLH in the community, as the current study draws from a non-probability sample of YLH already engaged in care.

Conclusions

Our study was bolstered by its use of a large, diverse sample of YLH and comprehensive examination of factors related to HIV care retention. Future research should continue to explore causal pathways believed to maintain clinic attendance among YLH in treatment. Clinics are urged to create youth-friendly environments that meet the changing developmental needs of youth (Tanner et al., 2014). This may include offering culturally-informed behavioral health treatment, access to community services, and programs involving peer and family engagement. Finally, efforts should be made to successfully transition young adults into adult care by reinforcing their treatment self-management skills and existing support networks, and helping them form new relationships with adult healthcare clinics and providers.

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Table 1.Factors Associated with Missing Two or More Clinic Visits in the Past Year ($N = 2125$)

	<i>n (%)</i> * or <i>M (SD)</i>	<i>OR</i>	<i>95% CI</i>	<i>AOR</i>	<i>95% CI</i>
Gender					
Male	1421 (64)	ref	ref	ref	ref
Female	731 (33)	1.26	1.05, 1.56	1.63	1.30, 2.04
Transgender male	14 (1)	.85	.38, 3.26	.76	.21, 2.80
Transgender female	69 (3)	1.85	1.20, 2.84	1.19	.69, 2.05
Age					
12–15	160 (7)	.61	.41, .91	.66	.41, 1.07
16–19	609 (28)	ref	ref	ref	ref
20–24	1435 (65)	1.19	.98, 1.45	.96	.74, 1.25
Race					
White	278 (13)	ref	ref	ref	ref
Black	1484 (67)	1.53	1.15, 2.02	1.76	1.23, 2.43
Asian/Pacific Islander	21 (1)	1.32	.51, 3.39	1.28	.46, 3.60
Native American/Alaskan Native	23 (1)	1.41	.57, 3.45	1.34	.50, 3.60
Mixed heritage	246 (11)	1.72	1.19, 2.48	1.71	1.13, 2.89
Other	143 (7)	1.34	.86, 2.09	1.42	.87, 2.33
Ethnicity					
Not Hispanic or Latino	1769 (80)	ref	ref	ref	ref
Hispanic or Latino	436 (20)	.78	.78, 1.23		
Sexual orientation					
Straight	1004 (45)	ref	ref	ref	ref
Gay	845 (38)	.95	.79, 1.15		
Bisexual	269 (12)	1.10	.84, 1.46		
Lesbian	23 (1)	1.98	.87, 4.53		
Other	63 (3)	.97	.59, 1.60		
Route of infection					
Perinatal	612 (28)	ref	ref	ref	ref
Behavioral	1519 (69)	1.43	1.17, 1.75	1.19	.90, 1.56
Don't know	82 (4)	1.77	1.10, 2.83	1.86	1.10, 3.15
No high school degree	762 (34)	1.23	1.03, 1.47	1.15	.91, 1.45
Not in school	1067 (48)	1.52	1.28, 1.81	1.13	.91, 1.40
Earned no money in past 30 days	652 (29)	.94	.80, 1.14		
Unemployed	1468 (66)	1.26	1.05, 1.52	1.04	.83, 1.30
Living with parents	1010 (46)	.83	.69, .99	1.07	.87, 1.32
Number of times moved in past year	1.79 (3.57)	1.10	1.06, 1.13	1.07	1.03, 1.10
Disclosed HIV status to someone	1774 (80)	1.43	1.14, 1.80	1.37	1.04, 1.81
<i>Social-cognitive resources</i>					
Appointment readiness	9.24 (1.81)	.88	.84, .93	.96	.90, 1.01

	<i>n</i> (%) [*] or <i>M</i> (<i>SD</i>)	<i>OR</i>	<i>95% CI</i>	<i>AOR</i>	<i>95% CI</i>
Appointment self-efficacy	4.61 (.53)	.25	.21, .30	.28	.23, .34
Adherence support	4.30 (.99)	.76	.70, .83	.88	.80, .98
Provider support	4.58 (.71)	.87	.78, .98	1.05	.90, 1.21
<i>Mental health</i>					
Psychological distress	.96 (.79)	1.68	1.50, 1.88	1.14	.99, 1.32
Suicidal ideation	335 (15)	1.67	1.32, 2.11	1.03	.77, 1.38
Suicide attempt	141 (6)	1.55	1.10, 2.19		
<i>Substance use</i>					
Alcohol use (any past 3 months)	1544 (70)	1.68	1.38, 2.05	1.18	.90, 1.54
Alcohol use (weekly or more)	472 (21)	1.28	1.04, 1.58		
Marijuana use (any past 3 months)	1094 (49)	2.13	1.79, 2.55	1.42	1.11, 1.81
Marijuana use (weekly or more)	611 (28)	1.82	1.51, 2.21		
Other drug use (any past 3 months)	510 (23)	1.76	1.43, 2.16		
Other drug use (weekly or more)	123 (6)	2.13	1.48, 3.08	1.60	1.05, 2.44
CRAFFT score 2	1215 (55)	2.13	1.77, 2.56	1.24	.95, 1.61
<i>Sexual risk behavior</i>					
Unprotected anal or vaginal sex	662 (30)	1.34	1.11, 1.63	1.00	.77, 1.30
Unprotected anal or vaginal sex w/ an HIV- or status unknown partner	478 (22)	1.25	1.01, 1.54		
Unprotected sex on alcohol/drugs	319 (14)	1.64	1.29, 2.08	1.09	.79, 1.51
<i>Legal involvement</i>					
Ever been incarcerated	707 (32)	1.81	1.51, 2.18	1.27	1.02, 1.59

*Percentages may not add up to 100% due to rounding and because descriptive information is based on raw data which includes missing data.

Note: Significant effects ($p < .05$) have *CI*'s that do not cross zero.