

165. Linkage to care and engagement in care for newly diagnosed HIV-positive youth within fifteen adolescent medicine clinics in the United States

By: Morgan Mari Philbin, [Amanda E. Tanner](#), Anna L. DuVal, Jonathan Ellen, Bill Kapogiannis, and J. Dennis Fortenberry

MM Philbin, AE Tanner, AL DuVal, J Ellen, B Kapogiannis, JD Fortenberry. (2012). Linkage to care and engagement in care for newly diagnosed HIV-positive youth within fifteen adolescent medicine clinics in the United States. *Journal of Adolescent Health* 50 (2), S92.

Made available courtesy of Elsevier: <https://doi.org/10.1016/j.jadohealth.2011.10.243>



This work is licensed under a [Creative Commons Attribution-NonCommercial-NoDerivatives 4.0 International License](#).

***© 2012 Society for Adolescent Health and Medicine. Reprinted with permission. This version of the document is not the version of record. ***

Abstract:

Purpose: The National HIV/AIDS Strategy emphasizes the importance of linkage to care (LTC) for newly diagnosed persons. However, 30% or more of newly diagnosed youth are not linked-to-care within 6 months. The study describes a structural intervention to enhance care linkage and engagement for newly diagnosed youth. SMILE in Caring for Youth (SMILE) is an NIH, CDC and the Adolescent Medicine Trials Network (ATN) collaboration that provided a full-time LTC outreach worker (OW) to each of the 15 ATN sites. The goal of the study is to report on preliminary findings regarding the success of the SMILE program for improving LTC outcomes.

Keywords: published abstract | linkage to care | HIV care | adolescent medicine

Article:

Purpose: The National HIV/AIDS Strategy emphasizes the importance of linkage to care (LTC) for newly diagnosed persons. However, 30% or more of newly diagnosed youth are not linked-to-care within 6 months. The study describes a structural intervention to enhance care linkage and engagement for newly diagnosed youth. SMILE in Caring for Youth (SMILE) is an NIH, CDC and the Adolescent Medicine Trials Network (ATN) collaboration that provided a full-time LTC outreach worker (OW) to each of the 15 ATN sites. The goal of the study is to report on preliminary findings regarding the success of the SMILE program for improving LTC outcomes.

Methods: OWs used a case-log to record the number of HIV-positive youth referred to them (e.g. from test sites), the number linked-to-care (defined as an HIV-related medical visit within 42 days of referral) and engaged in care (defined as a 2nd HIV-related medical visit within 16 weeks of 1st visit). OWs recorded demographics, case dispositions, and reasons for failure in care linkage/engagement. These data were compared against incidence data prior to the implementation of SMILE to assess preliminary intervention effectiveness.

Results: By Year 1, 1,013 HIV-positive youth were assigned disposition codes (ages 12-24, 79% male, 18% female, and 3% transgendered; 14.6% Hispanic/Latino ethnicity, 70.7% African American, 8.4% White). Mean referrals per site were 65.7 (range 20-185). Average referrals to OWs increased from 145 at baseline, to 192 in Quarter 2, and 248 in Quarter 4. Only 79.6% of initial referrals (806/1013) were eligible for LTC; the other 20.4% (207/1013), were not eligible due to the youth being outside a site's jurisdiction (37/1013) or already linked-to-care(170/1013). Among all LTC-eligible youth, a total of 550/806 (68.2%) were linked-to-care of which 489/550 (88.9%) were engaged in care. Only 60.7% (489/806) of eligible youth were ultimately linked and engaged in care. Of the LTC-eligible youth, LTC rates ranged from 40%-95% across sites, and engagement in care from 33-93%. Major reasons for LTC failure were insufficient contact information, inability to locate youth, youth's refusal of LTC, and repeated failure to attend appointments. Data sharing from testing sites to OWs and local health departments was a major barrier across all sites.

Conclusions: Care linkage/engagement rates for newly diagnosed HIV-positive youth are suboptimal even with a full-time worker dedicated solely to this purpose; barriers to care linkage/engagement are not simply due to lack of resources. Rather, structural barriers such as limited data sharing between testers and clinics, and local health department engagement hinder effective transfer of care from testing sites to HIV care sites. Many referred youth were out of jurisdiction or already linked-to-care, suggesting care fragmentation is a barrier. Substantial site-to-site variation suggests that structural barriers are larger in some locales. Additional improvements in HIV care linkage/engagement will require creative approaches to coordinated data sharing, as well as continued outreach services to support youth dealing with a major health crisis. These advances will be critical to successfully impact all key objectives addressed in the National HIV/AIDS Strategy.

Sources of Support

NIH3U01 HD040533-09S1.