

## HIV testing, care referral and linkage to care intervals affect time to engagement in care for newly diagnosed HIV-infected adolescents in fifteen adolescent medicine clinics in the United States

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### **Abstract:**

**Objective:** To examine how the time from HIV testing to care referral and from referral to care linkage influenced time to care engagement for newly diagnosed HIV-infected adolescents.

**Methods:** We evaluated the Care Initiative, a care linkage and engagement program for HIV-infected adolescents in 15 US clinics. We analyzed client-level factors, provider type, and intervals from HIV testing to care referral and from referral to care linkage as predictors of care engagement. Engagement was defined as a second HIV-related medical visit within 16 weeks of initial HIV-related medical visit (linkage).

**Results:** At 32 months, 2143 youth had been referred. Of these, 866 were linked to care through the Care Initiative within 42 days and thus eligible for study inclusion. Of the linked youth, 90.8% were ultimately engaged in care. Time from HIV testing to referral (eg,  $\leq 7$  days versus  $> 365$  days) was associated with engagement [adjusted odds ratio = 2.91; 95% confidence interval (CI): 1.43 to 5.94] and shorter time to engagement (adjusted hazard ratio = 1.41; 95% CI: 1.11 to 1.79). Individuals with shorter care referral to linkage intervals (eg,  $\leq 7$  days versus 22–42 days) engaged in care faster (adjusted hazard ratio = 2.90; 95% CI: 2.34 to 3.60) and more successfully (adjusted odds ratio = 2.01; 95% CI: 1.04 to 3.89).

**Conclusions:** These data address a critical piece of the care continuum and can offer suggestions of where and with whom to intervene to best achieve the care engagement goals outlined in the US National HIV/AIDS Strategy. These results may also inform programs and policies that set

concrete milestones and strategies for optimal care linkage timing for newly diagnosed adolescents.

**Keywords:** HIV | adolescent | time to linkage | care engagement | care linkage

## **Article:**

## **INTRODUCTION**

The purpose of this paper is to examine factors associated with the time required for adolescents to engage in HIV-related care after HIV testing. The development and scale-up of youth-focused intensive case-management and patient navigation services over the past 10 years has markedly improved initial entry into HIV care, although up to 30% of adolescents are not promptly linked to care after initial diagnosis.<sup>1</sup> Moreover, longer term treatment—including antiretroviral treatment (ART)—rarely begins before the second or subsequent visits. The time to ART initiation is critical, because earlier viral suppression improves an individual's HIV health outcomes and drastically reduces HIV transmission risk.<sup>2–7</sup> Despite its importance in the HIV continuum of care, little information exists to identify factors associated with time to engagement that can guide program or service planning to achieve these goals, particularly for adolescents. Specifically, there has been little focus on modifiable factors that contribute to the interval between HIV testing and care engagement.

Engagement refers to the maintenance of HIV-related health care after initial linkage, as demonstrated by an individual's motivation and readiness to attend a second HIV-related care appointment within a defined interval after linkage.<sup>8,9</sup> This is reflected in the HIV Medicine Association guidelines that highlight how the “emphasis should be placed on the importance of adherence to care rather than focusing solely on adherence to medications”.<sup>10</sup> The interval between HIV testing and engagement in care requires necessarily prior events such as a youth's receipt of positive test results, referral to care, and initial receipt of HIV-related services (eg, medical, social, psychological). In contemporary usage, these early events in the continuum of care collectively represent care linkage.<sup>9,11</sup>

Failures in timely care engagement may be especially important for adolescents as this age group constitutes 26% of new infections and approximately 60% of HIV-infected 13- to 24-year olds are undiagnosed.<sup>1,12,13</sup> Once diagnosed and linked to care, nearly one-third of adolescents drop out of care.<sup>1,14,15</sup> Adolescents consequently have lower rates of viral suppression and higher virologic rebound than adults: Only 6% of adolescents achieve initial viral suppression compared with 28% of HIV-infected adults.<sup>1,14</sup> Engagement is therefore an important point in the continuum of care because the full benefits of modern biomedical interventions—prevention of advanced disease, reduced transmission risk, and reduced community viral load—are enacted as part of sustained engagement in care.<sup>16,17</sup> Little research, however, has examined factors that influence the timeliness of engagement in care.

This paper examines social and behavioral factors associated with time to engagement in care for newly diagnosed HIV-infected adolescents. These data inform understanding of a critical

juncture in the HIV care continuum and suggest approaches to achieving the National HIV/AIDS Strategy's goal of “seamless” HIV care from HIV diagnosis to sustained viral suppression.<sup>7</sup>

## METHODS

Data were collected from 15 Adolescent Medicine Trials Network (ATN) clinic sites. These Adolescent Medicine Trial Units (AMTU) care for adolescents, aged 12–24 years, in 13 cities across the United States and Puerto Rico. The AMTUs are often the primary adolescent-specific HIV care providers in their respective cities and also offer psychosocial services such as mental health, housing, and vocational support. Each AMTU implemented the *SMILE* Program in 2010. This initiative is a collaborative effort of NICHD, Centers for Disease Control and Prevention, and the ATN designed to facilitate linkage to care for adolescents with new HIV infection diagnoses. The initiative facilitated formal relationships among the AMTU, health departments, and local youth-serving organizations involved with HIV testing and treatment<sup>18</sup> and involved development of formal linkage to care protocols and provision of an outreach worker to facilitate linkage services, and to coordinate referrals within a given catchment area. The majority of referrals were assigned to the outreach worker, though some were assigned to other AMTU staff or community organizations. *SMILE* was designed to address the variable quality and fragmentation of services characteristic of youth HIV linkage to care activities in 2010. *SMILE* also emphasized the importance of formal relationships with the health departments intended to improve access to real-time HIV testing data. The criteria for referral to *SMILE* were similar across sites, with variation in referral patterns because of the variable success of facilitating linkages between the health department, AMTU, and local organizations. Linkage was defined as an HIV-related medical visit within 42 days (ie, 6 weeks) of referral; engagement was a second HIV-related medical visit within 16 weeks of the initial visit. These definitions reflect the intensive case-management approach adopted for the *SMILE* program and are more restrictive than standards for care linkage and engagement that came into wider use with adult patients after initiation of this study.<sup>8,19</sup> The Institutional Review Board at each site approved all procedures.

### *Independent Measures*

Independent measures included *client-level* factors and *provider type*. *Client-level factors* included youths' self-reported age, gender, race/ethnicity, sexual identity, homeless status, mode of HIV acquisition, and illicit drug use in the last year (eg, marijuana and heroin). The *provider* was the person assigned to provide linkage, categorized as the AMTU outreach worker, other AMTU staff (eg, physicians, nurses, case managers), or non-AMTU staff (eg, non-AMTU clinic staff, community-based social worker).

### *Outcome Measures*

We defined 2 intervals of importance for understanding care engagement. The first interval was the time in days between an individual's first positive HIV test and a second HIV-related clinic visit within 16 weeks of the first HIV-related clinic visit (care engagement). This diagnosis–engagement interval provides insight into early factors (such as difficulty in locating patients for test results or because of inefficient referral networks) that could contribute to delays in receiving

care. A second interval was time (in days) from referral to the SMILE program until a second HIV-related clinic visit within 16 weeks of an initial HIV-related clinic. This referral–engagement interval variable provides program evaluation data and can be used to additionally refine standards of care for newly diagnosed HIV-infected youth. We also examined engagement as a dichotomous outcome, ie, whether an adolescent became engaged in care (or not) within 16 weeks of an initial HIV-related visit. This variable serves as a quality of care standard.<sup>8,19</sup>

### *Statistical Methods*

The proportional hazards regression analysis was used to examine the relationship of time from referral to engagement with potential impact factors such as age, gender, race/ethnicity, mode of HIV acquisition, client's housing status, drug use, case assignment status and time from referral to care linkage, and HIV testing to linkage. For those who engaged in care, the time was defined as the days from referral to the engagement (the second medical appointment). For those who were not engaged, we used days from referral to either the second medical appointment or the summation of lengths of referral to first medical appointment and half of 16 weeks after the first medical appointment. Covariates with an overall  $P$ -value of  $\leq 0.20$  were entered into the initial full multivariable model for model selection. The stepwise and backward model selection techniques were used to select the best final model. A similar analysis was performed for the outcome of time from HIV testing to engagement. To determine rates of engagement in care (no/yes), we used logistic regression analysis. All data analyses were run in SAS Version 9.3.

## **RESULTS**

### *Description of Sample*

After 32 months, 2143 youth were referred to the SMILE program. Of these, 344 were excluded for having failed earlier linkage to care efforts ( $n = 106$ ), having a prior positive test ( $n = 171$ ) and perinatal route of infection ( $n = 67$ ), leaving 1799 newly diagnosed cases referred to the SMILE program. Of these cases, 69.8% were linked to care, of which 89% were engaged in care; overall 62.1% of adolescents were linked to care and engaged in care. For the analyses in this paper, we additionally eliminated 145/1799 cases because they lacked an accurate test date (eg, missing year, testing date was in the future). Of the remaining 1655 cases, 866 were eligible for engagement in care because they completed an initial linkage to care visit within 42 days of referral.

The study sample was predominantly men (80%), black (77%), and had acquired HIV through male-to-male sexual contact (74%). The mean age was 20.7 years, 66% reported drug use in the last year and most (80%) were assigned to an AMTU outreach worker (Table 1).

### *Time From HIV Testing to Engagement in Care*

The unadjusted Cox model for time from HIV testing to engagement in care (Table 2) demonstrates that individuals who were referred and linked more quickly had a higher likelihood of care engagement, as did younger individuals, men, people who acquired HIV through male-to-male sexual contact, and individuals assigned to other AMTU staff. Specifically, individuals who

were referred to care within 365 days of being HIV tested had higher rates of care engagement than those who were referred after 365 days, though with a much greater effect size in the first 28 days compared with the rest of the first year. Individuals with shorter time intervals from referral to linkage were more likely to engage in care [hazard ratio (HR) = 1.36; 95% confidence interval (CI): 1.11 to 1.66]. Younger individuals also had a higher likelihood of engagement as did men (HR = 1.38; 95% CI: 1.13 to 1.67) versus women, HIV acquisition by male-to-male sexual contact (HR = 1.24; 95% CI: 1.04 to 1.48) versus different sex contact, and those who were assigned to other AMTU staff (HR = 1.51; 95% CI: 1.21 to 1.87) compared with an AMTU outreach worker. Ethnicity other than non-Hispanic white was associated with a lower likelihood of engagement.

The adjusted Cox model showed that individuals with shorter intervals for referral and linkage to care were more likely to engage in care, as were non-white clients and those assigned to other AMTU staff. Shorter intervals from HIV testing to referral (<365 days compared with >365 days) were much more likely to be engaged in care, though there is a decreasing magnitude of the trend as time from testing to referral lengthens. Individuals with shorter length from referral to linkage to care (<21 days compared with 22–42 days) also had greater likelihood of care engagement. Referral and linkage on the same day was not associated with engagement (Table 2). Compared with non-Hispanic white individuals, non-Hispanic blacks, non-Hispanic others, and Hispanics were less likely to be engaged in care. Clients who were assigned to other AMTU staff compared with an outreach worker (HR = 1.29; 95% CI: 1.02 to 1.62) were more likely to have shorter engagement in care intervals.

#### *Time From Referral to Engagement in Care*

Factors related to interval from SMILE program referral to engagement in the unadjusted model also included clients who used drugs in the last 12 months (Table 3). Individuals referred to the SMILE program within 28 days of testing had a higher likelihood of being engaged in care than those referred after 1 year. Similarly, individuals linked to care on the same day as referral and within 21 days of referral had a higher likelihood of engagement in care than those linked 22–42 days after referral. Clients who used drugs in the past 12 months (HR = 1.19; 95% CI: 1.02 to 1.39) and individuals assigned to other AMTU staff (HR = 1.27; 95% CI: 1.03 to 1.58) compared with AMTU outreach workers were more likely to engage. Hispanics were less likely to be engaged in care (HR = 0.57; 95% CI: 0.41 to 0.81) compared with Non-Hispanic Whites.

The results from the adjusted Cox model indicate that time from referral to linkage to care, time from HIV testing to referral, race/ethnicity, and mode of HIV acquisition were associated with engagement in care (Table 3). Subjects with a shorter time from HIV testing to referral (ie, <28 days compared with >365 days) had an approximate 41%–69% increased likelihood of shorter time to care engagement. The length from referral to linkage to care showed that individuals linked more quickly (ie, in the first 3 weeks) were also more likely to engage in care than those linked within 22–42 days. Compared with non-Hispanic whites, Non-Hispanic Blacks, Non-Hispanic Other, and Hispanics were less likely to be engaged in care. Individuals who reported acquiring HIV through male-to-male sexual contact had a shorter time to engagement in care than those who acquired HIV through heterosexual contact.

**Table 1.** Demographic Characteristics Among All 886 HIV-Positive Adolescents

	<b>n (%) (N = 866)</b>	<b>Mean (SD)</b>	<b>Median (Minimum–Maximum)</b>
Age (yrs), continuous		20.68 (2.22)	21 (13-24)
12–17	83 (9.63)		
18–20	301 (34.92)		
21–22	283 (32.83)		
23–24	195 (22.62)		
Missing	4		
Gender			
Men	695 (80.35)		
Women	148 (17.11)		
Transgender	22 (2.54)		
Missing	1		
Race			
White	87 (10.13)		
Black	660 (76.83)		
American Indian/Alaskan Native	2 (0.23)		
Asian	1 (0.12)		
Mixed race	70 (8.15)		
Other	29 (3.38)		
Not asked/refused to answer	10 (1.16)		
Ethnicity			
Hispanic	133 (15.48)		
Non-Hispanic	729 (84.52)		
Missing	7		
Race/ethnicity			
Non-Hispanic white	52 (6.08)		
Non-Hispanic black	635 (74.27)		
Non-Hispanic other	35 (4.09)		
Hispanic	133 (15.56)		
Missing	11		
Mode of acquisition			
Heterosexual contact	184 (21.27)		
Male-to-male sexual contact	641 (74.10)		
IDU + other	40 (4.62)		
Missing	1		
Time between HIV test date and referral to care initiative (d)		178.30 (434.30)	17 (0–4089)
0–7	286 (34.38)		
8–14	105 (12.62)		
15–28	104 (12.50)		
29–42	63 (7.57)		
43–60	49 (5.89)		
61–120	57 (6.85)		
121–180	20 (2.40)		
181–365	35 (4.21)		
365+	113 (13.58)		
Missing	34		
What is the client’s current housing status: homelessness			
Yes	15 (1.97)		
No	745 (98.03)		
Not assessed (unknown)/other/refuse to answer/missing	106		
Has the client used any of the drugs in the past 12 mo?			
Yes	572 (66.05)		
No	294 (33.95)		
Case assignment			
LTC OW	689 (79.65)		
Other AMTU staff	111 (12.83)		
Non-AMTU staff	65 (7.51)		
Engaged in care			
Yes	786 (90.76)		
No	80 (9.24)		

**Table 2.** Relationship of Time From HIV Testing to Engagement-In-Care With Potential Impact Factors (Cox Model)

	Total, n (%)	EIC, n (%)	No EIC, n (%)	HR* (95% CI)	P	Adjusted HR (95% CI*)	P
Days from HIV testing to referral							
0–7	286 (34.38)	265 (92.66)	21 (7.34)	123.44 (75.34 to 202.24)	<0.0001	155.19 (92.71 to 259.76)	<0.0001
8–14	105 (12.62)	99 (94.29)	6 (5.71)	126.13 (74.12 to 214.63)	<0.0001	149.15 (86.01 to 258.64)	<0.0001
15–28	104 (12.50)	98 (94.23)	6 (5.77)	91.17 (53.64 to 154.96)	<0.0001	117.68 (67.70 to 204.57)	<0.0001
29–365	224 (26.92)	2001 (89.73)	23 (10.27)	25.95 (15.80 to 42.63)	<0.0001	28.66 (17.13 to 47.95)	<0.0001
365+	113 (13.58)	94 (83.19)	19 (16.81)	1.00		1.00	
Days from referral to LTC							
0 d	114 (13.21)	103 (90.35)	11 (9.65)	0.84 (0.66 to 1.09)	0.1900	1.21 (0.92 to 1.58)	0.1727
1–7	263 (30.48)	242 (92.02)	21 (7.98)	1.36 (1.11 to 1.66)	0.0030	2.06 (1.67 to 2.54)	<0.0001
8–14	189 (21.90)	176 (93.12)	13 (6.88)	1.45 (1.17 to 1.80)	0.0007	1.82 (1.45 to 2.27)	<0.0001
15–21	107 (12.40)	97 (90.65)	10 (9.35)	1.25 (0.96 to 1.61)	0.0926	1.41 (1.09 to 1.84)	0.0097
22–42	190 (22.02)	165 (86.64)	25 (13.16)	1.00		1.00	
Age (yrs)							
12–17	83 (9.63)	81 (97.59)	2 (2.41)	2.05 (1.56 to 2.70)	<0.0001		
18–20	301 (34.92)	277 (92.03)	24 (7.97)	1.76 (1.44 to 2.15)	<0.0001		
21–22	283 (32.83)	255 (90.10)	28 (9.90)	1.33 (1.09 to 1.63)	0.0048		
23–24	195 (22.62)	171 (87.69)	24 (12.31)	1.00			
Gender							
Men	695 (80.35)	627 (90.22)	68 (9.78)	1.38 (1.13 to 1.67)	0.0012		
Women	148 (17.11)	139 (93.92)	9 (6.08)	1.00			
Transgender	22 (2.54)	20 (90.90)	2 (9.10)	0.89 (0.55 to 1.43)	0.6208		
Race/ethnicity							
Non-Hispanic white	52 (6.08)	50 (96.15)	2 (3.85)	1.00		1.00	
Non-Hispanic black	635 (74.27)	580 (91.34)	55 (8.66)	0.79 (0.59 to 1.06)	0.1156	0.52 (0.38 to 0.70)	<0.0001
Non-Hispanic other	35 (4.09)	29 (82.86)	6 (17.14)	0.54 (0.34 to 0.86)	0.0087	0.42 (0.26 to 0.68)	0.0004
Hispanic	133 (15.56)	119 (89.47)	14 (10.53)	0.79 (0.57 to 1.11)	0.1797	0.48 (0.34 to 0.68)	<0.0001
Mode of acquisition							
Heterosexual contact	184 (21.27)	171 (92.93)	13 (7.07)	1.00			
Male-to-male sexual contact	641 (74.10)	582 (90.80)	59 (9.20)	1.24 (1.04 to 1.48)	0.0154		
IDU + other	40 (4.62)	32 (80.00)	8 (20.00)	1.12 (0.76 to 1.64)	0.5731		
What is the client's current housing status: homelessness							
Yes	15 (1.97)	14 (93.33)	1 (6.77)	0.83 (0.49 to 1.41)	0.4806		
No	745 (98.03)	683 (91.68)	62 (8.32)	1.00			
Has the client used any of the drugs in the past 12 mo?							
Yes	572 (66.05)	522 (91.26)	50 (8.74)	1.09 (0.94 to 1.27)	0.2615		
No	294 (33.95)	264 (89.80)	30 (10.20)	1.00			
Case assignment							
LTC OW	689 (79.65)	631 (91.58)	58 (8.62)	1.00		1.00	
Other AMTU staff	111 (12.83)	101 (90.99)	10 (9.01)	1.51 (1.21 to 1.87)	0.0002	1.29 (1.02 to 1.62)	0.0320
Non-AMTU staff	65 (75.15)	53 (81.54)	12 (18.66)	1.05 (0.79 to 1.39)	0.7381	0.92 (0.68 to 1.24)	0.5808

\*HR, hazard ratio.

**Table 3.** Relationship of Time From Referral to Engagement-In-Care With Potential Impact Factors (Cox Model)

	HR (95% CI)	P	Adjusted HR (95% CI)	P
Days from HIV testing to referral				
0–7	1.41 (1.11 to 1.79)	0.0048	1.41 (1.11 to 1.80)	0.0056
8–14	1.69 (1.27 to 2.26)	0.0003	1.66 (1.24 to 2.22)	0.0007
15–28	1.49 (1.11 to 1.98)	0.0069	1.68 (1.24 to 2.26)	0.0007
29–365	1.10 (0.85 to 1.41)	0.4681	1.12 (0.87 to 1.45)	0.3820
365+	1.00		1.00	
Days from referral to LTC				
0	1.58 (1.23 to 2.04)	0.0004	1.77 (1.36 to 2.30)	<0.0001
1–7	2.53 (2.06 to 3.11)	<0.0001	2.90 (2.34 to 3.60)	<0.0001
8–14	2.03 (1.63 to 2.52)	<0.0001	2.17 (1.73 to 2.72)	<0.0001
15–21	1.61 (1.24 to 2.08)	0.0003	1.64 (1.26 to 2.14)	0.0003
22–42	1.00		1.00	
Age (yrs)				
12–17	1.21 (0.93 to 1.59)	0.1607		
18–20	1.12 (0.92 to 1.36)	0.2500		
21–22	0.93 (0.76 to 1.13)	0.4531		
23–24	1.00			
Gender				
Men	1.17 (0.97 to 1.41)	0.1018		
Women	1.00			
Transgender	0.98 (0.61 to 1.57)	0.9264		
Race/ethnicity				
Non-Hispanic white	1.00		1.00	
Non-Hispanic black	0.73 (0.54 to 0.98)	0.0364	0.56 (0.42 to 0.77)	0.0003
Non-Hispanic other	0.58 (0.36 to 0.92)	0.0210	0.45 (0.28 to 0.73)	0.0011
Hispanic	0.57 (0.41 to 0.81)	0.0013	0.44 (0.31 to 0.62)	<0.0001
Mode of acquisition				
Heterosexual contact	1.00		1.00	
Male-to-male sexual contact	1.15 (0.97 to 1.37)	0.1153	1.27 (1.06 to 1.52)	0.0099
IDU + other	0.82 (0.56 to 1.02)	0.2967	1.03 (0.69 to 1.55)	0.8698
What is the client's current housing status: homelessness				
Yes	1.31 (0.76 to 2.25)	0.3290		
No	1.00			
Has the client used any of the drugs in the past 12 mo?				
Yes	1.19 (1.02 to 1.39)	0.0229		
No	1.00			
Case assignment				
LTC OW	1.00			
Other AMTU staff	1.27 (1.03 to 1.58)	0.0278		
Non-AMTU staff	1.02 (0.76 to 1.36)	0.8960		

### *Factors Associated With Rates of Engagement in Care*

Adolescents with a shorter time from HIV testing to referral (0–7, 8–14, and 15–28 days versus >365 days) were more likely to engage in care as were those with shorter time in days from referral to linkage to care (1–7 and 8–14 days versus 22–42 days) (Table 4). Individuals who self-identified as non-Hispanic and those assigned to non-AMTU staff compared with the linkage to care outreach worker were less likely to engage in care.<sup>20</sup>



**Table 4.** Adjusted Relationship of Time in Days From Referral to Engagement-In-Care With Potential Impact Factors

	AOR* (95% CI)	P
Days from HIV testing to referral		
0–7	2391 (1.43 to 5.94)	0.0033
8–14	3.37 (1.25 to 9.07)	0.0164
15–28	3.61 (1.33 to 9.80)	0.0115
29–365	1.86 (0.92 to 3.74)	0.0834
365+	1.00	
Days from referral to LTC		
0	2.29 (0.98 to 5.37)	0.0571
1–7	2.01 (1.04 to 3.89)	0.0382
8–14	2.43 (1.13 to 5.27)	0.0238
15–21	1.32 (0.59 to 2.95)	0.4926
22–42	1.00	
Race/ethnicity		
Non-Hispanic white	1.00	
Non-Hispanic black	0.42 (0.10 to 1.82)	0.2488
Non-Hispanic other	0.17 (0.03 to 0.92)	0.0400
Hispanic	0.34 (0.07 to 1.59)	0.1701
Case assignment		
LTC OW	1.00	
Other AMTU staff	0.75 (0.35 to 1.62)	0.4674
Non-AMTU staff	0.32 (0.15 to 0.70)	0.0044

\*AOR, adjusted odds ratio

## DISCUSSION

This study demonstrates that the time interval between a newly diagnosed adolescent's HIV test and care referral and the time interval between care referral and first medical visit (linkage to care) have concrete implications for long-term HIV care engagement. Specifically, the results show that the speed with which an adolescent is initially incorporated into the network of care services matters for engagement. Those who have shorter intervals between HIV test and referral, and referral to linkage, are more likely to quickly engage in care, and more successfully.

These findings suggest that care engagement is the outcome of a process that begins very early in the HIV care continuum and may be influenced by factors other than support for adherence to HIV clinic appointments.<sup>21</sup> These data have quality of care implications for HIV testing programs in that the speed with which HIV-positive youth are referred for linkage has downstream implications for engagement—a step in the HIV Care Continuum that is critical for initiation of ART and other prevention services.<sup>9</sup> The data also support the importance in early, active patient engagement to reduce drop-out from care after initial linkage to care.<sup>22,23</sup>

Our data also suggest that HIV care is truly a continuum, so that earlier outcomes may be important throughout the posttest period, not just through effects on the next immediate continuum milestone. Even if a youth does not immediately link, early referral and connection to clinic staff can help support eventual engagement.<sup>24</sup> The findings also highlight which youth (ie, women, non-white youth, youth who acquired HIV through heterosexual sex) need additional support to be more quickly referred, linked, and eventually engaged in care. It also highlights the importance of where and to whom a youth is assigned to care. These data show that individuals

who were assigned to AMTU staff were more likely to engage, yet those assigned to other AMTU staff (compared with the outreach worker) had shorter engagement intervals. Outreach workers were often assigned the youth with most challenging barriers, which often impacted time to linkage and engagement. This highlights the variation in needs of individual youth and the importance of clinical infrastructure with capacity to provide clinical care and wraparound services by staff dedicated to the linkage process.

These findings are particularly meaningful because the HIV care continuum often depicts progress from HIV testing to care linkage and engagement as one step<sup>9,11</sup>; little attention has been given to the role of referral to care. Specifically, we found no research examining the length of the interval from HIV testing to referral, referral to linkage, or HIV testing to linkage and implications for care engagement with an ultimate goal of viral suppression. Irrespective of the strength of a care linkage system, an individual has to be tested and referred to care. These results demonstrate the important role timing plays in that initial step, suggesting the need for both a care linkage infrastructure and close collaborations between community-based organizations that provide testing, health departments, and adolescent medicine clinics.<sup>18</sup> Previous research<sup>25,26</sup> has demonstrated how community mobilization can improve community networks, which in turn facilitate the pathways through which HIV testing occurs and referrals to linkage are made. This is particularly true as calls to “test and treat” expand and cause HIV testing to occur in more diverse venues, many of which may not have as much experience referring and linking individuals into care. The diversity of testing locations will also become more salient as testing expands into lower prevalence areas that may not have strong referral networks. Given that individuals tested in community venues take longer to refer and link to care,<sup>27</sup> our work shows it is imperative to create an organized public health approach to facilitate individuals' pathway through the gaps in the care continuum between “test” and “treat” to improve engagement, and ultimately, viral suppression outcomes among HIV-infected youth.

The study found that the referral and linkage infrastructure seem to work more successfully for certain populations of youth, whereas others take longer to link and engage and will require more resources to ensure that they do. Such discrepancies may exist given the demographics of the US HIV/AIDS epidemic. For example, clinics may tailor their services to men who have sex with men, making women or heterosexual men feel less welcome or less comfortable.<sup>24</sup> Adolescents in particular may also feel that accessing care does not outweigh the social risk of inadvertent disclosure or stigma. Such individuals should be the focus of future interventions to facilitate successful engagement for all youth.

Providers described adolescents as frequently unwilling to accept their diagnoses or the level of clinical engagement their diagnosis would require. In such instances, providers advocated for other strategies (and the provision of wraparound services) to increase chances of eventual engagement. Many newly diagnosed adolescents refused to disclose to anybody because of a lack of family or community support; system fragmentation also compromises rapid linkage to care.<sup>28–30</sup> However, such findings are complicated by these data that demonstrate the need to refer and link youth as quickly as possible. Being able to expedite the referral and linkage process for adolescents requires testing staff and providers with youth-focused skills and a network of clinics and community organizations that can assist them.<sup>24</sup> Studies have shown the individual and community-level implications of delayed care linkage; the relationship between

rapid linkage and poorer engagement is likely because adolescents were still adjusting to their diagnoses, overwhelmed by the amount of medical information, and unsure of how to proceed or had insecurities in engaging with medical providers.<sup>20,21,24</sup> This study demonstrates that the definition of care linkage as one visit within a period of time may be insufficient to help an adolescent stay on the care continuum and ultimately become engaged in care. More specifically, care linkage is not a single event that involves only a medical visit and a blood draw. Instead, it should be treated as part of a larger process that requires multiple medical and non-medical visits, phone calls, emails, and/or texts, even for those who are linked on the first day. It is important to refer and link each individual to care as quickly as possible after testing to increase the speed and likelihood of engagement, ART prescription, and ultimate health outcomes.

### *Limitations*

Our study represents a large and comprehensive data set for care linkage and engagement for HIV-infected adolescents. HIV testing within communities, however, is neither systematic nor coordinated with mandated reporting. Such disjunctures often delayed a provider's ability to refer for care linkage by several months, and referral systems vary across the 15 ATN clinics. Referral bias is also possible: a small proportion (about 16%) of youth were already linked to care at the time of referral; these individuals were excluded from analysis. There were individuals who were not linked to care within 42 days and then re-entered into the database and linked to care during a second 42-day period; these individuals were duplicates and thus also excluded from the analyses. The ATN sites are all located in major urban metropolitan centers where the HIV epidemic is concentrated for youth and may not be generalizable to other settings in the United States.

### *Conclusions*

This research demonstrated that only 62% of newly diagnosed HIV-positive adolescents are linked and engaged in care within 22 weeks of referral, and thus identify an additional point in the HIV care continuum that needs to be examined—the time between HIV testing and referral and referral and linkage—as predictive of care engagement. Indeed, this gap in the care continuum must be addressed in order for the United States to successfully address the HIV epidemic. Our research suggests that each newly diagnosed HIV-infected youth needs to be linked to care as quickly as possible to facilitate a more rapid engagement in care, access to medications, and better long-term prognosis. Intensive linkage-focused interventions could increase rapid engagement and thus medication initiation and viral suppression. This focus on rapid linkage, however, should also incorporate an assessment of whether an adolescent is actually ready to participate in care. Our results highlight ways to approach care for newly diagnosed adolescents that may facilitate improvements in how youth initiate a lifetime of care. The processes through which a newly diagnosed HIV-infected adolescent is identified, referred, linked, and engaged in care is often complex and requires coordination between health departments, community organizations, and national-level policy making. Accordingly, these data should be used to build evidence and help construct a seamless continuum of care for HIV-infected youth to help fulfill the goals outlined in the US National HIV/AIDS Strategy.

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