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Original article

Linking HIV-Negative Youth to Prevention Services in 12 U.S. Cities: Barriers and Facilitators to Implementing the HIV Prevention Continuum

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A B S T R A C T

Purpose: Linkage of HIV-negative youth to prevention services is increasingly important with the development of effective pre-exposure prophylaxis that complements behavioral and other prevention-focused interventions. However, effective infrastructure for delivery of prevention services does not exist, leaving many programs to address HIV prevention without data to guide program development/implementation. The objective of this study was to provide a qualitative description of barriers and facilitators of linkage to prevention services among high-risk, HIV-negative youth. Design: Thematic analysis of structured interviews with staff implementing linkage to prevention services programs for youth aged 12–24 years.
Methods: Twelve adolescent medicine HIV primary care programs as part of larger testing research program focused on young sexual minority men of color. The study included staff implementing linkage to prevention services programs along with community-based HIV testing programs. The main outcomes of the study were key barriers/facilitators to linkage to prevention services.
Results: Eight themes summarized perspectives on linkage to prevention services: (1) relationships with community partners, (2) trust between providers and youth, (3) youth capacity to navigate prevention services, (4) pre-exposure prophylaxis specific issues, (5) privacy issues, (6) gaps in health records preventing tailored services, (7) confidentiality of care for youth accessing services through parents'/caretakers' insurance, and (8) need for health-care institutions to keep pace with models that prioritize HIV prevention among at-risk youth. Themes are discussed in the context of factors that facilitated/challenged linkage to prevention services.
Conclusions: Several evidence-based HIV prevention tools are available; infrastructures for coordinated service delivery to high-risk youth have not been developed. Implementation of such infrastructures requires attention to community-, provider-, and youth-related issues.

IMPLICATIONS AND CONTRIBUTION

Although linkage of HIV-negative youth to prevention services is increasingly important with growing utilization of pre-exposure prophylaxis along with behavioral and other prevention-focused interventions, effective infrastructure for delivery of prevention services is underdeveloped. The current study reports themes on barriers and facilitators to creation of such an infrastructure.

Conflicts of Interest: The authors have no conflicts of interest to disclose.
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The HIV Prevention Continuum differs from the better known HIV Continuum of Care for HIV-positive youth in its emphasis on prevention among high-risk HIV-negative individuals, connecting HIV testing to a youth-friendly infrastructure for long-term prevention services (including pre-exposure prophylaxis [PrEP]), with retention of these youth over time to reinforce prevention behaviors, to intervene in lapses of prevention behaviors, and to identify early incident infections [1–3]. Current research and policy only address the initial step of the Prevention Continuum—HIV testing [1–6]. Ideally, each testing event is a prevention opportunity, either by linking HIV-positive youth to treatment services, or by linking HIV-negative youth to prevention services [1,5,7]. Evidence-based best practices for linkage to care for youth testing positive are increasingly well described [8–10].

However, systematic, community-focused approaches of linkage to prevention services for youth—following a negative HIV test—are not well described. Practically speaking, infrastructure for such comprehensive HIV prevention services does not exist. For example, PrEP, as a biomedical prevention intervention, requires linkage—preferably at the time of testing—to a youth-friendly health-care provider capable of prescribing and monitoring medications [5,7]. Other prevention services are not necessarily associated with PrEP provision. For example, screening, brief intervention, referral, and treatment for mental health and substance use are not an automatic concomitant of PrEP prescription and monitoring. Clinics providing PrEP could also provide evidence-based interventions to reduce HIV-related behavioral risks [11], but such interventions are peripheral to the clinical requirements for determining indications for a medication, prescription to eligible patients, and monitoring effectiveness and side effects.

Legal and ethical barriers further complicate implementation of HIV prevention services for minors. Currently, only a few states expressly permit minor consent for sexually transmitted infections (STIs) and HIV prevention services [9], leaving the majority of youth without access to prevention services in the absence of parental permission. Barriers to legal access profoundly impact youths' use of prevention services [10]. The bottom line is that no well-defined approach exists for provision of HIV prevention services—especially PrEP—for at-risk youth [12,13].

The research presented here describes the systematic implementation of programs—as part of a larger community-based testing and prevention program—for linkage to prevention services for youth, aged 13–24 years who are at risk but are HIV negative. The community-based strategies for HIV testing and linkage to health care for HIV-positive youth are described elsewhere [2]. Our objective was to provide guidance toward the implementation of community-based, comprehensive HIV prevention services for youth.

Methods

To address the legal, ethical, and public health challenges of comprehensive HIV prevention services for youth, we implemented a pilot demonstration project named Connect to Test and Prevent (C2TaP). C2TaP was a multisite implementation science project to identify the processes and strategies by which at-risk youth were tested for HIV, with linkage to prevention services for those who tested negative. The sites were located in urban, resource-challenged communities with high HIV burden. Within each community, we built upon stakeholder networks developed in prior research, including Connect to Protect (C2P, the HIV prevention community mobilization efforts of the Adolescent Trials for HIV/AIDS Prevention Interventions [ATN]) and the Strategic Multisite Initiative for the Identification, Linkage and Engagement (SMILE) in care of HIV-infected youth demonstration project designed to connect newly infected youth to youth-friendly HIV care [14,15]. Further, C2TaP incorporated four principles of implementation science: (1) understanding the implementation environment; (2) observing the process of implementation; (3) testing implementation approaches; and (4) linking implementation evidence to policy, larger program design, and sustainable scale-up [16]. Thus, the purpose of this qualitative evaluation of the C2TaP demonstration project was to describe strategies that were successful and those that were less successful or ineffective in identifying and recruiting at-risk youth for HIV testing and linkage to prevention services.

C2TaP was implemented by 12 Adolescent Medicine Trials Network for HIV/AIDS Interventions (ATN) Adolescent Medicine Trial Units (referred hereafter as sites) and was funded by the Eunice Kennedy Shriver National Institute for Child Health and Human Development and the National Institute on Minority Health and Health Disparities. Implementation activities were conducted between June 1, 2015, and February 29, 2016.

The primary goal of C2TaP was to link HIV-negative youth aged 13–24 years to prevention services. Sites were asked to emphasize testing and prevention services for African-American and Latino young men who have sex with men (subsequently identified as YMSM of color) since these populations are disproportionately represented among new HIV infections [13]. Each site developed and implemented a site-specific HIV testing strategy that used local epidemiological data and built upon ongoing C2P collaborations with local community partners [14,15,17]. Prevention services were broadly defined to include providing access to PrEP, periodic rescreening or testing following high-risk exposures, STI screening, behavioral risk-reduction counseling, referral to online resources, and linkage to other community-based prevention and support services that address mental health, substance abuse, housing, and food security. Linkage to prevention and support services was provided by linkage coordinators who were specifically trained to work with youth and marginalized populations. Newly identified youth living with HIV across all sites were linked to HIV care: overall, 1,172/1,679 (69.8 %) youth were linked to care, of whom 1,043/1,172 (89 %) were engaged in care [18].

Evaluation data and analyses

Informants. Informants were identified collaboratively by C2TaP staff and staff of the ATN's National Coordinating Center (the C2TaP coordination and oversight center). Informants included three individuals from each site, including HIV testing staff, navigators, nurses, project directors, and site principal investigators). The participant sample intentionally focused on site staff members to gain the perspectives of those who planned and implemented the pilot demonstration project. Although study resources did not allow for the direct interviewing of youth recipients of services, their perspectives were gathered at individual sites during the planning and development of projects to ensure a youth-informed design. Also, the youth's perspective was captured indirectly via the staff that was interviewed (see Table 1 for description of informants).

Data collection tools. Interview guides were informed by aims of the demonstration project, the National HIV/AIDS Strategy, and