

Adolescent to adult HIV health care transition from the perspective of adult providers in the United States

By: [Amanda E. Tanner](#), Morgan M. Philbin, Alice Ma, Brittany D. Chambers, Sharon Nichols, Sonia Lee, J. Dennis Fortenberry, and Adolescent Trials Network for HIV/AIDS Interventions

AE Tanner, MM Philbin, A Ma, BD Chambers, S Nichols, S Lee, JD Fortenberry, Adolescent Trials Network for HIV/AIDS Interventions. Adolescent to adult HIV health care transition from the perspective of adult providers in the United States. *Journal of Adolescent Health* 61 (4), 434-439.

Made available courtesy of Elsevier: <https://doi.org/10.1016/j.jadohealth.2017.05.011>



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Abstract:

Purpose: The HIV Care Continuum highlights the need for HIV-infected youth to be tested, linked, and maintained in lifelong care. Care engagement is important for HIV-infected youth in order for them to stay healthy, maintain a low viral load, and reduce further transmission. One point of potential interruption in the care continuum is during health care transition from adolescent- to adult-centered HIV care. HIV-related health care transition research focuses mainly on youth and on adolescent clinic providers; missing is adult clinic providers' perspectives.

Methods: We examined health care transition processes through semi-structured interviews with 28 adult clinic staff across Adolescent Trials Network sites. We also collected quantitative data related to clinical characteristics and transition-specific strategies.

Results: Overall, participants described health care transition as a “warm handoff” and a collaborative effort across adolescent and adult clinics. Emergent transition themes included adult clinical care culture (e.g., patient responsibility), strategies for connecting youth to adult care (e.g., adolescent clinic staff attending youth's first appointment at adult clinic), and approaches to evaluating transition outcomes (e.g., data sharing). Participants provided transition improvement recommendations (e.g., formalized protocols).

Conclusions: Using evidence-based research and a quality improvement framework to inform comprehensive and streamlined transition protocols can help enhance the capacity of adult clinics to collaborate with adolescent clinics to provide coordinated and uninterrupted HIV-related care and to improve continuum of care outcomes.

Keywords: Adolescents | Health care transition | HIV | HIV care | Youth

Article:

HIV rates in the United States (U.S.) continue to rise among youth (ages 13–24 years), who account for 22% of all new HIV infections [1]. The HIV Care Continuum highlights the need for HIV-infected youth to be tested, linked, and maintained in care as part of achieving optimal health [2]. However, fewer than half of HIV-infected youth in the U.S. know their status, only one quarter are engaged in care, and approximately 6% achieve viral suppression; in contrast, 51% of adults are engaged in care and 28% are virally suppressed [2], [3]. Indeed, there are many factors across diagnostic and care systems that challenge youth's ability to progress through the care continuum [4]. One stage that has received scant attention is during the transition from adolescent to adult HIV care.

Although transition to adult care is important for adolescents living with a variety of noninfectious chronic diseases [5], including diabetes [6] and cancer [7], it is especially critical for HIV-infected youth in order for them to remain healthy, maintain a low viral load, and reduce further transmission [8], [9]. Approximately 25,000 HIV-infected youths are scheduled to transition in the next decade [10], demonstrating the need for effective transition approaches to support care engagement and continued treatment in adult HIV care settings. Initially, successful transitions do not necessarily suggest long-term engagement [11]; only 50% of youth who successfully transition were retained in adult care after 1 year [12].

To improve the transition process for HIV-infected youth, the American Academy of Pediatrics [13] released recommendations for HIV-related health care transition: (1) development of written policies to guide transition; (2) joint creation of a transition plan by youth, family, and providers; (3) planned facilitation of youths' connection to adult clinics as transition is initiated; and (4) communication between adolescent and adult clinics during the transition process for quality assurance review. However, these guidelines and previous HIV-related transition research focus almost exclusively on adolescents and adolescent/young adult clinics [14], [15], [16], [17]. The adult clinic perspective is missing, although it plays a critical role in health care transition [12], [15], [18]. Understanding adult providers' attitudes and comfort in treating youth is essential to ascertain preparation gaps and needs. Accordingly, this study examined HIV-related health care transition approaches and processes for behaviorally infected youth from the perspectives of adult clinic staff.

Methods

As part of the larger Comprehensive Assessment of Transition and Coordination for HIV-Positive Youth as they Move from Adolescent to Adult Care (CATCH) study, data were collected from adult clinics that received youths who were transitioning from Adolescent Trials Network (ATN) clinical sites. The ATN was a clinical research network located in geographically dispersed cities across the United States (e.g., Baltimore, Chicago, Los Angeles, Miami, and New Orleans) that provided comprehensive HIV-related care for adolescents aged 13–24 years [19]. Adolescent clinic staff at the 14 ATN clinics identified 20 adult clinics to which they referred youth for adult HIV care. Providers (n = 39) at all the identified adult clinics

were contacted via email and/or phone and invited to participate. Of these, six were not able to participate (e.g., moving to new job and did not work in adult clinic), and five did not respond despite multiple contacts. Institutional Review Boards at the University of North Carolina Greensboro and all participating ATN sites approved the study protocol. All interviewees provided verbal consent.

Qualitative data

Twenty-eight semi-structured interviews were conducted with medical and social service providers (e.g., case managers, nurses, physicians, and social workers). Purposive sampling was used to choose individuals whose role included receiving and supporting youth as they transitioned from pediatric/adolescent to adult clinical HIV care. This provided a comprehensive assessment of the transition processes and protocols and illuminated the role of context in facilitating transition. Interviews occurred from August 2015 to June 2016 and lasted approximately 45 minutes (range: 23–54 minutes); they were conducted over the phone, digitally recorded, and professionally transcribed. Interviewers prepared field notes after each interview.

Interviewers used a topic guide that focused on site-specific organization and characteristics; transition processes and protocols; facilitators and barriers to transition; and relationships with adolescent clinics. Prior HIV and other chronic disease transition research informed interview questions. Questions focused on (in order) clinic-specific characteristics (e.g., What is your patient population? Do you have relationships with adolescent care clinics? How is your clinic different from the youths' adolescent clinics?), site-specific transition process and protocols (e.g., What does your process look like for receiving transitioning youth? What are ways to facilitate transition?), descriptions of health care transition (e.g., Can you describe a representative example of a recent transitioning youth?), factors affecting health care transition (e.g., What do you consider indicators of “successful” transition? Do you have a sense of drop out at transition? How do you reengage those who drop out?), and transition recommendations (e.g., What suggestions do you have for how to keep youth in care during transition?).

The constant comparative method [20], [21] was applied to examine how providers described and approached health care transition. Two researchers trained in qualitative research methods independently read and coded each transcript to create an initial codebook. Subsequently, a list of thematic codes based on the literature was incorporated to ensure that both theory-based and emergent concepts were included. This codebook was then reviewed by other team members [22]. A data table was created to summarize and refine codes [21]; then, a matrix was developed to compare adult clinics' descriptions of health care transition processes, which included differences between and within adult clinics. Researchers applied the finalized coding structure to all transcripts resulting in a 90% inter-rater agreement. Following the procedures of the constant comparative method, negative cases were searched regarding health care transition approaches and related themes. The coding matrix was then modified as needed and returned to the data for additional comparisons [21]. The research team conducted weekly meetings throughout the coding process to resolve any discrepancies.

Quantitative data

Quantitative data were also collected on specific clinic characteristics and services available across the 20 adult clinics. Data included logistical characteristics (e.g., clinic/provider associated with the same institution as the adolescent clinic and/or serves HIV-infected patients only) and comprehensive patient services (e.g., mental health services, support groups, and/or reproductive health services). Strategies used and topics covered to support transition were also assessed. Descriptive analyses were conducted using SPSS version 24.

Results

Participant and clinic characteristics

Most adult clinic staff were female ($n = 22$) and represented a range of clinical roles, including physicians ($n = 11$), social workers ($n = 5$), and care linkage coordinators or supervisors ($n = 4$). Staff had worked at the adult clinics for an average of 9 years (range: 2–25 years; standard deviation = 7.2). Table 1 summarizes participant characteristics.

Table 1. Adult clinic staff characteristics ($N = 28$)

Characteristics	n (%)
Gender	
Male	6 (21.4)
Female	22 (78.6)
Role in adult clinic	
Physician	11 (39.3)
Nurse practitioner	2 (7.1)
Social worker	5 (17.9)
Case manager	3 (10.7)
Care linkage/patient coordinator or supervisor	4 (14.3)
Other (pharmacist, family advocate, substance abuse specialist/retention staff)	3 (10.7)

Adult clinics frequently were located either within the same building or campus as the adolescent clinic ($n = 6$) or associated with the same institution ($n = 8$). One-third of adult clinics served only HIV patients ($n = 7$). Co-located services were provided onsite at most adult clinics including sexually transmitted infection testing and treatment ($n = 20$), case management ($n = 18$), reproductive health services ($n = 17$), pharmaceutical services ($n = 16$), and support groups ($n = 12$). Most adult clinics accepted payments on a sliding scale ($n = 16$).

Adult clinic staff reported using an array of educational topics (e.g., life skills planning and health behaviors) and strategies (e.g., transition-specific staff person and insurance registration) to support youth during transition. Tables 2 and 3 present more details on clinic characteristics, services, and transition-related strategies.

Table 2. Adult clinic characteristics and services ($N = 20$)

Clinical characteristics	Yes n (%)
Clinic/provider associated with the same institution as the adolescent (ATN) clinic	8 (40.0)
Clinic/provider associated with the same building or campus as the adolescent (ATN) clinic	6 (30.0)
Hospital clinic (located within a hospital)	7 (35.0)
Community clinic (not located within a hospital)	11 (55.0)
Accepts HIV-positive patients only	7 (35.0)
Provides services to adults only (i.e., 18 years or older)	13 (65.0)

Clinical characteristics	Yes n (%)
Provides HIV treatment services only, including monitoring and prescribing of ART but does not provide other general primary care	5 (25.0)
Adolescent providers also see patients here	9 (45.0)
Easily accessible by public transportation (i.e., less than ½ mile from bus or train stop)	19 (95.0)
Open outside usual workday hours (i.e., early mornings, evenings, and/or weekends)	9 (45.0)
Accepts Medicaid	20 (100)
Accepts payments on a sliding scale	16 (80.0)
Patient services	
STI testing and treatment	20 (100)
Case management services	18 (90.0)
Reproductive health services (contraception)	17 (85.0)
Mental health services	16 (80.0)
Pharmaceutical services	16 (80.0)
HIV-positive support groups	12 (60.0)
Anoscopy	7 (35.0)
Colposcopy	6 (30.0)
Obstetrics	6 (30.0)
Drug and alcohol treatment	5 (25.0)

ART = antiretroviral therapy; ATN = Adolescent Trials Network; STI = sexually transmitted infections.

Table 3. Adult clinic transition educational topics and strategies (N = 20 adult clinics)

	n (%)
Education on life skills planning and development	
Teaches youth how to schedule appointments	18 (90)
Teaches youth how to refill prescriptions	18 (90)
Teaches youth how to call health care providers with questions or problems	19 (95)
Teaches youth about insurance protocols (e.g., making insurance claims and carrying insurance card)	17 (85)
Teaches youth how to interpret and understand medical records (e.g., HIV-1 RNA level, and CD4 T-cell count results)	16 (80)
Teaches youth the benefit of other health care team members at adult clinic (e.g., case manager, dietitian, and health educator)	19 (95)
Education on individual health behaviors	
Discusses mental and psychosocial health issues and how to seek help (e.g., mental health and substance use) with youth	20 (100)
Discusses reducing risk taking behaviors (e.g., tobacco, alcohol, and drug use) with youth	20 (100)
Discusses sexual activity and safety (e.g., number of partners and condom use) with youth	20 (100)
Discusses screening and prevention of sexually transmitted infections and cervical cancer with youth	20 (100)
Discusses preconception care (preparing for a safe pregnancy and healthy baby) with youth	17 (85)
Discusses need for other services (e.g., oral/dental care, vision and eye exams, and immunization) with youth	18 (90)
Clinical strategies	
Clinic has transition protocol (formal or informal)	16 (80)
Clinic has a specific “transition” staff person (e.g., social worker and case manager)	11 (55)
Clinic has adult provider go to adolescent clinic to treat or meet youth just prior to transition	7 (38.9)
Clinic has adolescent clinic staff attend first adult clinic appointment with youth	6 (35.3)
Clinic receives health information from the adolescent care team	17 (94.4)
Clinic evaluates transition outcome (e.g., track or follow-up with adolescent clinic and electronic health records)	13 (68.4)
System-level strategies	
Assesses current health insurance plan and new options (e.g., family plan, employer plan, and healthcare.gov) with youth	19 (95)
Discusses confidentiality/parental involvement (e.g., HIPAA and parental insurance) with youth	17 (85)
Reviews health insurance changes, responsibility for self-care, and share resources with youth	18 (94.7)

HIPPA = Health Insurance Portability and Accountability Act.

Transition processes

Although often informal, most adult clinics had codified transition processes: four maintained a formal health care transition protocol, 14 reported an informal transition process, and two had no protocol or standard process. Overall, participants described health care transition as a “warm handoff” (nurse practitioner, W-01C) and a collaborative effort across adolescent and adult clinics. Emergent transition themes included adult clinical care culture and expectations, strategies for connecting youth to adult care, and approaches to evaluating transition outcomes. Participants also provided recommendations for improving the health care transition process.

Adult clinical culture and expectations

The culture and behavioral expectations at adult clinics emerged as particularly relevant to health care transition. Specifically, adult clinic providers expected youth to direct their own care and many approached health care transition under the assumption that adolescent clinics had ensured the youth had arrived with a specific skill set (e.g., education about insurance registration and medication adherence). This expectation in part stemmed from adolescent clinics having more resources and smaller caseloads than most adult clinics. For example, a clinical social worker noted that adult clinics do not “have the ability to be able to check up with them [youth] at every stop”; instead, youth need “to be able to [call] one of us if they need something” (R-02A).

Although adult clinic providers believed that adolescent clinic staff were responsible for youths' health care transition preparation, many adult staff felt that youth were underprepared to meet the adult clinics' behavioral expectations. For instance, a case manager reported, “[youth] need so much more education regarding how to use the service system...Because then they don't know how to call for a refill, how to do all those things” (K-02A). Staff noted that some of the strategies used by the adolescent clinic, such as seeing youth even when they were late for an appointment, hampered youth's ability to be successful at the adult clinic. The effect of adolescent clinic staff's “handholding” was highlighted by a case manager (U-03A), “I think one thing that has crippled or crushed some [youth] is that everything is done for them...So get them more involved. Teach them or train them to do what needs to be done.”

Strategies for developing connections between youth and adult clinics

Some adult clinics staff acknowledged that they could do more to support transition. Thus, they attempted to work with adolescent clinics to support health care transition using collaborative strategies aimed to connect youth to adult clinics and increase successful health care transition. The strategies used by adult clinics helped “soften that transition and make it more fluid” (care linkage coordinator, S-03A).

One strategy included adult clinic staff conducting the patient's first adult care visit at the adolescent clinic before continuing their care at the adult clinic. This practice occurred at other sites (most frequently at those located in the same medical system), as one nurse practitioner (Q-01B) noted: “When I am at the [adolescent clinic], I get to meet the people who will be transitioning, and they usually start this process at about age 21... at least like two to three years of talking before they actually transition.” However, other staff (especially those in different medical systems) discussed the challenges in implementing this process:

I wanted to work half day a week in the adolescent clinic. I felt that I could get to know [youth] over there, so that they would see the same doctor at the adult clinic. [But] I don't have control of their budget, so I can't pay myself to do that, unfortunately. But I think that would be helpful, and I'd be willing to do that if it could work out for me to do that. (physician, W-01A)

Another strategy included having adolescent clinic staff accompany youth to their first adult clinic appointment. One nurse practitioner (Q-01B) reported: "Once they [youth] reach the age of 24, the case managers come with the young adults, on their first visit to sort of transition them, to tell them where they need to go, what office, and help them with that." This process allowed youth to have assistance in navigating the new clinic.

After the youth transitioned to adult care, staff described other strategies to continue to strengthen youth's connection to adult clinics. For example, one adult clinic had an HIV-positive peer navigator, who was also a patient at the clinic, meet with youth to provide "a buffer...a personal experience of someone who's actually going through similar things" (physician, X-01D). The peer navigator often accompanied youth to their medical visits and provided emotional support, even after hours.

Transition evaluation approaches

Relationships between the adolescent and adult clinics were identified as essential tools for evaluating the health care transition process. Interclinic relationships helped facilitate communication and "data sharing from one clinical entity to another" (physician, X-01A), which was important for evaluating health care transition outcomes (e.g., appointment adherence and viral load suppression). Adult clinics varied in how and what they evaluated. Some clinics indicated that health care transition evaluation was not part of their "typical protocol" and done informally, on a case-by-case basis (social worker, Q-01C). Thus, staff reported the need "for more structured ways to follow up from the adolescent program to us [adult clinic] because it is so informal, just so that nobody gets missed" (pharmacist, N-01A). Other clinics, however, engaged in more in-depth clinical transition evaluation approaches. For example, they assessed more comprehensive patient-level outcomes, including: lost at follow-up, missed appointments within 6 months, reengaged in care if missed appointments, and medication adherence.

Recommendations for a more streamlined transition process

Participants described multiple ways to improve the health care transition process, specifically related to clinical policies and culture, staff training, and creating "youth friendly" clinical spaces. First, the staff suggested changes to the existing clinical policies at both the adolescent and adult clinics:

With regards to policies, maybe a little bit more consistency. Maybe even the pediatric physicians could be less open to clients showing up two hours late...I mean, we all want them to get in there, we all want to be seen, so we're grateful that we're seeing them two hours late, but I don't know what the right answer is there. (case manager, K-02A)

On the other hand, some adult providers described a need for adult clinics to have “a little more flexibility,” so that youth have the “opportunity to understand what the rules are on that adult side and to then learn and then before they are held quote-unquote ‘accountable’ to all the rigid standards that are on that side” (physician, X-01D). Consistency in policies between clinics was described as a way to ease the challenges that youth may have in navigating the different behavioral expectations across the clinics. These policies then could be formalized into transition protocols to facilitate communication between clinics. One physician (X-01A) recommended that protocols include “an electronic form that reminds us [adult providers]...When someone's between the ages of 15 and 24, in the pediatric side, they could put that in their medical chart to come up as reminders.”

Adult clinic staff also identified the need for more adolescent-specific training to ensure that care was tailored to meet youth's unique needs. Participants agreed that staff should be “trained to care for youth specifically and address their needs, both from an HIV standpoint but also from a developmental standpoint” (physician, X-01D) to reduce health care transition-related disengagement. The need for training on youth-specific developmental processes was described as ongoing: “To be able to help the youth to grow in those areas of being more responsible, being more assertive, being more accountable for taking the initiative to get themselves into care, and staying in care, and staying compliant” (case manager, U-03A). This training was discussed as helpful in meeting the unique needs of youth and helping them connect to the adult clinic for longer term care engagement.

In addition to adapting the adult providers' approach, participants also stressed that the adult clinical environments need to be more “youth friendly” (physician, X-01D), which a nurse practitioner (W-01C) described as:

The adult clinic is a really nice clinic. It's very open and bright...And there's privacy. Each room is very clearly allotted for each patient, so there's privacy and a feeling of confidentiality...Front staff, medical assistant staff have been very warm and friendly with the youth, and our psychosocial staff, too, is working with the adolescent staff, multidisciplinary team.

Adult clinic staff reported that this type of “friendly” clinical space and staff were essential components of successful transition and keeping youth engaged in care over the long term.

Discussion

This study examined the role of adult clinics in the health care transition process for HIV-infected youth, an area underexplored in the health care transition literature (for exceptions, see [23]). The transition processes we observed both aligned and conflicted with the American Academy of Pediatrics' [13] guidelines with providers reporting a more passive role of adult clinics during health care transition. Our results suggest specific changes within a quality improvement framework to support health care transition, including recognizing the specific care culture and behavioral expectations of adult clinics to ensure adequate preparation of youth for health care transition, the creation of interclinic transition protocols to formalize strategies to

facilitate youths' connection to adult clinics, and developing stronger collaborations between adult and adolescent clinics for more efficient data sharing for health care transition evaluation.

Adult clinic staff reported that youth often struggled to meet the behavioral expectations of the adult clinics. New requirements for adult care included implicit expectations that youth comport themselves as adults and accept associated responsibilities (e.g., being on time for appointments), which influenced the type and amount of support clinics offered (or were able to provide due to limited resources) during transition. For instance, as the “receiver” in the transition process, adult clinics and providers assumed that responsibility for transition preparation and coordination (e.g., appointment scheduling and medication management) rested primarily with the adolescent clinics or patients themselves (despite most adult clinics reporting the provision of life skills/health care management support). Evidence of this relatively passive role of adult clinics in the transition process is seen in the American Academy of Pediatrics [13] guidelines, which provide little information related to the role and responsibilities of adult clinics in the transition process. Adult clinics clearly play a significant role in receiving youth during health care transition; thus, future, revised health care transition guidelines should include a more active role for adult clinics in supporting these efforts.

Although adult staff typically did not view health care transition preparation as within their purview, they described being more active in developing youths' connections to the adult clinics. For example, providers seeing youth at the adolescent clinics before health care transition or letting adolescent clinic staff attend youth's first adult clinic appointments. However, some participants described logistical challenges to these arrangements (e.g., billing). These issues, similar to other chronic disease health care transition [5], [6], [7], highlight the need for more formalized interclinic relationships (e.g., memoranda of understanding) and health care transition protocols to support adult clinics' ability to provide this type of assistance [19].

The dearth in health care transition literature from the perspective of adult providers across chronic diseases makes it challenging to assess the role that adult clinics could play in supporting transition. Adult clinics are different from adolescent clinics (e.g., space and provider training) and thus have distinct barriers to health care transition [5]. For example, adult facilities are often intimidating spaces for youth as they are less “friendly” than adolescent clinics [13], [15]. Furthermore, participants stated that adult providers lacked training and experience in treating youth and were more likely to work in HIV-specific clinics (e.g., adult infectious disease) [13], [15]. Although not all adult clinics were able to create a “youth friendly” environment, the way that staff, including the front desk, approached youth who were transitioning to adult care was important. Participants discussed the need to train adult clinic staff (providers and other staff) about youths' unique needs, particularly given that adolescent and adult HIV clinical staff often differed in their expectations of, and orientation toward, youth.

Formal protocols and stronger interclinic relationships may also improve overall quality improvement efforts (e.g., formalized interclinic data sharing and communication strategies) necessary to evaluate health care transition outcomes [15], [19]. Results suggest that adult clinic involvement in health care transition is crucial and highlight the importance of cultivating interclinic connections to support health care transition and provide uninterrupted care [24]. Acknowledging the role and importance of these relationships will be essential for developing

streamlined, comprehensive, and context-specific health care transition protocols and interventions for HIV-infected youth.

Limitations and future research

Several limitations should be considered. First, although the ATN clinical sites represent a wide geographic range, the sites represented primarily urban areas with relatively high HIV prevalence among youth. Health care transition may be affected by different issues in lower prevalence cities or for youth living in rural areas with less developed transportation infrastructures [25]. The study design also relied on a purposive sample of adult clinical staff perspectives and focused primarily on health care transition as a discrete process. Participants had diverse training, skill sets, and time practicing in the clinics, which may have influenced their perspectives on transition and the relationships they had with staff at the adolescent clinics.

The role of the adult clinic in HIV-related transition processes has been largely ignored by health care transition literature. Our results suggest that adult and adolescent clinic involvement is essential to provide coordinated care during HIV-related health care transition. Overall, adult clinics perceived a passive health care transition role (with primary responsibility placed on the youth and adolescent clinics); however, adult clinics' active engagement in supporting health care transition is crucial for successful transition outcomes [15], [23]. Using evidence-based research and a quality improvement framework to inform comprehensive and streamlined transition protocols can help enhance the capacity of adult clinics to collaborate with adolescent clinics to provide coordinated and uninterrupted HIV-related care and improve continuum of care outcomes.

Acknowledgments

The authors acknowledge the contribution of the investigators and staff at the following sites who participated in this study: University of South Florida, Tampa (Emmanuel, Straub, Enriquez-Bruce), Children's Hospital of Los Angeles (Belzer, Tucker), Children's National Medical Center (D'Angelo, Trexler), Children's Hospital of Philadelphia (Douglas, Tanney), John H. Stroger Jr. Hospital of Cook County and the Ruth M. Rothstein CORE Center (Martinez, Henry-Reid, Bojan), Montefiore Medical Center (Futterman, Campos), Tulane University Health Sciences Center (Abdalian, Kozina), University of Miami School of Medicine (Friedman, Maturo), St. Jude's Children's Research Hospital (Flynn, Dillard), Baylor College of Medicine, Texas Children's Hospital (Paul, Head); Wayne State University (Secord, Outlaw, Cromer); Johns Hopkins University School of Medicine (Agwu, Sanders, Anderson); The Fenway Institute (Mayer, Dormitzer); and University of Colorado (Reirden, Chambers). The investigators are grateful to the members of the local youth Community Advisory Boards for their insight and counsel and are indebted to the youth who participated in this study.

Funding Sources

This work was supported by the Adolescent Trials Network for HIV/AIDS Interventions (ATN) (A.E.T., protocol chair) from the National Institutes of Health (U01 HD 040533 and U01 HD 040474) through the National Institute of Child Health and Human Development (B).

Kapogiannis), with supplemental funding from the National Institutes on Drug Abuse (S. Kahana), and Mental Health (P. Brouwers and S. Allison). The ATN's Community Prevention Leadership Group scientifically reviewed the study protocol. Network, scientific, and logistical support was provided by the ATN Coordinating Center (C. Wilson and C. Partlow) at the University of Alabama at Birmingham. The ATN Data and Operations Center at Westat Inc. (D. Monte) provided network operations and analytic support. M.M.P. was supported by an NIDA-funded K01 (K01DA039804A).

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