

Factors Affecting Linkage to Care and Engagement in Care for Newly Diagnosed HIV-Positive Adolescents within Fifteen Adolescent Medicine Clinics in the United States

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Abstract:

Early linkage to care and engagement in care are critical for initiation of medical interventions. However, over 50 % of newly diagnosed persons do not receive HIV-related care within 6 months of diagnosis. We evaluated a linkage to care and engagement in care initiative for HIV-positive adolescents in 15 U.S.-based clinics. Structural and client-level factors (e.g. demographic and behavioral characteristics, clinic staff and location) were evaluated as predictors of successful linkage and engagement. Within 32 months, 1,172/1,679 (69.8 %) of adolescents were linked to care of which 1,043/1,172 (89 %) were engaged in care. Only 62.1 % (1,043/1,679) of adolescents were linked and engaged in care. Linkage to care failure was attributed to adolescent, provider, and clinic-specific factors. Many adolescents provided incomplete data during the linkage process or failed to attend appointments, both associated with failure to linkage to care. Additional improvements in HIV care will require creative approaches to coordinated data sharing, as well as continued outreach services to support newly diagnosed adolescents.

Keywords: Adolescents | HIV | Linkage to care | Engagement in care

Article:

Introduction

Linkage to care (LTC) refers to the process of initiating HIV-related medical, psychological and social services for newly diagnosed HIV-positive persons [1]. Failures in linkage are associated with lower levels of viral suppression, and greater likelihood of viral resistance [2, 3]. In the

United States, only about 28 % of HIV-positive individuals achieve viral suppression, in part due to LTC failures. [4, 5] Interventions focused on case-management and structural issues have improved LTC rates among newly diagnosed HIV-positive adults but these interventions have not included adolescents [6–8].

Engagement in care refers to the maintenance of HIV-related health care following initial linkage [9]. The process of engagement requires—at minimum—adherence to scheduled clinic visits (usually at defined 3–6 months intervals) [10]. Although up to 90 % of recently diagnosed individuals complete a second HIV-related visit after linkage, only 45–55 % complete at least one visit every 6 months [11, 12]. Engagement is associated with improved clinical status and reduced mortality, [1, 9, 13, 14] and increases the likelihood of viral load suppression, which is an important secondary HIV transmission prevention strategy [12].

Approximately 60 % of HIV-positive 13–24 year olds are undiagnosed, supporting the importance of expanded testing efforts in this age group [15, 16]. However, increased testing creates a need for HIV-related health services, few of which are specifically designed for adolescents [17]. Adolescents delay linkage for longer periods and are less likely to link to care compared to older adults. [12, 18–21] For adolescents linked to care, engagement is relatively high, with up to 83 % in care for up to a year following initial linkage [22]. However, adolescents in treatment fail about one-third of scheduled visits, and approximately 30 % of adolescents drop out of care after being engaged [18]. Adolescents have lower rates of viral suppression, and higher rates of virologic rebound compared to adults [23].

Care linkage and engagement represent a continuum of needed services that likely differ in terms of client and provider characteristics [6, 24, 25]. Yet almost no information exists to guide program and service planning to engage newly diagnosed adolescents in a “seamless” continuum of HIV-related care, as emphasized in the U.S. National HIV/AIDS Strategy [26]. Here, we present national-level data on HIV care linkage and engagement for HIV-positive adolescents.

Methods

Data were collected from 15 Adolescent Medicine Trials Network for HIV/AIDS Interventions clinic sites. These clinics, known as Adolescent Medicine Trial Units (AMTU), care for adolescents, ages 12–24, in 13 cities across the U.S. and Puerto Rico. Each AMTU implemented the Care Initiative in 2010. This initiative is a collaborative effort of the National Institute for Child Health and Human Development, the Centers for Disease Control and Prevention, and the Adolescent Trials Network. The care initiative facilitated formal relationships among the AMTU, local health departments, and local youth-serving organizations involved with HIV testing and treatment [27]. Memoranda of understanding between AMTU and local health departments specifically addressed the provision of public health authority (PHA) to the AMTU. Sites receiving PHA could directly contact newly diagnosed adolescents to arrange linkage. Each AMTU employed a trained outreach worker (OW) to contact youth, arrange HIV care, and

obtain de-identified client data. Each local Institutional Review Board reviewed and approved all procedures.

Clinic and Provider Measures

Two categories of independent measures were *client-level* and *clinic/provider-level* factors. *Client-level* factors were derived from data recorded by the OW and included age, gender, self-reported race/ethnicity, education, sexual identity, homeless status, health insurance status, mode of HIV acquisition, lifetime history of syphilis, marijuana use in the past 12 months, and other drug use.

Clinic/provider-level factors were largely derived from AMTU-reported data, memoranda of understanding between sites and local health departments, and analyses of qualitative interviews culled from three visits to each site [28]. *Clinic/provider-level* factors included clinic characteristics, person providing linkage to care, data-sharing/OW function, and assessment of OW effectiveness. OW effectiveness was derived from site visits and staff interviews and based on experience, integration within the clinical site, subjective relationship with the health department and other partners, and reported relationships with clients. These assessments were coded as higher and lower effectiveness.

Clinic characteristics assessed potential ‘adolescent-friendliness’ and were coded based on the population served in the specific clinic space (adolescent only, shared adolescent/pediatrics, specialty HIV care only [including adolescent and adult patients], and shared pediatric/adolescent check-in but separate clinic space) [29]. The person providing LTC was coded as the AMTU OW, other AMTU staff, or non-AMTU staff. A variable capturing each site’s data sharing and OW function was based on two site-specific characteristics: how the AMTU OW interacted with clients, and whether local health authorities granted PHA. In most (14/15) AMTU, the OW directly interacted with youth. In the remaining site, the OW coordinated and verified linkage but had no patient interaction. PHA was based in 45 CFR § 164.512(b)(1)(i) (The privacy rule) which permits public health authorities to act in collaboration with other entities in sharing of personal health information for the purposes of preventing or controlling a disease [30]., PHA was coded as absent or present based on memoranda of understanding: 8 AMTU sites received PHA and 7 did not. Sites were denied PHA for a variety of reasons (e.g., health departments’ privacy concerns, provision conflicting directly with state law). Some sites obtained PHA but received data in aggregate rather than client level.

Taken together, three data sharing and OW function models were identified [27]: Model A—real time data shared with OWs working directly with patients (2 AMTU sites); Model B—real time data shared with OWs not interacting with patients (1 AMTU site); and, Model C—aggregate data used by OWs directly interacting with patients (12 AMTU sites).

Outcome Measures

The two outcome variables were linkage to care and engagement in care. Linkage was defined as an HIV-related medical visit within 42 days of referral. Engagement was defined as a second HIV-related medical visit within 16 weeks of initial visit. Other studies define linkage as attending an appointment within 30 days of HIV-diagnosis [31] and engagement as a second HIV-related visit within 3–4 months after an initial visit [11,13, 32]. Some research defines engagement as a broader process that includes both linkage and retention in care [33]. The goal of this study is to better understand the explicit factors that influence multiple steps in the care continuum. As such, we chose to differentiate between linkage and engagement.

Statistical Methods

The analysis used basic frequencies and Chi square tests, as well as generalized linear models (PROC GENMOD). GENMOD was used to run logistic regression analysis (using a logit link function) to reflect clustering within sites. Models were explored through a stepwise process, where significant predictors were added individually, and checked for collinearity and interactions; only significant ($p < 0.05$) terms were retained in final models. During exploratory data analysis, missing data for various risk variables were found to be strongly associated with LTC. Thus, GENMOD was used for LTC (for cases with complete data) and to model predictive factors for missing data. The analysis adjusted for confounders by including them in these models. All data analysis was run in SAS Version 9.2.

Results

By 32 months into the program, 2,076 youth were referred, of which 80.9 % (1,679/2,076) were eligible for linkage (Table 1). The remainder (19.1 % [397/2,076]), were ineligible due to being outside a site’s jurisdiction ($n = 61$) or already linked ($n = 336$). A total of 1,172/1,679 (69.8 %) were linked. LTC rates ranged from 52–89 % among sites. Reasons for linkage failure ($n = 507/1,679$; 30.2 %) included insufficient contact information (52/507; 10.3 %), inability to locate (144/507; 28.4 %), refused LTC services (53/507; 10.5 %), failed appointments (211/507; 41.6 %), and other (47/506; 9.3 %) (data not shown).

Table 1 Linkage to care and engagement in care, by site

Site	Eligible referrals (%)	Linked to care (%)	Engaged in care (%)	Linked and engaged (%)
A	65 (3.9)	34 (52.3)	26 (76.5)	40.0
B	160 (9.5)	95 (59.4)	67 (70.5)	41.9
C	70 (4.2)	51 (72.9)	47 (92.2)	67.1
D	105 (6.3)	61 (58.1)	59 (96.7)	56.2

E	147 (8.8)	95 (64.6)	84 (88.4)	57.1
F	105 (6.3)	70 (66.7)	61 (87.1)	58.1
G	103 (6.1)	63 (61.2)	61 (96.8)	59.2
H	60 (3.6)	44 (73.3)	36 (81.8)	60.0
I	90 (5.4)	60 (66.7)	55 (91.7)	61.2
J	102 (6.1)	83 (81.4)	70 (84.3)	68.6
K	169 (10.1)	126 (74.6)	118 (93.7)	69.9
L	288 (17.2)	208 (72.2)	202 (97.1)	70.1
M	124 (7.4)	102 (82.3)	90 (88.2)	72.6
N	82 (4.9)	73 (89.0)	60 (82.2)	73.2
O	9 (0.5)	7 (77.8)	7 (100.0)	77.8
Overall	1,679 (100)	1,172 (69.8)	1,043 (89.0)	62.1

Among youth linked to care, 1,043/1,172 (89.0 %) were subsequently engaged. Engagement rates ranged from 71–100 % across sites. Overall, 62.1 % (1,043/1,679) of eligible adolescents were ultimately linked and engaged (Fig. 1). Successful HIV care linkage and engagement was reported for less than two-thirds of adolescents in eight sites (Table 1). Success was not simply a matter of referral volume, as the site with lowest number of referrals (Site O) and the site with the most referrals (Site L) both linked and engaged two-thirds or more of referred patients.

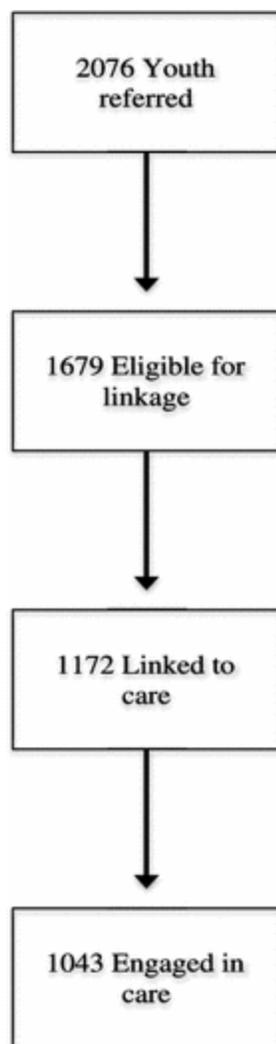


Fig. 1 The number of adolescents that were eligible for linkage, linked, and engaged in care. Missing data did not necessarily eliminate individuals from being counted within each level (as it was often individual variables that were missing, not complete data)

Factors Associated with Linkage to Care

Of eligible referred youth, 78.4 % were male, median age was 21 years, and 68.4 % reported race-ethnicity as non-hispanic black. The most common mode of transmission was male-to-male sexual contact (63.6 %). *Client-level factors* potentially associated with LTC are shown in Table 2. Proportionally fewer males (68.8 %) were linked than females (76.5 %). The proportion of youth linked was greater among 15–17 year olds (78.7 %) than 22–24 year olds (69.8 %). Linkage among Hispanic youth (70.9 %) and those indicating “other” race/ethnicity (44.2 %) was lower than non-Hispanic whites (81.3 %). Persons with “missing” sexual identities had a lower rate of linkage (36 %) than persons with heterosexual identities (75.1 %). Rates of linkage were similar for all modes of HIV acquisition except “other”, which had much lower rates

(32.0 %). Persons with housing had a significantly higher rate of linkage than those who were homeless. The absence of history of syphilis was associated with higher rates of linkage than those with syphilis history; however, “unknown” syphilis history had a significantly lower rate of linkage (81.8, vs. 73.4 % and 41.8 % respectively).

Table 2 Demographic and behavioral characteristics of newly diagnosed youth, by linkage to care and engagement in care status

	Linked to care N (%)	Odds ratio^a(95 % CI)	Engaged in care N (%)	Odds ratio^a(95 % CI)
Current gender				
Male	906 (68.8)	0.68 (0.51–0.91)*	807 (89.1)	1.03 (0.65–1.63)
Female	231 (76.5)	Ref	205 (88.7)	Ref
Transgender	34 (69.4)	0.70 (0.36–1.35)	31 (91.2)	1.31 (0.37–4.59)
Missing	1 (8.3)	0.03 (0.00–0.22)*	0 (0.0)	–
Age (years)				
12–14	9 (64.3)	0.78 (0.26–2.35)	9 (100.0)	–
15–17	111 (78.7)	1.60 (1.04–2.47)*	103 (92.8)	1.94 (0.90–4.18)
18–21	553 (70.1)	1.01 (0.81–1.27)	500 (90.4)	1.2 (0.97–2.10)
22–24	488 (69.8)	Ref	424 (86.9)	Ref
Missing	11 (30.6)	0.19 (0.09–0.39)*	7 (63.6)	0.26 (0.08–0.93)
Race/ethnicity				
Non-hispanic white	78 (81.3)	Ref	74 (94.8)	Ref
Non-hispanic black	830 (72.2)	0.60 (0.35–1.02)	737 (88.8)	0.43 (0.15–1.20)
Hispanic	192 (70.9)	0.56 (0.32–1.0)*	169 (88.0)	0.40 (0.13–1.19)
Other	72 (44.2)	0.18 (0.10–0.33)*	63 (87.5)	0.38 (0.11–1.29)
Education				

Grade 8 or less	37 (78.7)	0.66 (0.31–1.39)	33 (89.2)	0.75 (0.25–2.26)
Grade 9–11	238 (81.5)	0.79 (0.53–1.17)	219 (92.0)	1.05 (0.57–1.92)
Grade 12-GED	325 (86.0)	1.09 (0.73–1.62)	296 (91.1)	0.93 (0.54–1.59)
College and above	348 (84.9)	Ref	319 (91.7)	Ref
Missing	224 (40.6)	0.12 (0.09–0.17)*	176 (78.6)	0.33 (0.20–0.55)*
Sexual orientation				
Heterosexual	299 (75.1)	Ref	260 (87.0)	Ref
Homosexual	619 (78.3)	1.2 (0.90–1.59)	553 (89.3)	1.26 (0.82–1.92)
Bisexual	140 (80.5)	1.36 (0.88–2.11)	128 (91.4)	1.60 (0.81–3.16)
Missing	114 (35.96)	0.19 (0.13–0.26)*	102 (89.47)	1.28 (0.64–2.53)
Mode of acquisition				
Perinatal	42 (73.68)	Ref	38 (90.48)	Ref
Heterosexual contact	252 (74.78)	1.06 (0.56–2.01)	220 (87.30)	0.72 (0.24–2.16)
Male to male contact	809 (75.75)	1.12 (0.61–2.04)	727 (89.86)	0.93 (0.32–2.68)
IDU	1 (100.0)	–	0 (0.00)	–
Other	62 (31.96)	0.17 (0.09–0.33)*	52 (83.87)	0.55 (0.16–1.88)
Missing	6 (27.27)	0.13 (0.04–0.41)*	6 (100.0)	–
Current health insurance				
Yes	385 (85.4)	Ref	341 (88.6)	Ref
No	245 (78.8)	0.64 (0.44–0.93)*	213 (86.9)	0.86 (0.53–1.40)
Unknown/not asked	542 (59.1)	0.25 (0.18–0.33)*	489 (90.2)	1.19 (0.78–1.82)
Homeless				

Yes	23 (56.1)	Ref	19 (82.6)	Ref
No	984 (82.1)	3.6 (1.91–6.79)	890 (90.5)	1.99 (0.66–5.98)
Not assessed	165 (37.5)	0.47 (0.25–0.90)*	134 (81.2)	0.91 (0.29–2.86)
Syphilis				
Yes	209 (73.4)	Ref	186 (89.0)	Ref
No	774 (81.8)	1.5 (1.13–2.12)	699 (90.3)	1.15 (0.70–1.89)
Unknown	189 (41.8)	0.25 (0.18–0.34)*	158 (83.6)	0.63 (0.35–1.13)
Marijuana				
Yes	519 (81.2)	Ref	465 (89.6)	Ref
No	483 (80.0)	0.92 (0.70–1.22)	440 (91.1)	1.19 (0.78–1.81)
Unknown	170 (39.0)	0.15 (0.11–0.19)*	138 (81.2)	0.50 (0.31–0.81)*
Other drug use				
Yes	158 (81.0)	Ref	144 (91.1)	Ref
No	844 (80.5)	0.97 (0.66–1.43)	761 (90.2)	0.89 (0.49–1.61)
Unknown	170 (39.0)	0.15 (0.10–0.22)*	138 (81.2)	0.42 (0.21–0.82)*

^aOdds ratio estimates were not calculated in categories where all outcomes were linked to care. Similarly, ORs were not calculated where all outcomes were engaged in care. For these categories, a “–” is shown

* Results are significant

Missing client demographic and behavioral data were important indicators of linkage failure. In some instances (e.g., age), the percentage of missing data was small but still associated with decreased likelihood of linkage. For other characteristics (e.g. education level), the proportion of missing data was 32.9 %, of which only 41 % were LTC. When missing data was reported as “unknown” for all categories except drug use, linkage rates were significantly lower than for clients for whom those data were available (Table 2).

Linkage rates were similar by geographic region, though the Midwest had significantly higher rates than the South (Table 3). Model A had significantly higher LTC rates than Model B. Sites judged to have lower OW effectiveness had higher linkage rates (OR = 1.34, 95 % CI 1.09–1.66). The rate of successful linkage for cases assigned to the OW (75.1 %) were significantly higher than those assigned to non-AMTU personnel (52.9 %).

Table 3 Linkage to care and engagement in care, by clinic and provider characteristics

	Linked to care N (%)	Odds ratio (95 % CI)	Engaged in care N (%)	Odds ratio (95 % CI)
Region				
Midwest	228 (77.8)	1.73 (1.27–2.36)	208 (91.2)	1.36 (0.81–2.30)
Northeast	185 (71.7)	1.25 (0.92–1.70)	161 (87.0)	0.88 (0.53–1.45)
South	578 (67.0)	Ref	511 (88.4)	Ref
Puerto Rico	60 (66.7)	0.99 (0.62–1.56)	55 (91.7)	1.44 (0.56–3.73)
West	121 (69.1)	1.10 (0.78–1.57)	108 (89.3)	1.09 (0.58–2.04)
Data sharing and outreach worker function^a				
Model A	269 (68.5)	Ref	261 (97.0)	Ref
Model B	95 (59.4)	0.67 (0.46–0.99)*	67 (70.5)	0.07 (0.03–0.17)*
Model C	808 (71.8)	1.17 (0.91–1.50)	715 (88.5)	0.24 (0.11–0.49)*
Clinic characteristics				
Adolescent only	413 (71.1)	Ref	342 (82.8)	Ref
Shared	499 (68.2)	0.83 (0.65–1.05)	466 (93.4)	2.93 (1.90–4.53)
HIV-only	165 (72.7)	1.03 (0.73–1.45)	151 (91.5)	2.24 (1.22–4.10)*
Separate clinic space	95 (64.6)	0.71 (0.48–1.04)	84 (88.4)	1.59 (0.80–3.12)
Outreach worker effectiveness				
Higher	613 (67.0)	Ref	562 (91.7)	Ref
Lower	559 (73.2)	1.34 (1.09–1.66)*	481 (86.1)	0.56 (0.39–0.81)*

Provider assigned to linkage to care				
Outreach worker	846 (75.1)	Ref	771 (91.1)	Ref
Other AMTU staff	138 (73.0)	0.90 (0.63–1.27)	122 (88.4)	0.74 (0.42–1.31)
Non-AMTU staff	185 (52.9)	0.37 (0.29–0.48)*	147 (79.5)	0.38 (0.25–0.58)*

^aModel A—real time data sharing from local health department with direct outreach worker/client contact; Model B—real time data sharing from local health department without direct outreach worker/client contact; Model C—Aggregate data only from local health department, with direct outreach worker/client contact

* Results are significant

In multivariable, mixed effects models (Table 4), LTC rates were significantly higher for Midwest sites and lower in Puerto Rico as compared with the South, higher in adolescent-only clinics than HIV-only or shared, and higher when AMTU OWs were assigned to the case as compared to other AMTU staff. No other demographic or provider characteristics, including OW effectiveness, were associated with significant differences in linkage.

Table 4 Mixed effects model for clinic/provider predictors of linkage to care and engagement in care

	Linkage to care		Engagement in care	
	Estimate (SE)	Odds ratio (95 % CI)	Estimate (SE)	Odds ratio (95 % CI)
Region				
Midwest	1.29 (0.21)	3.63 (2.43,5.43)	NA	–
Northeast	–0.19 (0.39)	0.83 (0.39,1.76)	NA	–
South	Ref	–	NA	–
Puerto Rico	–0.59 (0.24)	0.55 (0.35,0.88)	NA	–
West	0.05 (0.29)	1.05 (0.59,1.86)	NA	–
Data sharing and outreach worker function				
Model A	NA	–	Ref	–

Model B	NA	–	–2.64 (0.002)	0.07 (0.07,0.07)
Model C	NA	–	–0.78 (0.12)	0.46 (0.36,0.58)
Outreach worker effectiveness				
Higher	NA	–	Ref	–
Lower	NA	–	–0.9 (0.15)	0.41 (0.3,0.55)
Clinic characteristics				
Adolescent only	Ref	–	NA	–
HIV-only	–1.00 (0.35)	0.37 (0.18,0.74)	NA	–
Shared	–0.91 (0.37)	0.40 (0.20,0.83)	NA	–
Separate clinic space	–0.47 (0.25)	0.62 (0.38,1.02)	NA	–
Provider assigned to linkage to care				
Outreach worker	Ref	–	NA	–
Other AMTU staff	–1.39 (0.53)	0.25 (0.09,0.70)	NA	–
Non-AMTU staff	–0.16 (0.45)	0.85 (0.36,2.04)	NA	–

All variables in Tables 2 and 3 were initially considered for these models. See “Methods” section for a discussion of model selection

Factors Associated with Engagement in Care

Only two demographic characteristics—age and education—were significantly associated with engagement (Table 2). In each case, missing data were associated with a lower rate of successful engagement. Engagement was 63.6 % for those whose age was missing compared with 86.9 % for 22–24 year olds. Engagement was 78.6 % for those missing education data compared to 91.7 % for those with college or above.

Sites in clinic engagement Models B and C had significantly lower rates of engagement than those in Model A (real time data shared with OWs working directly with patients) (Table 3). Clinics serving adolescent and pediatric patients and those that focused on HIV only were more successful in engaging adolescents than those that were adolescent only (see Table 3). OWs judged to be of lower effectiveness were also associated with lower rates of engagement (86.1 %) compared to those with higher effectiveness (91.7 %).

In multivariable mixed effects models, data sharing model and OW effectiveness were both significantly associated with engagement. Both Models B and C had significantly lower rates of engagement than Model A. Sites with lower OW effectiveness had significantly lower rates of engagement than those with higher effectiveness (Table 4). Other demographic and clinic/provider variables considered were not significant in the final adjusted model (see Tables 2 and 3 for all variables).

Factors Associated with Missing Data

To additionally explore issues related to missing data, five key client demographic variables with high rates of missing data were selected: housing status, insurance status, STD history, substance use, and risk behaviors. 47 % of study subjects were missing one or more of these items. The percent of subjects with missing data for these items varied substantially between sites ($p < 0.0001$), from 19 to 90 %, with a median of 72 % and IQR of 43–61 % (data not shown).

A mixed effects model using generalized estimating equations was used to control for multiple subjects within site (Table 5). Five clinic/provider characteristics (region of clinic, data sharing model, clinic characteristics, functional PHA status, and provider assigned to linkage) were included to assess potential variation in regional policies related to HIV testing and linkage. Sites in the Midwest and Puerto Rico were significantly less likely to have missing data, and sites in the West were significantly more likely to have missing data, compared to sites in the South. Clinics that served only HIV patients had less missing data than adolescent only clinics. Cases handled by other AMTU staff had significantly more missing data than those handled by the OW. Other demographic and clinic/provider variables considered were not significant in the final adjusted model (see Tables 2 and 3 for all variables).

Table 5 Mixed effect model for any missing data on housing status, insurance status, STD history, substance use, and risk behaviors

	Estimate (SE)	Odds ratio (95 % CI)
Region		
Midwest	-0.75 (0.09)	0.47 (0.40,0.57)
Northeast	0.20 (0.24)	1.22 (0.76,1.96)
South	Ref	–
Puerto Rico	-1.07 (0.16)	0.34 (0.25,0.47)
West	0.52 (0.08)	1.68 (1.43,1.97)
Clinic characteristics		

Adolescent only	Ref	–
HIV-only	–1.26 (0.19)	0.29 (0.20,0.41)
Shared	–0.18 (0.19)	0.84 (0.57,1.21)
Separate clinic space	–0.5 (0.35)	0.6 (0.31,1.19)
Provider assigned to linkage to care		
Outreach worker	Ref	–
Other AMTU staff	1.9 (0.39)	6.66 (3.11,14.29)
Non-AMTU staff	0.69 (0.48)	1.99 (0.78,5.06)

All variables in Tables 2 and 3 were initially considered for these models. See “Methods” section for a discussion of model selection

Discussion

Only 62 % of HIV-positive adolescents and young adults were both linked to, and engaged in, care during the first 6 months following diagnosis. Thus, more than one-third of newly diagnosed youth do not receive the full benefits of intensive early medical treatment. This conflicts with the National HIV/AIDS Strategy goals of “seamless” linkage to care [26]. Moreover, opportunities for post-diagnosis transmission prevention—including reduction of viral load—are lost for the not-in-care youth. Because case-management models are the standard for HIV linkage, our research provided support for full-time OWs to facilitate the linkage and engagement process. An important lesson of this research is that even with this level of personal support, linkage and engagement rates varied substantially among sites, suggesting that additional factors influence care engagement.

One local structural factor affecting linkage and engagement is the quality of collaboration between local health departments and HIV treatment sites. By requiring formal memoranda of understanding between AMTUs and local health departments—specifically around formal PHA—the authors of the study protocol hoped to better understand local structural facilitators to linkage and engagement. This is important due to studies showing that health departments and community organizations can respond to the introduction of HIV-related services with indifference or even active resistance [34–36]. In multivariable models, linkage and engagement rates were higher at sites where PHA allowed OWs to directly interact with newly diagnosed youth. These data suggest that HIV-related care within communities can be improved by close collaborations within communities between public health systems and HIV-treatment systems [9, 34].

We found differences in factors associated with HIV care linkage and engagement. Linkage depends on both client-level characteristics (i.e., gender, race/ethnicity, and housing) and clinic/provider factors (i.e., public health authority and OW qualifications). High quality data sharing is critical, as shown by the substantial reductions in care linkage when key data were missing. Thus, local structural factors such as relationships between diagnostic and treatment facilities may substantially affect linkage. Engagement, by contrast, is largely associated with clinic and provider characteristics. Well-trained personnel and quality care infrastructure can influence longer-term care engagement.

This research demonstrates several of the key elements of best practices models that can facilitate the coordination of community-wide HIV testing and treatment. Failure of linkage and engagement are key attrition sources in the ‘HIV/AIDS care continuum’ between HIV diagnosis and achieving an undetectable viral load [37]. Improved understanding of linkage and engagement can inform approaches to a population-wide implementation of an “HIV treatment as prevention” philosophy [38]. In particular, adolescents may require carefully integrated, community-wide services to fully realize the benefits of contemporary HIV-related care.

Our study represents a large and comprehensive data set for care linkage and engagement among HIV-positive adolescents. However, HIV testing within communities is neither systematic nor coordinated, and data from mandated reporting often lags the need for linkage by several months. Referral bias is also possible: a small proportion (about 16 %) of youth was already linked at the time of referral; these individuals were, however, excluded from analysis. Our study presents an exploratory analysis with many descriptive statistics; because of the exploratory nature, we have not adjusted for multiple comparisons and care should be taken when drawing conclusions. Additionally, the limited number of sites in Models A and B limits our ability to generalize conclusions drawn from these data.

An additional issue relates to missing data and its importance in the ultimate success of care linkage and engagement. Sensitive items in our study, such as history of STIs, drug use, or sexual risk behaviors, were subject to extensive missing data; respondents with such missing data were much less likely to be linked to care. While the missing data makes it difficult to assess relationships between sensitive items and linkage, the more important result may be that persons unwilling to report these data were less willing to follow up on treatment. Our study was designed to optimize health information sharing to facilitate care. However, HIV remains an intensely stigmatized condition, and appropriate privacy safeguards exist in tension with the necessary activation of appropriate supports for treatment. Systematic efforts to improve HIV-related care will continue to involve social, policy, and practice-related efforts to provide high-quality health information sharing across the various systems involved in HIV testing and treatment, while maintaining high standards of privacy for persons living with HIV.

Conclusions

These study findings show that linkage is most affected by client and clinic-level factors while engagement is most influenced by clinic and provider-level factors, thus highlighting the importance of taking a comprehensive approach to increase adolescents' linkage and engagement rates. HIV care linkage and engagement are complex processes best addressed through coordinated local and national efforts. Locally, improved information transfer and identification of structural barriers to linkage and engagement are needed. Nationally, models for best practices, and implementation of these models could facilitate improvements in how youth enter HIV care for their lifetime. Only through addressing individual- and structural-level barriers to care linkage and engagement will we be able to fully realize the goals of the National HIV/AIDS Strategy [26].

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