



# Improving Timely Linkage to Care among Newly Diagnosed HIV-Infected Youth: Results of SMILE

Robin Lin Miller · Danielle Chiaramonte ·  
Trevor Strzyzkowski · Dhruv Sharma ·  
Kaston Anderson-Carpenter · J. Dennis Fortenberry

Published online: 1 November 2019  
© The New York Academy of Medicine 2019

**Abstract** Delayed linkage to care deprives youth living with HIV of the benefits of HIV treatment and risks increased HIV transmission. Developing and testing linkage-to-care models that are capable of simultaneously addressing structural and individual obstacles are necessary to attain national goals for timely linkage of newly diagnosed youth to care. We assessed an integrated, multi-pronged strategy for improving youth's timely linkage to care carried out in eight adolescent medicine clinical trials units (AMTUs) in the USA. In phase I, the intervention strategy paired intensive medical case management with formalized relationships to local health departments, including granting of public health authority (PHA) to four of the AMTUs. In phase II, local coalitions run by the AMTUs to address structural changes to meet youth's HIV prevention and HIV testing needs began to advocate for local structural changes to improve timely access to care. Results of an ARIMA model demonstrated sustained decline in the average number of days to link to care over a 6-year period (ARIMA (1,2,1) AIC = 245.74, BIC = 248.70,  $p < .01$ ). By the end of the study, approximately 90% of youth linked to care had an initial medical visit in 42 or fewer days post-diagnosis. PHA improved the timeliness of linkage to care ( $b = -69.56$ ,  $p < .05$ ). A piecewise regression suggested the addition of structural

change initiatives during phase II made a statistically significant contribution to reducing time to linkage over and above achievements attained via case management alone ( $F(3,19) = 5.48$ ,  $p < .01$ ; Adj.  $R^2 = .3794$ ). Multi-level linkage-to-care interventions show promise for improving youth's timely access to HIV medical care.

**Keywords** Youth · Adolescence · HIV/AIDS · Linkage-to-care · Structural change

## Introduction

In the USA, youth aged 13–24 are the least likely among people of any age group to link to HIV medical care in a timely manner following a positive HIV test result [1]. Fewer than half of the more than 60,000 youth living with HIV in the USA are estimated to know their HIV status; approximately 62% of these youth link to medical care within 6 months to 1 year of receiving their diagnoses [1, 2]. Black gay and bisexual male youth—among the highest risk group in the nation—are especially likely to delay entry into care, often waiting until they experience advanced disease [3–6]. Delayed linkage to care deprives youth of the benefits of HIV treatment and risks increased HIV transmission. Interventions to improve rates of timely linkage to care for youth represent an urgent national priority [7].

Medical case management and patient navigation models for promoting linkage to care are increasingly common; however, passive referral systems remain widely employed in venues that offer HIV testing, despite

R. L. Miller (✉) · D. Chiaramonte · T. Strzyzkowski ·  
D. Sharma · K. Anderson-Carpenter · J. D. Fortenberry  
Michigan State University, East Lansing, MI, USA  
e-mail: mill1493@msu.edu

evidence that passive systems of referral are often least successful in promoting linkage to care [8, 9]. Passive referral systems may be especially prone to fail for newly diagnosed youth because of the multiple structural and individual challenges youth face to follow through on medical referrals. At the structural level, challenges to accessing care for HIV-infected youth include lack of access to health insurance and reliable transportation, economic insecurity, and housing instability [2, 10–13]. Fragmented systems of care and a lack of youth-focused and youth-friendly care are also attributed with poor rates of linkage to and sustained engagement in care [14]. Fortenberry and colleagues argue that entrenched and pervasive structural barriers are more likely to impede youth's access to care than individual barriers [1]. They note that most evidence-informed interventions such as medical case management target individual barriers to linkage to care rather than structural barriers.

At the individual level, newly diagnosed youth may be paralyzed by stigma and shame over their HIV diagnosis [15]. Youth may be especially concerned about disclosing their status to others, including medical professionals, thereby limiting their access to social and material supports at an especially vulnerable time [16]. Disclosure of HIV status to friends and family may prompt youth's fear of rejection or reprisal and engender tension and conflict, especially if HIV-status disclosure also forces other disclosures that a youth has heretofore kept private (e.g., information on sexual orientation, sexual activity, drug use). Youth's degree of cognitive, emotional, and social development may impede their ability to cope with the fears and concerns propelled by stigma, overwhelming their ability to marshal the social support and resolve needed to act on referrals. The effect of stigma on unwillingness to disclose HIV status is associated with delayed entry into care among adults, a phenomenon that is likely to be acute among youth [17]. An HIV diagnosis also requires youth make the psychological transition to accepting lifelong medical treatment and monitoring. Youth may lack psychological readiness to make this transition, delaying their entry into treatment [1].

### **The Strategic Multisite Initiative for the Identification, Linkage to, and Engagement in Care of Youth with Undiagnosed HIV Infection**

Developing and testing linkage-to-care models that can mitigate the problems created by fragmented service

systems and that are capable of simultaneously addressing structural and individual obstacles to linkage to care are necessary to attain national goals for timely linkage of newly diagnosed youth to medical care. In 2009, the Adolescent Medicine Trial Network for HIV/AIDS Interventions entered into a strategic partnership with the US Centers for Disease Control and Prevention and the US Health Resources and Services Administration to develop and assess an integrated, multi-pronged strategy for improving youth's timely linkage to care [18, 19]. Implemented in a total of 20 US adolescent medicine clinical trials units (AMTUs) over a 6-year period, the initiative included two primary phases.<sup>1</sup>

In phase I, 15 AMTUs designated a full-time linkage-to-care coordinator whose efforts were exclusively dedicated to facilitating youth's timely entry into and sustained engagement in HIV medical care. During this initial phase, coordinators created formal referral communication networks among diverse HIV test sites and local HIV clinical providers with expertise in serving youth. They also established formal memorandum of understanding with their local health departments [18]. In some cases, this formal agreement included granting public health authority (PHA) to the Strategic Multisite Initiative for the Identification, Linkage to, and Engagement in Care of Youth with Undiagnosed HIV Infection (SMILE) program, permitting the coordinator to access real-time information on new HIV diagnoses. The specific arrangements for data exchange on new HIV diagnoses among youth varied markedly among the sites.

In phase II, 13 AMTUs (8 continuing and 5 new) paired their SMILE linkage-to-care program with the efforts of their local youth-focused HIV coalition, which was also run by the AMTU [19]. Coalitions were originally established to pursue community structural changes to improve youth's access to HIV prevention and HIV testing. Phase II of SMILE expanded the coalitions' advocacy for structural changes to include changes aimed at improving timely access to medical care. Coalitions were asked during this phase to advocate for changes in the capability of local systems to respond to youth effectively, foster productive connections between elements of the youth-serving system of care and support, and pursue changes to institutional,

<sup>1</sup> AMTUs were located in Baltimore, MD; Boston, MA; Bronx, NY; Chicago, IL; Denver, CO; Detroit, MI; Fort Lauderdale, FL; Houston, TX; Los Angeles, CA; Manhattan, NY; Memphis, TN; Miami, FL; New Orleans, LA; Philadelphia, PA; San Francisco, CA; San Juan, PR; Tampa, FL; Washington D.C.

city, and regional policies and practices that would facilitate youth's immediate access to post-diagnosis care. For example, structural changes pursued and achieved included developing systems for seamless access to public transportation post-diagnosis and modifying policies and practices for establishing a youth's immediate entitlement eligibility and securing of health benefits without income verification [19].

The overall achievements of the effort have been previously described [18]. However, prior investigations have not examined the unique contributions of granting PHA to improving timely linkage to care or of the structural changes pursued during phase II of SMILE. The principal aims of the current study were to identify whether PHA improved linkage to care and determine if the local structural change initiatives pursued by each site in phase II made a significant contribution to improvements in timely linkage to care over and above those achieved via the coordinators' one-on-one efforts working with youth, medical providers, and HIV-testing sites. Finally, we sought to corroborate any quantitative evidence for the initiatives' contributions to improvements in linkage to care by identifying how the

initiative was perceived by members of the local communities in which SMILE I and II were implemented.

## Methods

The current study focuses on the eight AMTUs that participated in both SMILE I and II (see Table 1). The study employed an interrupted time series design to compare the number of days between youth's HIV-positive diagnosis and attendance at their first post-diagnosis medical care appointment during each of the intervention's two phases. All study procedures were reviewed and approved by the responsible human subjects' committee at each AMTU and those at each non-AMTU investigator's institutions.

## Procedures and Measures

Anonymized data were electronically extracted from patient records over the life of the study. Data captured included youth demographic characteristics (e.g., self-reported age, mode of HIV acquisition,

**Table 1** SMILE I and SMILE II sites ( $N=8$ )

Location	Site	Granted public health authority	Structural change example
Los Angeles, CA	Children's Hospital of Los Angeles	Yes	The Los Angeles County Probation Department created guidelines for post-incarceration placement of youth living with HIV, including referral to a linkage-to-care specialist.
Washington, DC	Children's National Medical Center	Yes	The Institute for Public Health Innovation established a youth navigation program to assist HIV-infected youth transitioning to adult care.
Tampa, FL	University of South Florida	Yes	Hillsborough County Health and Human Services Ryan White Administration amended their Ryan White Service Delivery Program Guidelines to exempt minors and young adults with HIV from providing income eligibility documentation.
Miami, FL	University of Miami	No	The Miami-Dade Office of Grants Coordination amended their Ryan White Service Delivery Program Guidelines to exempt minors and young adults with HIV from providing income eligibility documentation.
Chicago, IL	John H. Stroger Jr. Cook County Hospital	No	Stroger Hospital implemented a new practice of notifying a linkage-to-care specialist of any youth testing HIV-positive in the emergency department.
New Orleans, LA	Tulane Medical Center	No	Louisiana's Juvenile Justice System implemented screening of youth at intake and a formal linkage-to-care referral process.
Bronx, NY	Montefiore Medical Center	No	The Adolescent AIDS Program established extended clinic hours.
Memphis, TN	St. Jude's Research Hospital	Yes	Four youth-serving health care providers established policies requiring personnel ensure newly diagnosed HIV-positive youth are referred to a linkage-care-specialist.

gender, sexual orientation, ethnicity, race), dates of HIV testing, and dates of being referred to and linked to medical care, if youth were linked. Data were securely transmitted over an analog phone line in encrypted form to a central server located at the study's Data Operations Center once daily. For the purposes of this study, we created two outcome measures using these data. The first, successful linkage to care, was operationalized as attending an initial post-diagnosis appointment with an adolescent medicine or infectious disease physician within 42 days of diagnosis. This variable is dichotomous. The second, days to linkage to care, is the number of days between a youth's first HIV-positive test result and the date of their initial medical appointment with a medical care provider, typically at the AMTU. A total of 178 cases were missing the date of their HIV test. In those cases, we substituted the youth's SMILE registration date for their HIV test date. We used as independent variables time, youth demographic characteristics (e.g., race, ethnicity, age, transmission mode), and whether the AMTU had received PHA. In addition, we obtained data on intervention costs. Data on intervention costs were reported for 2-month intervals on four occasions during SMILE I (baseline, end of year 1, end of year 2, end of study). A senior staff member at each AMTU recorded all personnel, non-personnel, and one-time expenses over each of these periods. Cost data were separately recorded for data collection personnel and non-personnel expenses and for intervention personnel and non-personnel expenses, allowing us to examine the costs of implementing phase I intervention activity separate from the cost of evaluating it.

To understand local perceptions of SMILE, we completed 223 key informant interviews by telephone with 192 youth and adults from the 8 AMTUs. These interviews were conducted as part of a larger key informant study on the contributions of the coalitions to structural change [20]. Informants were youth and adults who were perceived as knowledgeable about youth HIV-related issues in their local community. Informants were nominated by the coalitions' coordinators and recruited for participation by an independent investigative team. The phone interview asked informants to describe changes in their local community, both positive and negative, related to youth's ability to access HIV prevention, testing, and medical care. Informants were also asked to describe how the changes they noted had come

about and what role, if any, the AMTU's coalition played in the changes they had observed. Interviews were audio-recorded with the consent of the respondent and transcribed verbatim. Transcripts were cleaned and imported into NVivo 11 for coding and analysis. The average length of an interview was approximately 53.5 min (range = 14 to 180 min).

### Participants

For the current analyses, we focus on the 2142 newly diagnosed HIV-positive youth ages 12–24 who were referred to each of the eight sites and were eligible for their services (see Table 2). Youth were eligible for SMILE services if they were not already linked to care and lived in the geographic jurisdiction covered by the SMILE program. We excluded 159 youth with missing data or data entry errors, 135 youth who reported perinatal HIV acquisition, and 20 youth who had tested HIV-positive prior to SMILE, but who were linked to care through it once the program began its operation. As shown in Table 2, a majority of referred youth were Black ( $n = 1741$ ; 81%) and male ( $n = 1711$ ; 80%); sex with another man was the most common reported mode of HIV acquisition ( $n = 1359$ ; 63%). Key informants included 39 youth and 153 adults. Approximately 75% of informants had at one time been a member of their local coalition.

### Statistical Analysis

After completing basic data cleaning and removing cases with missing data, we calculated the linkage-to-care interval in days and estimated the proportion of youth linked within a 42-day window by quarter. To address the primary research questions, we created a panel dataset organized by quarter in order to perform an interrupted time series analysis on SMILE's overall effects, followed by an ordinary least squares (OLS) regression to assess the specific contribution of PHA and a piecewise linear regression to assess the role of structural change. These methods are widely used for evaluating the impact of interventions on data over time [21–24]. We used an autoregressive integrated moving average (ARIMA) to fit a model of days to link to care over time. Stationarity was assessed using the augmented Dickey-Fuller test, which required a differencing factor of 1 ( $b = -4.79$ ,  $p < .01$ ) [24]. The differenced model adequately captured all autocorrelation (Ljung-Box statistic  $Q = 1.69$ ,  $p = \text{ns.}$ ). Autocorrelation function

**Table 2** Characteristics of youth referred to SMILE I and II

Characteristic		Frequency (%)	
		Youth referred ( <i>N</i> = 2142)	Youth linked ( <i>N</i> = 1516)
Black race	Yes	1741 (81.3)	1242 (81.9)
	No	401 (18.7)	274 (18.1)
Hispanic	Yes	239 (11.2)	184 (12.1)
	No	1903 (88.8)	1332 (87.9)
Gender identity	Female	371 (17.3)	281 (18.5)
	Male	1711 (79.9)	1198 (79.0)
	Transgender	48 (2.2)	37 (2.4)
	Unknown	12 (< 1)	0 (0)
Age	12–17	203 (9.5)	162 (10.7)
	18–20	734 (34.3)	556 (36.7)
	21–24	1205 (56.3)	798 (52.6)
Route of HIV acquisition	Heterosexual contact	497 (23.2)	371 (24.5)
	Male-to-male sexual contact	1359 (63.4)	1034 (68.2)
	Other	47 (2.2)	34 (2.2)
	Unknown	239 (11.2)	77 (5.1)

and partial autocorrelation function plots were used to determine potential values for the autoregressive and moving average orders. We then used Akaike information criterion (AIC) and Bayesian information criterion (BIC) to identify the most parsimonious ARIMA model; we used maximum likelihood methods to estimate model parameters. After evaluating if there was significant change over time, to address our question about the effect of PHA, we ran an OLS regression to examine differences in days to linkage to care between sites that were not granted PHA as compared with those that were granted PHA. We then ran a piecewise linear regression to estimate the effect of the intervention phases (medical case management vs. medical case management coupled with local structural change initiatives) on days to linkage to care. Piecewise linear regression models fit two or more linear regression lines to data that have abrupt changes in slope [25]. Additionally, piecewise regression analyses can be used to examine differential intercepts between intervention phases. The piecewise linear regression model used two segments to model the linear relationship between time and linkage to care across intervention phases. We identified the significance of discontinuity at the  $p < .05$  level. Finally, we examined whether youth's demographic characteristics

as recorded in their medical record were associated with linkage to care (yes/no) using a multivariable logistic regression with a logit link. Analyses of all linkage-to-care data were performed using Stata/SE version 14.2 and R. Cost data were analyzed using Excel.

#### Qualitative Analysis of Informant Interviews

Queries were run on the acronym “SMILE” in all key informant interviews, resulting in 75 identified passages of text. Two coders independently read the assigned passages. Coders were instructed to read three lines above and below the paragraph that mentioned SMILE to understand the context in which the program was discussed. After coders completed their initial reading of the text, the coders began to note themes, such as advantages of SMILE, challenges associated with the program's implementation, loss of funds to support the program, and collaboration with other government entities or organizations. Coders created a separate thematic summary of each of the interviews they read. Coders met regularly throughout the coding process to discuss emergent themes and patterns.



## Results

### Reduced Time to Linkage to Care

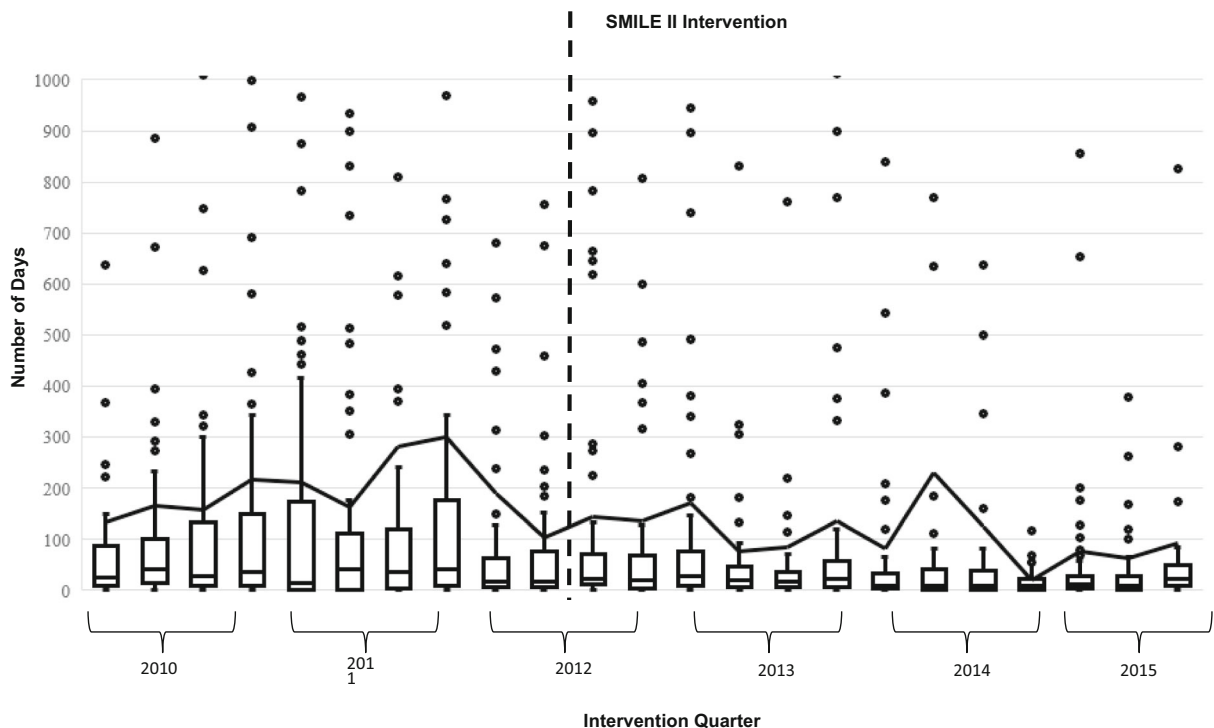
Of 2142 youth referred to the SMILE program, 1516 were successfully linked to care (70%). Examining only linked cases ( $N = 1516$ ) (Fig. 1), during the first year of SMILE I, the average number of days from test date to first linkage to care stayed steadily above 100 days. The median was 28. By the fifth and final year of the SMILE program, the average number of days between test date and linkage to care had decreased to 44 and the median number of days had declined to 10. In Fig. 2, we display the average proportion of youth linked to care within 42 days. As shown, the proportion of youth linked within a timely fashion rose steadily from 70% linked within 42 days in the first year of SMILE to almost 90% linked within 42 days in the final year of SMILE II. The result of an ARIMA model demonstrated the overall SMILE initiative made a significant contribution to timely linkage to care (ARIMA (1,2,1) AIC = 245.74, BIC = 248.70,  $p < .01$ ).

**PHA** Examining PHA, we observed that the four sites that were granted PHA from the onset of SMILE I were

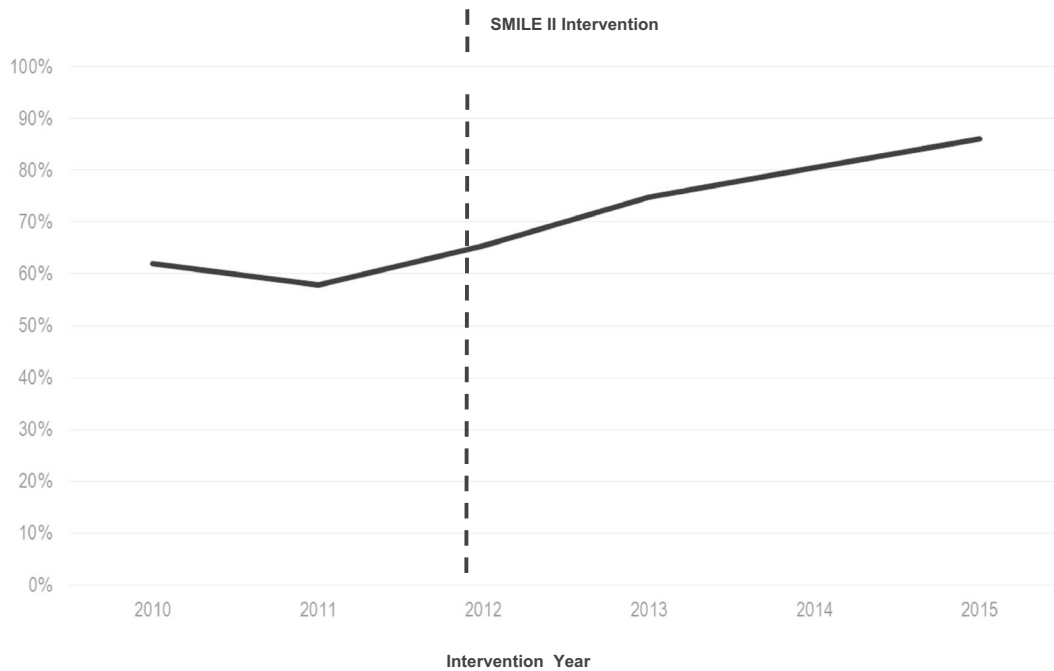
significantly more likely to link youth to care in fewer days than were the four non-PHA sites ( $b = -69.56$ ,  $p < .05$ ; 95% CI =  $-136.78$ ,  $-2.34$ ). Specifically, sites with PHA linked patients to care approximately 69.6 days sooner than those sites without it.

**Structural Change Initiatives** Results of the piecewise regression analyses showed that the introduction of structural change initiatives made a notable improvement over and above the case management component ( $F(3,19) = 5.48$ ,  $p < .01$ ; Adj.  $R^2 = .3794$ ). We assessed whether the difference in intercepts for the average days to link to care during SMILE I and SMILE II differed from zero. Results indicated a significant decrease in days to linkage to care during SMILE II relative to SMILE I ( $b = -65.69$ ,  $p < .01$ ). No difference in slopes was observed ( $p = \text{ns}$ ) between the two periods.

**Youth Characteristics** Finally, we examined whether youth's demographic characteristics were associated with linkage to care (see Table 3). Among all referred youth, as age increased by 1 year, youth were 0.90 times less likely to ever link to care ( $b = -0.10$ , SE  $b = 0.02$ ,  $p < .001$ ). Hispanic youth were 1.96 times more likely to ever link to care than youth who were not Hispanic ( $b =$



**Fig. 1** Box and whisker plot of number of days to linkage from HIV test date by intervention quarter



**Fig. 2** Proportion of youth linked to care in 42 or fewer days by intervention year

0.67, SE  $b = 0.20$ ,  $p < .01$ ). Black youth were 1.56 times as likely to ever link to care than youth of other races ( $b = 0.45$ , SE  $b = 0.15$ ,  $p < .01$ ).

**Cost** We calculated the mean and median cost for operating the program in its start-up quarter and at the end of 2012 (see Table 4). The average start-up cost per youth per quarter was \$2644 US. Once the program was stably

**Table 3** Demographic predictors of ever linked to care among newly diagnosed youth ( $N = 2140$ )

	b	SE b	Odds ratio
Age (years)	-0.10	0.02	.90**
Gender			
Male			Ref
Female	0.27	0.13	1.31*
Transgender	0.41	0.35	1.51
Race			
Non-Black			Ref
Black	0.45	0.15	1.56**
Ethnicity			
Non-Hispanic			Ref
Hispanic	0.67	0.20	1.96**

$\chi^2_{(5)} = 42.68^{**}$ ; Nagelkerke's  $R^2 = .028$

\* $p < .05$ , \*\* $p < .01$

operating, the average cost per youth per quarter was \$2978 US. During the first quarter (2010.2), 35 of 62 youth were linked to care (56%). During the final cost assessment interval, 75 of 86 youth were linked to care (87%). We calculated the incremental costs of the case management component of the intervention by dividing personnel costs by the difference between these two linkage rates. The quarterly incremental costs associated with medical case manager were \$3282.67 per percent increase in linkage rate. On average, linkage costs were lower for sites granted PHA.

**Key Informant Perceptions** Informants reported positively on the program's effects. Four themes were prominent in their observations.

**SMILE was Designed with Youth's Needs in Mind** Informants commented that SMILE excelled at youth-tailored approaches to linkage-to-care. Among the most common examples that informants cited were concerted efforts at both the individual and structural levels to ease the cost, inconvenience, and burden of travel on youth to medical facilities for care.

**Intensive Medical Case Management Sets SMILE Apart** According to informants, by prioritizing hands-on one-on-one intervention tailored to each newly

**Table 4** Quarterly intervention costs in US Dollars during initial 2 years of program operation ( $N=8$ )

Start-up				End of year 2	
	Personnel	Non-personnel	One-time startup costs	Personnel	Non-personnel
Average site cost (range)	\$24,420 (\$17,270–\$36,864)	\$3064 (\$498–\$10,585)	\$867 (\$0–\$3047)	\$23,799 (\$17,567–\$37,272)	\$12,309 (\$4503–\$23,335)
Median site cost	\$23,678	\$2602	\$552	\$22,501	\$13,401
Average site cost per youth linked (range)	\$2605 (\$176–4213)	\$327 (\$168–\$1058)	\$92 (\$0–\$507)	\$1963 (\$1064–\$3105)	\$1015 (\$429–\$1537)
Average site cost with PHA	\$23,469	\$4081	\$365	\$20,990	\$10,959
Average site cost without PHA	\$25,430	\$2424	\$1370	\$26,610	\$13,660

diagnosed youth, SMILE positively sets itself apart from other local efforts. SMILE was said to have earned youth's trust by consistently following up to make sure their needs were being met. The one-on-one case management and outreach approach allowed SMILE to reach youth who would not have sought care on their own.

*SMILE Took a Holistic Approach* Informants noted that SMILE assisted youth with a wide range of needs to facilitate youth's linkage to and engagement in care. Informants listed the diverse types of help youth received in the domains of housing, employment, and education.

*SMILE Reduced the Stigma of Seeking Care* SMILE was reported to have reduced the stigma of seeking care by establishing itself as a highly visible youth safe space and by specializing in meeting the needs of gay and bisexual and transgender youth. Informants discussed the impact SMILE had on reducing the stigma of care seeking among newly diagnosed youth primarily in the context of SMILE's defunding, noting that once the program ended, youth lacked available alternatives that youth perceived as supportive and trustworthy through which to obtain assistance to navigate health care access.

## Discussion

We evaluated a two-phase, multi-component, multi-site initiative to improve the proportion of youth linked to care in timely fashion. In phase I, a linkage-to-care specialist (primarily focused on linking youth to care through collaboration with health departments, testing sites, and

medical providers) was associated with increases in the overall proportion of youth linked to care and the speed with which their linkage occurred. This finding is consistent with findings of other research—typically focused on adults—that document significant improvement of linkage to care both in terms of proportion of people linked and the time between testing and first medical clinic appointment [26, 27]. Our findings suggest that such specialists—although resource intensive—are critical in terms of forming trusted relationships with young clients who are often responding to HIV with few resources and supports [27]. The observed rates of linkage and the timeliness of youth linkage to care represent significant improvements over passive referral approaches for adolescents and young adults and are consistent with those shown with intensive case management or patient navigator approaches [28].

In addition, we found that PHA granted to AMTUs speeded youth's linkage. Each AMTU's request for PHA provided a formal structure for data exchange between the local health department and the local AMTU. When granted, PHA authority gave AMTU personnel access to protected health information as allowed by 45 Code of Federal Regulations § 164.512(b)(1)(i) (The Privacy Rule) [19]. Even when PHA was not received, memoranda of agreement between SMILE and health departments strengthened communication and relationships between AMTU and local health departments [29]. Prior analyses suggest that formalizing these relationships improved timely linkage to care [9]. The current analyses demonstrate that PHA itself contributes to timely linkage to care, in addition to these close relationships between community agencies (such as AMTUs) and local health departments.

In phase II, we found that within about 3 years, systematic structural change initiatives added to each



site's linkage to care activities were associated with a stable pattern of rapid linkage to care for newly diagnosed youth. The average proportion of youth linked to care ultimately met or surpassed the 2020 goals for timely linkage to care [7]. The findings are especially important for their relevance to young Black gay and bisexual men who comprise a majority of the youth linked through SMILE, a population for which linkage-to-care disparities have been persistent [30]. Young racial and sexual minority people may be especially influenced by medical distrust, in addition to the effects of structural stigmas associated with the intersection of race and sexual identity [31].

Key informants observed that the youth-friendly focus of the intervention, its focus on each individual young person, its holistic approach, and its embeddedness within communities were all crucial to reducing the stigma and mistrust of newly diagnosed youth and creating trustworthy spaces for initiation of their care [32]. Simultaneously, structural changes created an enabling environment in support of youth's access to care. Our findings point to the potential benefits of multi-level intervention strategies for improving timely linkage to care for vulnerable youth.

Finally, the cost of the initiative fell within the estimated range for other cost-effective linkage programs, although none of these have focused on adolescents and youth. For example, Kim et al. reported cost per client ranges of \$502–\$3218 in the five-site evaluation of *Positive Charge*, a linkage to HIV care initiative implemented in New York, Chicago, Louisiana, North Carolina, and the San Francisco/Bay Area [33].

Despite the encouraging results from this investigation, several limitations of our study merit discussion. First, because the sites involved in the initiative changed over time, we are only able to examine a minority of the sites that participated in the initiative at any point in time. We chose to examine the subset of AMTUs that participated in both SMILE phases because that allowed us to use a quasi-experimental design that permits strong causal inferences to be made. However, we cannot be certain that our findings generalize to the entire initiative. Second, we cannot attribute observed changes during SMILE II to specific structural changes because our data and study design only permit us to examine the aggregated effect of structural change efforts. We are left to assume that each change is of roughly equal merit in reducing delays to link to care. Given the diverse structural changes that were pursued and the wide variation

among sites in the number and nature of structural changes, future research might closely examine the contribution of specific types of changes to improved linkage rates. Additionally, although we could examine PHA, which is itself a specific form of structural change, replications with a larger number of sites are necessary to provide a more sensitive estimate of the contribution of PHA to speeding linkage to care. Third, we relied on clinical records with more than ideal rates of missingness. Moreover, missingness was probably more common for those youth who could not be linked to care in part because of a lack of completed and reliable information about them. Additionally, because of the small number of sites that participated in both phases of the demonstration and the small number of youth diagnosed on any given day or in any given month, we used a panel data set aggregated to quarter to examine change over time in days to linkage to care. Doing so prevented us from co-varying the effects of youth characteristics on days to linkage to care, which would require an individual-level dataset. Finally, the cost data we collected are limited to only the first 2 years of phase I. They do not include estimates of the cost of the structural change phase of the study.

## Conclusion

Integrated, multi-level interventions that draw on existing community resources can dramatically improve timely linkage to care among high-risk youth. Structural change initiatives can enhance the impact of individual-level medical case management and support the development of stable linkage systems. Future research should examine the disaggregated contributions of specific types of structural change in order to identify which offer the most potent enhancements to youth's environments and contribute most meaningfully to youth's ability to swiftly link to HIV medical care after an initial HIV-positive diagnosis.

**Acknowledgements** This work was supported by Grants No. 5 U01 HD040533 and 5 U01 HD 40474 to the Adolescent Medicine Trials Network for HIV/AIDS Interventions (ATN) from the National Institutes of Health through the Eunice Kennedy Shriver National Institute of Child Health and Human Development (B. Kapogiannis, MD), with supplemental funding from the National Institute on Drug Abuse (K. Davenny, PhD) and National Institute on Mental Health (S. Allison, PhD, P. Brouwers, PhD). The study was scientifically reviewed by the ATN's Community and Prevention Leadership Group. Network scientific and logistical support

was provided by the ATN Coordinating Center (C. Wilson, C. Partlow, J. Merchant) at the University of Alabama at Birmingham. ATN Data and Operations support was provided by Westat, Inc. (Jim Korelitz, PhD, Barbara Driver, RN, MS). We are grateful to Chittrak Banerjee, Timothy Thompson, and Taylor Whittington for their research assistance.

## References

- Centers for Disease Control and Prevention. HIV among Youth. HIV and Youth CDC Fact Sheet 2018. Available at: <https://www.cdc.gov/hiv/group/age/youth/index.html>. Retrieved March 22, 2019.
- Zanoni BC, Mayer KH. The adolescent and young adult HIV cascade of care in the United States: exaggerated health disparities. *AIDS Patient Care STDs*. 2014;28:128–35.
- Centers for Disease Control and Prevention. Estimated HIV incidence and prevalence in the United States, 2010–2015. HIV Surveillance Supplemental Report 2016; 23 (Suppl 1). Available at: <https://www.cdc.gov/hiv/pdf/library/reports/surveillance/cdc-hiv-surveillance-supplemental-report-vol-23-1.pdf>. Retrieved February 11, 2019.
- Centers for disease control and prevention. HIV among African American gay and bisexual men. HIV and African American Gay and Bisexual Men CDC Fact Sheet 2018. Available at: <https://www.cdc.gov/hiv/group/msm/bmsm.html>. Retrieved February 13, 2019.
- Millett GA, Peterson JL, Flores SA, et al. Comparisons of disparities and risks of HIV infection in black and other men who have sex with men in Canada, UK, and USA: a meta-analysis. *Lancet*. 2012; **July**:11–8.
- Rebeiro PF, Ivey KS, Craig KS, Hulan T, Huaman MA, Nash R, et al. New faces of HIV infection: age, race, and timing of entry into HIV care in the southeastern United States. *J Int Assoc Provid AIDS CARE*. 2017;16:347–52.
- White House Office of National AIDS Policy National HIV/AIDS strategy for the United States: updated to 2020. AIDS Policy 2015; <https://files.hiv.gov/s3fs-public/nhas-update.pdf>. Retrieved September 7, 2018.
- Torian LV, Wiewel EW, Liu K, et al. Risk factors for delayed initiation of medical care after diagnosis of human immunodeficiency virus. *Arch Gen Intern Med*. 2008;168:1181–7.
- Philbin, MM, Tanner, AE, DuVal, A, et al. Factors affecting linkage to care and engagement in care for newly diagnosed HIV-positive adolescents within fifteen adolescent medicine clinics in the United States. *AIDS Behav*. 2014;18:1501–1510.
- Minnear TD, Gaur AH, Thridandapani CS, et al. Delayed entry into and failure to remain in HIV care among HIV-infected adolescents. *AIDS Res Hum Retrovir*. 2013;29:99–104.
- Fortenberry, JD, Martinez, J, Rudy, BJ, et al. Linkage to care for HIV-positive adolescents: A multisite study of adolescent medicine trials units of the Adolescent Trials Network. *J Adolesc Health*. 2012;51:551–556.
- Chiaromonte, D, Strzyzkowski, T, Acevedo-Polakovich, I, et al. Ecological barriers to HIV service access among youth men who have sex with men and high-risk young women from low-resourced urban communities. *J HIV AIDS Soc Serv*. 2018;31:1–22.
- Griffin-Tomas M, Cahill S, Kapadia F, et al. Access to health services among young adult gay men in New York City. *Am J Mens Health*. 2018, DOI:<https://doi.org/10.1177/1557988318818683>.
- Griffith DC, Agwu AL. Caring for youth living with HIV across the continuum: turning gaps into opportunities. *AIDS Care*. 2017;29:1205–11.
- Tso LS, Best J, Beanland R, Doherty M, Lackey M, Ma Q, et al. Facilitators and barriers in HIV linkage to care interventions: a qualitative evidence review. *AIDS*. 2016;30:1639–53.
- Lee S, Yamazaki M, Harris RD, et al. Social support and HIV-status disclosure to friends and family: implications for HIV-positive youth. *J Adolesc Health*. 2015;57:73–80.
- Smith R, Rossetto K, Peterson BL. A meta-analysis of disclosure of one's HIV-positive status, stigma, and social support. *AIDS Care*. 2008;20:1266–75.
- Fortenberry, JD., Koenig, LJ, Kapogiannis, BG, et al. Implementation of an integrated approach to the National HIV/AIDS Strategy for improving Human Immunodeficiency Virus care for youths. *JAMA Pediatr*. 2017;171:687–693.
- Boyer, CB., Walker, BB, Chutuaape, KS, et al. Creating systems change to support goals for HIV continuum of care: The role of community coalitions to reduce structural barriers for adolescents and young adults. *J HIV AIDS Soc Serv*. 2016;15:158–179.
- Miller, RL., Reed, SJ, Chiaromonte, D, et al. Structural and community change outcomes for the Connect-to-Protect coalitions: Trials and triumphs securing adolescent access to HIV prevention, testing, and medical care. *Am J Community Psychol*. 2017;60:199–214.
- Yanik EL, Tamburro K, Eron JJ, et al. Recent cancer incidence trends in an observational clinical cohort of HIV-infected patients in the US, 2000 to 2011. *Infect Agents Cancer*. 2013;8:1–6.
- Walley AY, Xuan Z, Hackman HH, Quinn E, Doe-Simkins M, Sorensen-Alawad A, et al. Opioid overdose rates and implementation of overdose education and nasal naloxone distribution in Massachusetts: interrupted time series analysis. *BMJ*. 2013;346:f174.
- Hartman DP, Gottman JM, Jones RR, et al. Interrupted time-series analysis and its application to behavioral data. *J Appl Behav Anal*. 1980;13(4):543–59.
- Wagner AK, Soumerai SB, Zhang F, Ross-Degnan D. Segmented regression analysis of interrupted time series studies in medication use research. *J Clin Pharm Ther*. 2002;27:299–309.
- Muggeo VMR. Estimating regression models with unknown break-points. *Stat Med*. 2003;22:3055–71.
- Gomez CA, Tat SA, Allen D, et al. What will it take to end the HIV/AIDS epidemic? Linking the most disenfranchised into care through outreach. *AIDS Patient Care STDs*. 2017;31(3):122–8.
- Bendetson J, Dierst-Davies R, Flynn R, Beymer MR, Wohl AR, Amico KR, et al. Evaluation of a client-centered linkage

- intervention for patients newly diagnosed with HIV at an urban United States LGBT center: the linkage to care specialist project. *AIDS Patient Care STDs*. 2017;31(7):283–9.
28. Broaddus MR, Owczarzak J, Schumann C, Koester KA. Fostering a “feeling of worth” among vulnerable HIV populations: the role of linkage to care specialists. *AIDS Patient Care STDs*. 2017;31(10):438–46.
  29. Okeke N, McFarland W, Raymond HF. Closing the gap? The HIV continuum in care for African-American men who have sex with men, San Francisco, 2004–2014. *AIDS Behav*. 2017;21:1741–4.
  30. Eaton LA, Driffin DD, Kegler C, Smith H, Conway-Washington C, White D, et al. The role of stigma and medical mistrust in the routine health care engagement of black men who have sex with men. *Am J Public Health*. 2015;105(2):e75–82.
  31. Miller, RL., Reed, SJ, Chiamonte, D, et al. Structural and community change outcomes for the Connect-to-Protect coalitions: Trials and triumphs securing adolescent access to HIV prevention, testing, and medical care. *Am J Community Psychol*. 2017;60:199–214.
  32. The Positive Charge Intervention Team, Charles V, Riordan M, et al. Cost and threshold analysis of positive charge, a multi-site linkage to HIV care program in the United States. *AIDS Behav*. 2015;19:1735–41.
  33. Tanner AE, Philbin M, DuVal A, et al. ‘Youth friendly’ clinics: Considerations for linking and engaging HIV-infected adolescents into care. *AIDS Care*. 2014; 26(2):199–205.
  34. Cheung YW, Lai KS. Lag order and critical values of the augmented dickey-fuller test. *J Bus Econ Stat*. 1995;13(3): 277–80.
  35. Camacho-Gonzalez AF, Gillespie AS, Thomas-Seaton L, et al. The metropolitan Atlanta community adolescent rapid testing initiative study: closing the gaps in HIV care among youth in Atlanta, Georgia, USA. *AIDS*. 2017;31(Suppl 3): S267–75.

**Publisher's Note** Springer Nature remains neutral with regard to jurisdictional claims in published maps and institutional affiliations.