

# Early Linkage and Retention in Care: Findings from the Outreach, Linkage, and Retention in Care Initiative Among Young Men of Color Who Have Sex with Men

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## Abstract

Early linkage and retention in HIV clinical care is essential for optimal disease management, promotion of health, and receipt of secondary prevention messages to decrease onward transmission of HIV. Youth, specifically racial/ethnic minority young men who have sex with men (YMSM), continue to acquire new HIV infections and have been shown to be less likely to engage in regular HIV care and adhere to scheduled medical visits. The goal of the current study was to evaluate the characteristics of participants and program delivery that were associated with early linkage and retention in HIV care among HIV-infected YMSM of color enrolled in an outreach, linkage, and retention study. Of the 334 patients included in the linkage analysis, 72% were linked to care within 30 days of diagnosis, 81% within 60 days, and 87% within 90 days. While no patient-level characteristics were associated with early linkage, having the person who provided the positive HIV test result refer the patient to HIV care ( $p=0.048$ ), specifically calling to make the appointment ( $p=0.009$ ), was associated with earlier linkage. Retention of Latino participants (96.2%) was significantly higher than for the African-American (79.9%) youth ( $p=0.006$ ). Overall, 221 participants had at least 1 year of possible follow-up and 82.8% of these participants were retained at 1 year. While unique challenges exist in the care of adolescents infected with HIV from identification to engagement and retention in clinical care, programs that are responsive and dedicated to the needs of these youth can be successful in retaining them in care.

## Introduction

THERE EXIST UNIQUE CHALLENGES in the care of adolescents infected with HIV, from identification to engagement and retention in clinical care.<sup>1,2</sup> Early linkage and maintenance in care can maximize the potential for anti-retroviral therapy (ART) regimens to restore immunity and promote overall health and wellness.<sup>3-5</sup> Moreover, early identification and treatment can reduce secondary HIV infections and transmission of drug-resistant strains through education regarding safe sexual practices and other harm reduction techniques.<sup>6-8</sup>

Prior studies have indicated that youth and minorities are less likely to engage in regular HIV care, with young racial/

ethnic minority men who have sex with men (YMSM) being particularly difficult to engage.<sup>9,10</sup> Prior research has found that being young, a racial/ethnic minority, or having public or no health insurance was associated with attending fewer HIV clinic visits per year.<sup>11</sup> Outcomes can be improved by providing linkage and retention services that are youth-specific, culturally sensitive, and comprehensively address the multitude of mental health, substance use, and social issues.<sup>12,13</sup>

In 2003, the HIV/AIDS Bureau (HAB) of the Health Resources and Services Administration funded a Special Projects of National Significance (SPNS) Initiative to identify innovative strategies for outreach, linkage, entry, and retention in care for HIV-positive YMSM of color. Early results were published in 2009 and found that over the first 28 months,

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only 11.4% of study visits were missed without explanation or patient contact. Characteristics associated with retention in the study included being less than 21 years old, having a history of depression, receipt of SPNS YMSM program services, and feeling respected at clinic. Characteristics associated with worse retention included having a CD4 count less than 200 cells/mm<sup>3</sup> at baseline, and being Latino.<sup>14</sup> That report focused on retention in the study as a proxy for retention in care. The purpose of this analysis, which includes data on clinical visits, is to update and expand the findings presented in that earlier report, and to examine the characteristics of participants and program delivery that were associated with early linkage and retention in HIV care.

## Methods

### Participants

Participants were enrolled at eight SPNS-funded demonstration sites (Bronx, NY; Chapel Hill, NC; Chicago, IL; Detroit, MI; Houston, TX; Los Angeles, CA; Oakland, CA; and Rochester, NY), each with its own outreach, linkage, and retention strategies. Interventions at the sites varied based on local program design. Each of the eight sites operated independently but used a common data collection tool and common eligibility requirements (except as noted below) to allow for cross-site comparisons. Data collected from the sites were entered into a secure web-based data entry portal maintained by the evaluation center. Data were collected between June 1, 2006 and August 31, 2009.

Eligible participants were (a) born male; (b) HIV-infected and not currently in care; (c) self-reported sex with males; (d) self-identified as Hispanic ethnicity or nonwhite race; (e) between 13 and 24 years old at the time of the first interview; and (f) able to provide written informed consent. Eligible participants were administered a standardized face-to-face interview by experienced interviewers at baseline and every 3 months thereafter. All participants provided written informed consent to participate in the study. Local Institutional Review Boards (IRBs) and The George Washington University IRB approved all instruments and protocols. Uni- and bivariate analyses were used to describe participants and potential confounders.

### Statistical analysis

For new-to-care participants, three sites (Bronx, NY; Chapel Hill, NC; and Rochester, NY) enrolled youth who were diagnosed with HIV within the past 6 months; one site (Chicago, IL) enrolled youth diagnosed within the past 3 months; and three sites enrolled all youth who had never been in care (Detroit, MI; Houston, TX; Los Angeles, CA). One site (Oakland, CA) only enrolled youth who had been newly diagnosed within 30 days and, because this criterion would bias that site's linkage to care rate, they were excluded from this linkage analysis. Six sites (Bronx, NY; Chapel Hill, NC; Detroit, MI; Los Angeles, CA; Oakland, CA; and Rochester, NY) also enrolled youth who were not new to care but had received either intermittent or no care for at least 6 months.

Clinical data were abstracted from medical records and assigned to the appropriate time window (baseline, 6-month follow-up, 12-month follow-up) based on the participant's

date of entry into the study. Baseline values were required to be within 2 months of study entry; 6-month follow-up values were required to be between 4 and 8 months after study entry; and 12-month values were required to be between 10 and 14 months after study entry. If there were two clinical values within a window, the average of the two was used for analysis.

Pearson's Chi-square test was used to compare those participants new-to-care to those with previous care experiences; those with early linkage to those with delayed linkage; and those retained 1 year or more to those retained less than 1 year. Generalized estimating equations (GEE) with exchangeable correlation matrices were used to examine changes over time on key variables to adjust for the repeated measures on the same individuals. SAS v.9.1 (SAS Institute, Cary, NC) was used for all statistical analyses.

### Variable definition

**Early linkage.** We defined linkage in care based on self-report of the time interval between when a participant first tested positive and when they first saw a medical provider. We classified those participants with a reported HIV medical visit within 30 days of their self-reported date of HIV diagnosis as having early linkage. For the 10 persons who did not report how much time elapsed between diagnosis and entry into care, the time between their self-reported diagnosis date and the date of their first HIV visit according to medical record review was used to estimate their time to link to care.

**Retention in care.** We defined retention as having at least three HIV care visits within the first year after enrollment with at least one visit in the first 6 months and one visit in the second 6 months. Participants who entered the study after August 31, 2008 were excluded from the retention analysis since they had less than 1 year of follow-up before the end of the study.

**Social support.** A ten-item scale was used to measure social support, with higher values indicating more social support. Nine items such as, "How often do you feel that you don't have people to hang out with?" and "How often do you feel you have no one to turn to?" were scored from 1 to 4 with 1="never," 2="sometimes," 3="most of the time," and 4="always." One item, "How often do you see/hear from close friends?" was scored from 1 to 5 with 1="less than once a month," 2="monthly," 3="a few times a month," 4="a few times a week," or 5="daily." Items worded negatively were reverse coded so that a higher value would indicate more social support. The average of the questions was computed to get a mean score for social support. If more than 25% of the items were skipped, the participant was assigned a missing value for the social support scale. The Cronbach  $\alpha$  for the scale was 0.79.

**Critical need variable.** If a participant answered "yes" to any items assessing unstable housing; used alcohol on  $\geq 7$  days in past 2 weeks; reported emotional or psychological problems from using alcohol/drugs in past 3 months; or scored  $\geq 16$  on the Center for Epidemiologic Studies Depression Scale (CES-D),<sup>14a</sup> they were characterized as having an immediate critical psychosocial need.

## Results

### Prior care experiences

Characteristics of the entire sample ( $n=363$ ) are presented in Table 1. Two-thirds ( $n=244$ ) of the sample was never previously in care, while one-third ( $n=119$ ) reported prior care experiences but had been either out of care for at least 6 months ( $n=90$ ) or had less than two HIV primary care visits in the previous 6 months ( $n=29$ ). Participants who were new to care were more likely to be younger ( $p<0.0001$ ), African-American ( $p<0.0001$ ) and less likely to be on ART ( $p=0.0002$ ) compared to those with previous care experiences.

### Linkage

Of the 334 patients included in the linkage analysis, 72% ( $n=239$ ) were linked to care within 30 days of diagnosis, 81% ( $n=270$ ) within 60 days of diagnosis, and 87% ( $n=291$ ) within 90 days. No client-level characteristics were associated with early linkage. However, if the person who provided the positive test result referred the participant to care ( $p=0.048$ ), specifically if he or she called to make the appointment ( $p=0.009$ ), linkage to care was earlier (Table 2).

### Retention

Overall, 221 participants had at least 1 year of possible follow-up (enrolling on or before August 31, 2008). A large percentage (82.8%) of these participants was retained at one

year (Table 3). There was no difference in retention at 1 year between those participants who were new to care or those being re-engaged (84.3% versus 80.0%, respectively). Retention of Latino participants (96.2%) was significantly higher than for the African-American (79.9%) youth ( $p=0.006$ ). While retention varied by site, these findings should be viewed with caution due to low numbers of participants at some sites. Specific interventions used by the sites associated with improved retention were having the availability of youth-focused support groups and programs ( $p=0.002$ ) and having a medical provider with experience treating HIV-infected youth ( $p=0.001$ ). As expected, persons with better retention in care were less likely to have a last known CD4 count below 200. Table 4 demonstrates the changes over time from baseline to 6 and 12 months on barriers to care and health outcomes. The youth reported increases in insurance ( $p<0.0001$ ) and decreased episodes of running out of money or having to borrow money in the prior 3 months ( $p=0.002$ ) at both 6- and 12-month follow-up compared to baseline. We saw positive changes over time in use of ART ( $p<0.0001$ ) and a decrease in hospital and emergency room visits ( $p<0.0001$ ) at both follow-up points.

## Discussion

The purpose of this initiative was to find, link, and retain young racial/ethnic minority MSM in HIV care. Overall, we were successful in linking a large number of these youth to care in a timely fashion and retaining them at 1 year of

TABLE 1. CHARACTERISTICS OF RACIAL/ETHNIC MINORITY YMSM STRATIFIED BY HIV CARE EXPERIENCES (N=363)

	Never in care N=244	Previous care experiences N=119	p Value Chi-square test
Age, mean (SD)	20.0 (1.91)	21.1 (1.79)	<0.0001 <sup>a</sup>
Ethnicity			
African-American	176 (72.1)	66 (55.5)	<0.0001
Hispanic	35 (14.4)	43 (36.1)	
Multiracial/other	33 (13.5)	10 (8.4)	
Education			
Some HS or less	68 (27.9)	37 (31.1)	0.019
HS or GED	79 (32.4)	22 (18.5)	
Some college or more	97 (39.7)	60 (50.4)	
Ran out of money for basic needs, last 3 months			0.716
Many times	73 (30.7)	37 (34.9)	
Once/twice/few	112 (47.0)	48 (45.3)	
Never	53 (22.3)	21 (19.8)	
Had to borrow money to get by, last 3 months			0.956
Many times	52 (21.7)	22 (21.0)	
Once/twice/few	129 (54.0)	56 (53.3)	
Never	58 (24.3)	27 (25.7)	
Time since diagnosis (days), median (IQR)	59.5 (29–104.5)	536 (302–885)	<0.0001
CD4 count category (%) <sup>b</sup>			
<200 cells/mm <sup>3</sup>	28 (13.7)	9 (9.1)	0.125
201–349 cells/mm <sup>3</sup>	43 (21.1)	29 (29.3)	
350–499 cells/mm <sup>3</sup>	45 (22.1)	28 (28.3)	
≥500 cells/mm <sup>3</sup>	88 (43.1)	33 (33.3)	
Undetectable HIV viral load, <200 copies/ml (%) <sup>c</sup>	5 (2.7)	16 (21.1)	0.001
On antiretroviral therapy (ART) <sup>d</sup>	38 (17.0)	39 (35.5)	0.0002

<sup>a</sup>t-test was performed.

<sup>b</sup>No CD4 cell count data on 60 participants (40 never in care and 20 with previous care).

<sup>c</sup>No HIV viral load data on 100 participants (57 never in care and 43 with previous care).

<sup>d</sup>Includes being prescribed ART that day.

TABLE 2. CLINICAL CHARACTERISTICS OF RACIAL/ETHNIC MINORITY YMSM STRATIFIED BY TIME FROM HIV DIAGNOSIS TO ENTRY INTO CARE (N=334)

	“Early” Linkage, ≤30 days (N=239) N (%)	“Delayed” Linkage, >30 days (N=95) N (%)	p Value Chi-square test
Site			0.029
Bronx, NY	47 (81.0)	11 (19.0)	
Houston, TX	30 (60.0)	20 (40.)	
Los Angeles, CA	46 (70.8)	19 (29.2)	
Rochester, NY	5 (62.5)	3 (37.5)	
Chapel Hill, NC	64 (79.0)	17 (21.0)	
Detroit, MI	29 (58.0)	21 (42.0)	
Chicago, IL	18 (81.8)	4 (18.2)	
Age			0.541
≤18	41 (68.3)	19 (31.7)	
19–24	198 (72.3)	76 (27.7)	
Race/ethnicity			0.135
African American	160 (70.2)	68 (29.8)	
Latino/Hispanic	54 (79.4)	14 (20.6)	
Currently in school			0.082
Yes	91 (77.8)	26 (22.2)	
No	143 (68.8)	65 (31.2)	
Currently employed			0.795
Yes	107 (70.9)	44 (29.1)	
No	127 (72.2)	49 (27.8)	
Health insurance status			0.496
Yes	149 (70.3)	63 (29.7)	
No (do not have it)	90 (73.8)	32 (26.2)	
Prior HIV care experiences			0.163
Yes	179 (73.7)	64 (26.3)	
No	60 (65.9)	31 (34.1)	
Depressive symptoms			0.663
≥16	117 (70.5)	49 (29.5)	
<16	104 (72.7)	39 (27.3)	
Moved ≥1 time in last 3 months	94 (72.9)	35 (27.1)	0.661
Prior HIV testing			0.589
1–2 times	98 (68.5)	45 (31.5)	
3–5 times	88 (73.3)	32 (26.7)	
>5 times	49 (74.2)	17 (25.8)	
Person who provided positive results referred to care			0.048
Yes	200 (74.9)	67 (25.1)	
No	26 (60.5)	17 (39.5)	
Person who referred to care... <sup>a,b</sup>			
Called and made appointment			0.009
Yes	120 (81.1)	28 (18.9)	
No	80 (67.2)	39 (32.8)	
Helped with transportation			0.290
Yes	45 (80.4)	11 (19.6)	
No	155 (73.5)	56 (26.5)	
Took to appointment			0.160
Yes	46 (82.1)	10 (17.9)	
No	154 (73.0)	57 (27.0)	
Told where to go			0.595
Yes	106 (76.3)	33 (23.7)	
No	94 (73.4)	34 (26.6)	
Reason tested <sup>b</sup>			
Sick	71 (74.0)	25 (26.0)	0.537
Risk event <sup>c</sup>	65 (66.3)	33 (33.7)	0.172
Part of physical/routine exam	46 (65.7)	24 (34.3)	0.223
Testing or outreach event	6 (66.7)	3 (33.3)	0.742
Other/not reported	63 (73.3)	23 (26.7)	0.685

<sup>a</sup>Only includes participants who answered yes to the question “Did the person who gave you the positive test result refer you for medical care?”

<sup>b</sup>Could choose more than one response.

<sup>c</sup>Risk event includes: condom broke or did not use a condom during sex, thought might be HIV-positive, informed to get tested by disease intervention specialists (DIS) or partners.

TABLE 3. CLINICAL CHARACTERISTICS OF RACIAL/ETHNIC MINORITY YMSM STRATIFIED BY RETENTION IN CARE FOR ONE YEAR (N=221)

	Retained ≥1 year (N=183) N (%)	Retained <1 year (N=38) N (%)	p Value Chi-square test
Site			<0.0001 <sup>a</sup>
Oakland, CA	6 (42.9)	8 (57.1)	
Bronx, NY	41 (97.6)	1 (2.4)	
Houston, TX	21 (72.4)	8 (27.6)	
Los Angeles, CA	45 (97.8)	1 (2.2)	
Rochester, NY	3 (100)	0	
Chapel Hill, NC	37 (75.5)	12 (24.5)	
Detroit, MI	24 (82.8)	5 (17.2)	
Chicago, IL	6 (66.7)	3 (33.3)	
Age			0.326
≤18	31 (77.5)	9 (22.5)	
19–24	152 (84.0)	29 (16.0)	
Race/ethnicity			0.006
African American	115 (79.9)	29 (20.1)	
Latino/Hispanic	50 (96.2)	2 (3.9)	
Currently in school			0.798
Yes	68 (83.9)	13 (16.1)	
No	114 (82.6)	24 (17.4)	
Currently employed			0.206
Yes	86 (79.6)	22 (20.4)	
No	93 (86.1)	15 (13.9)	
Health insurance			0.814
Yes	124 (83.2)	25 (16.8)	
No (don't have it)	59 (81.9)	13 (18.1)	
Prior HIV care experiences			0.428
Yes	60 (80.0)	15 (20.0)	
No	123 (84.3)	23 (15.7)	
Depressive symptoms			0.858
≥16	89 (82.4)	19 (17.6)	
<16	79 (81.4)	18 (18.6)	
Moved ≥1 time in last 3 months			0.306
Yes	67 (79.8)	17 (20.2)	
No	109 (85.2)	19 (14.8)	
Critical need variable <sup>b</sup>			0.720
Yes	111 (82.2)	24 (17.8)	
No	62 (82.7)	13 (17.3)	
Retention intervention (site specific)			
Case management <sup>c</sup>	143 (84.6)	26 (15.4)	0.199
Support groups <sup>d</sup>	45 (97.8)	1 (2.2)	0.002
Medical providers with expertise in HIV+ youth <sup>e</sup>	135 (78.5)	37 (21.5)	0.001
Flexible appointments <sup>f</sup>	52 (78.8)	14 (21.1)	0.343
Early Entry into Care (<30 days) <sup>g</sup>			0.405
Yes	125 (86.2)	20 (13.8)	
No	39 (81.3)	9 (18.8)	
Social support variable, Mean (SD)	3.20 (.56)	3.17 (.55)	0.755
Friends <sup>h</sup>			0.727
None	21 (11.9)	4 (11.1)	
1–3	104 (58.8)	19 (52.8)	
4+	52 (29.4)	13 (36.1)	
Last known CD4 cell count	(n=145)	(n=11)	
Mean (SD)	495 (227)	412 (304)	0.258
≥200 cells/mm <sup>3</sup>	137 (94.5)	7 (63.6)	0.005
Last known HIV viral load	(n=66)	(n=14)	
Mean (SD), log10	3.28 (1.1)	3.58 (1.2)	0.349
<200 copies/ml	15 (22.7)	3 (21.4)	0.916

<sup>a</sup>Exact Pearson Chi-square test.

<sup>b</sup>Unstable housing, depressed, alcohol use on ≥7 days in past 14 days, had emotional or psychological problems from alcohol/drugs in past 3 months, scored ≥16 on CES-D.

<sup>c</sup>Service available at sites: Bronx, NY; Chicago, IL; Detroit, MI; Houston, TX; Los Angeles, CA; and Oakland, CA.

<sup>d</sup>Service available at sites: Bronx, NY; Chapel Hill, NC; Chicago, IL; Detroit, MI; Houston, TX; Oakland, CA; and Rochester, NY.

<sup>e</sup>Service available at sites: Bronx, NY; Chapel Hill, NC; Chicago, IL; Detroit, MI; Houston, TX; and Oakland, CA.

<sup>f</sup>Service available at sites: Bronx, NY; Houston, TX; and Oakland, CA.

<sup>g</sup>Excludes Oakland, CA.

<sup>h</sup>How many friends do you feel comfortable with that you can talk to about private matters, or can call on for help?

TABLE 4. DESCRIPTIVE STATISTICS AND HEALTH OUTCOMES OF RACIAL/ETHNIC MINORITY YMSM AT BASELINE, 6 MONTHS, AND 12-MONTH FOLLOW-UP

	Time			p Value GEE regression model
	Baseline (N = 363) n (%)	6 months (N = 232) n (%)	12 months (N = 173) n (%)	
Education (HS degree or more)	258 (71.1)	122 (71.4)	98 (71.5)	0.242
No insurance	134 (36.9)	43 (19.3)	28 (16.9)	<0.0001
Borrow or run out of money, past 3 months	298 (86.1)	133 (77.3)	99 (73.3)	0.002
Disclosure <sup>a</sup> , mean (SD)	3.2 (2.1)	3.3 (2.3)	3.6 (2.4)	0.029
CD4 cell count	(n = 192)	(n = 131)	(n = 102)	0.629
<200 cells/mm <sup>3</sup>	25 (13.0)	9 (6.9)	8 (7.8)	
201-349 cells/mm <sup>3</sup>	45 (23.4)	28 (21.4)	20 (19.6)	
≥350 cells/mm <sup>3</sup>	122 (63.6)	94 (71.7)	74 (72.6)	
Undetectable HIV viral load (<200 copies/mL)	(n = 185)	(n = 122)	(n = 92)	0.657
	16 (8.6)	38 (31.1)	22 (23.9)	
ART use	(n = 334)	(n = 207)	(n = 153)	<0.0001
	77 (23.1)	85 (41.1)	66 (43.1)	
Hospital or ER use (%)	132 (37.1)	31 (18.0)	22 (16.2)	<0.0001

<sup>a</sup>Number of people to whom disclosed HIV status.

follow-up. To have maximum impact on both the individual and population level, once a client is diagnosed they need to be immediately linked to care. A recent meta-analysis found that only 69% of HIV-diagnosed persons in the United States (US) entered care.<sup>15</sup> Similarly, a prospective study found that 40% of persons recently diagnosed with HIV infection did not visit a clinician at least once within 6 months.<sup>16</sup>

In our study, we report extremely high rates of early linkage with 87% of the cohort being linked to care within 90 days. Most experts recommend linkage to care within 3 months and define failure as when a maximum of 6 months elapse following their HIV diagnosis without a medical visit.<sup>17</sup> Prior studies of the characteristics of new HIV-infected patients who failed to attend their initial scheduled appointment found that in addition to patient characteristics (younger age, black race, and public insurance), longer waiting time from the call to schedule the visit to the actual appointment date was associated with failure to establish care.<sup>18,19</sup> Scheduling an appointment promptly in the immediate time period surrounding testing takes advantage of the teachable moment associated with receiving an HIV diagnosis. During this critical period, youth may be more receptive to secondary prevention messages, behavior change, and engagement with the health care system.<sup>20</sup> In one study, most (77%) of those who ever entered care did so within the first 3 months following diagnosis.<sup>21</sup> We found that having the person who informed the youth of their diagnosis provide the initial referral to care significantly predicted earlier linkage. This may indicate that proactive linkage, perhaps in the form of a simple phone call, could be an especially useful and inexpensive intervention for this population.

We were extremely successful at retaining these young men in care, with a retention rate of 83% at 1 year. To our knowledge, this is one of the highest retention rates reported, using stricter retention criteria than often used in previous research.<sup>10,16</sup> As our cohort was either new-to-care or re-engaging after intermittent past adherence to medical visits, we chose our retention measure to reflect the need for more frequent initial visits to establish provider-patient

relationships, to provide education around diagnosis, and to start and monitor response to ART. In a recent meta-analysis, retention was 59% in eight studies that used a threshold of three or more HIV medical visits in 12 months, a criteria similar to the one that we used.<sup>15</sup> If we use a more liberal cutoff of one visit in each 6-month period, our retention rate increases to 89%. These results are even more noteworthy as our cohort consisted of racial/ethnic minority youth who in other studies have had lower retention rates than the general HIV-infected population.<sup>1,9,10,22-24</sup>

While each site utilized different retention strategies and had varying overall success at retention, some interventions were universal and likely contributed to our success. All sites used clinic appointment reminders and some form of case finding for patients who had missed appointments (typically in the form of telephone calls, Short Message Service (SMS) texts, e-mails or in rare cases, home visits). Previous studies found that receiving clinic reminders can increase attendance at visits.<sup>25</sup> In addition, all sites assisted patients in some way with transportation, either helping to coordinate transportation, providing financial assistance in the form of gasoline cards or bus passes, or escorting patients to their medical visits. Unfortunately, over a third of the sample was unable to be included in this retention analysis due to enrolling after August 31, 2008. However, of the young men who had between 6 months and 12 months of follow-up ( $n = 65$ ), 82% had at least two visits, and 55% had three or more medical visits in that brief time interval.

Most of the sites had a small number of dedicated providers who were actively engaged in the initiative and responsible for providing quality care to youth in an ongoing fashion. Previous research has identified the pivotal role of HIV providers in the success of engagement in care for people living with HIV.<sup>26,27</sup> Patients who feel like their provider is accepting, consistent, and responsive to their varying life circumstances are more likely to remain in care.<sup>25</sup> The importance of establishing and maintaining a positive provider-patient relationship that engenders mutual trust, respect, and lack of judgment may be even more important for gay and bisexual

youth who may lack social support and often experience multiple layers of stigma from their families.<sup>2,28</sup> Although we could not definitively assess the relationship between patients and providers, among 183 patients who responded to a multiple choice question as to why they went to their medical appointments, 52% ( $n=96$ ) responded that they like their providers and 53% ( $n=97$ ) said they felt respected in the clinic (data not shown).

Previous research has documented the positive relationship between patients' receipt of ancillary services and their retention in primary HIV medical care.<sup>29,30</sup> In one important study, a higher proportion of 136 case-managed participants compared to 137 standard-of-care participants visited an HIV clinician at least twice within 12 months (64 versus 49%, respectively).<sup>16</sup> While patients at the sites that utilized case management services did not show improved retention in our study, our rates of retention for patients at those sites was 85%, considerably higher than rates found in the previous study. Interestingly, the patients at the sites with youth-specific support groups and social events showed higher retention, which is a finding not previously reported in the literature. In focus groups conducted with HIV-infected youth, participants stressed that to be successful, support services should be skills oriented, culturally sensitive, and focused on healthy living.<sup>31</sup>

Prior studies have demonstrated a relationship between a lack of retention in HIV care and worse clinical outcomes including higher viral loads, lower CD4 counts, and decreased survival.<sup>3,32</sup> In a study by Giordano and colleagues, patients out of care for as little as 3 months in their first year of therapy had worse survival.<sup>3</sup> Sherer *et al.* found that being in regular care was associated with lower viral loads in all time periods.<sup>30</sup> We did find a trend toward improved health outcomes as measured by a decrease in hospital and ER use ( $p<0.0001$ ) and increases in ART use ( $p=<0.0001$ ) for those retained in care at 6- and 12-month follow-up. This has the potential to decrease overall health care costs as well as to improve the quality of life for these young men.<sup>33-35</sup>

This study has several limitations. As we enrolled only participants who were linking to care at dedicated SPNS demonstration sites, our population may not be generalizable to HIV-infected young racial/ethnic minority MSM who fail to enter care. However, a third of our sample had been either "lost to care" or had poor adherence to medical visits, which indicates that we reached an "at risk" population with our interventions and kept this group in care. Participants in our study received a small monetary incentive to complete study-related surveys at 3-month intervals. However, participants did not need to remain in care to complete these surveys, which could have been conducted outside of the clinical setting or via the telephone. Additionally, while this study involved interventions to link these YMSM in care, the time from diagnosis to linkage to care for those young men who were previously in care reflects experiences that occurred prior to this study. Also of note, there were no significant differences between those new to care and those with prior care experiences in terms of early versus delayed linkage. Finally, we may have underestimated retention, since we do not know if participants moved or chose to get care elsewhere.

To our knowledge, this cohort represents the largest and most geographically diverse sample focusing on racial/ethnic minority YMSM entering care. As the HIV epidemic does not

appear to be abating in this population, identifying best practices to link and retain these young men in care is critically important. Our findings would suggest that retention rates can be increased by engaging young racial/ethnic minority men early after their HIV diagnosis, providing a safe and nonjudgmental environment for care (*e.g.*, including offering participation in youth-specific programming), fostering a mutually gratifying relationship between the patient and his medical provider. Moreover, utilizing mobile technology is vital to establish and maintain a "connection to care" with these youth and facilitate ongoing communications (*e.g.*, reminders for medical appointments, rescheduling missed visits). These simple, inexpensive, and yet critically important interventions could be easily adopted by many clinics providing care for these young men with significant improvements in retention rates realized. While previous studies have found that engagement is worse for those groups continuing to be infected and affected by the epidemic, namely youth and minorities, programs that are responsive and dedicated to the needs of these youth can be successful in keeping them in care.

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