Published in final edited form as:

AIDS Educ Prev. 2017 April ; 29(2): 93–104. doi:10.1521/aeap.2017.29.2.93.

Understanding care linkage and engagement across 15 adolescent clinics: Provider perspectives and implications for newly HIV-infected youth

Morgan M. Philbin, PhD[1], **Amanda E. Tanner, PhD**[2], **Anna DuVal, MPH**[3], **Jonathan M. Ellen, MD**[4], **Bill Kapogiannis, MD**[5], and **J. Dennis Fortenberry, MD**[6] **The Adolescent Trials Network for HIV/AIDS Interventions**

[1]Department of Sociomedical Sciences, Columbia University Mailman School of Public Health, New York, NY

[2]Department of Public Health Education, University of North Carolina Greensboro, Greensboro, NC

[3]Department of Emergency Medicine, Johns Hopkins School of Medicine, Baltimore, MD

[4]Department of Pediatrics, Johns Hopkins University School of Medicine, All Children's Hospital, Johns Hopkins Medicine, St. Petersburg, Florida

[5]Maternal and Pediatric Infectious Disease Branch, *Eunice Kennedy Shriver* National Institute of Child Health and Human Development, National Institutes of Health, Bethesda, MD

[6]Department of Pediatrics, Indiana University School of Medicine, Indianapolis, IN

Abstract

The National HIV/AIDS Strategy emphasizes rapid care linkage and engagement for HIV-infected individuals, though many adolescents are never tested, delay entering care, and frequently dropout. We conducted 183 staff interviews at 15 adolescent medicine clinics (baseline n=64, Year 1 n=60, Year 2=59). We used a constant comparative thematic method to examine how providers approached and discussed care linkage/engagement. Qualitative analyses revealed differences in providers' conceptualizations of linkage and engagement. Providers saw linkage as mechanistic and health system driven. It was defined by number of clinic visits, and involved relatively little youth agency. In contrast, providers defined engagement by youths' responsibility and participation in their own care and involvement in ancillary services. Linkage and engagement are related but distinct aspects of care that require different resources and level of staff involvement. Integrating an understanding of these differences into future interventions will allow clinic staff to help youth improve long-term health outcomes.

Keywords

Adolescent health; HIV/AIDS; linkage to care; engagement in care; qualitative

---

Corresponding Author: Morgan Philbin, PhD, MHS, Assistant Professor, 722 West 168th Street; Floor 5, Rm 536, New York, NY 10032, mp3243@cumc.columbia.edu, 212-342-2804.

Conflicts of Interest: The Authors have no interests to declare

Introduction

The organization of HIV clinical care for adolescents has changed profoundly during the past decade. HIV-infected adolescents have become a significant proportion of the larger epidemic (Centers for Disease Prevention and Control, 2013) concurrently with advances in HIV therapeutics that–in the United States–have led clinicians to label HIV as a chronic condition and have allowed for decades of health and wellbeing. Achieving health and wellbeing for people living with chronic conditions is contingent upon an accessible and sustainable system of care that is responsive to patients' changing needs over the life course (Oni et al., 2014). The challenges of adapting chronic care models to HIV care, at the individual level, are highlighted by evidence that many HIV-infected adolescents are never tested, often fail timely entry into care, drop out at disproportionately high rates, and transition to adult services in ways that often lead to long interruptions of care (Tanner et al., 2016; Whiteside et al., 2014).

On a population level, the HIV Care Continuum illustrates the difficulty of living with HIV as a chronic condition (Greenberg, Purcell, Gordon, Barasky, & del Rio, 2015; Mugavero, Amico, Horn, & Thompson, 2013; Whiteside et al., 2014). Stages within the Care Continuum–testing, care linkage and engagement, and medication initiation–provide sequential markers toward a clinical and public health goal of sustained viral suppression. These markers represent points where surveillance data can demonstrate the adequacy of health care systems in meeting the needs of HIV-infected individuals (Das et al., 2013). For example, evidence that a substantial proportion of newly diagnosed persons fail initial care linkage led to intensive case management and patient navigator interventions to facilitate this key early Care Continuum outcome (Gardner, McLees, Steiner, del Rio, & Burman, 2011; Gardner et al., 2009; Giordano et al., 2007). Likewise, interventions to improve care engagement and antiretroviral adherence are being implemented, although seldom in the context of a comprehensive approach to testing, care linkage, and ultimate care engagement (Mugavero et al., 2013). Existing efforts are largely focused on adults rather than adolescents, who comprise over a quarter of new HIV infections in the U.S. (Centers for Disease Prevention and Control, 2015); adaptation of the Care Continuum model to include issues relevant to HIV-infected adolescents is relatively recent (Kurth, Lally, Choko, Inwani, & Fortenberry, 2015).

Adolescents face unique challenges to entry into and maintenance of HIV care with the frequent clinic visits characteristic of contemporary HIV medicine and adherence to the daily medication regimens (Zanoni & Mayer, 2014). Structural barriers to care such as under-employment, unstable housing, poverty, substance use, lack of educational opportunities, stigma, and lower levels of family support further constrain adolescents' behaviors (e.g., HIV management and health promoting decisions) (Philbin et al., 2014a). Adolescents test for HIV more frequently in community-based rather than clinic-based venues, (Swenson, Hadley, Houck, Dance, & Brown, 2011) which have lower rates of linkage success (Centers for Disease Prevention and Control, 2011) due to the structural fragmentation of testing and care sites (Tanner et al., 2013). Adolescents also delay care linkage for longer periods and are less likely to enter care, compared to older adults (Castle et al., 2011; Grant et al., 2006; Hall et al., 2012; Hosek et al., 2008; Minniear et al., 2012). These structural barriers are further complicated by adolescents' unique developmental stage that impacts coping skills, impulsivity, risk taking and inattention to details, which may complicate medication adherence and care engagement. Appointment adherence is challenging: adolescents miss about one-third of scheduled visits, and approximately 30% drop out of care (Minniear et al., 2012). Adolescents also have lower rates of viral suppression (~6% vs. 29%), and higher rates of virologic rebound, than adults (Ryscavage, Anderson, Sutton, Reddy, & Taiwo, 2011). For adolescents, care linkage and engagement more often resembles a series of recurrent passages than a continuum, with care interrupted by periods of disengagement followed by re-established care (Zanoni & Mayer, 2014).

This paper addresses the relative lack of data to guide the development of integrated clinical services for HIV-infected adolescents. Improvement of such services is particularly important because adolescence is often ambiguously represented in service delivery systems, divided between pediatric and adult specialties; HIV medicine is also largely a domain of adult specialties and the way care is often provided (i.e., in a non youth-friendly way) may affect outcomes (Kasedde, Kapogiannis, McClure, & Luo, 2014; Kendall et al., 2015). Since systems of care for HIV-infected adolescents lack a clear means for assessment of best practices, (Kapogiannis, Legins, Chandan, & Lee, 2014) we interviewed health services providers with specific experience in the care and treatment of HIV-infected adolescents. These interviews addressed two key stages on the HIV Care Continuum: care linkage and engagement. Understanding potential distinctions between these two early stages of care is important to guide program design to reduce adolescent-specific barriers, appropriately direct resources, and provide supports for different types of needs.

Methods

Data were collected through the evaluation of SMILE (*Strategic Multisite Initiative for the Identification, Linkage, and Engagement in Care of Youth with Undiagnosed HIV Infection*), developed to improve care linkage and engagement for HIV-infected adolescents (Philbin, et al., 2014b). SMILE created formal networks among testing, referral, and clinical agencies (including local health departments), and supported care linkage through the provision of case management and patient navigator services for newly diagnosed adolescents (Tanner et al., 2013). Details of the SMILE intervention, including linkage and engagement outcomes, are described elsewhere (Philbin, et al., 2014b).

The SMILE qualitative evaluation included 183 semi-structured individual interviews at 15 geographically dispersed adolescent HIV medicine clinics (e.g., San Francisco, New Orleans, Miami, Baltimore and Chicago). In addition to speaking with ATN staff (i.e., outreach workers and linkage coordinators) we used purposive sampling to conduct interviews with medical and social service providers at each site (e.g., case managers, nurses, social workers and physicians). These interviews occurred across three annual site visits from 2010–2012 (Prior to SMILE initiation N=64, Year 1 N=60, Year 2 N=59). The first or second author conducted interviews; no financial incentives were provided. Analyses of the interviews conducted prior to SMILE initiation and at Year 1 demonstrated the importance of providers' different approaches to linkage and engagement; as such, we added questions to the Year 2 interview guide that explicitly asked participants to discuss their understanding and conceptualization of care linkage and engagement. Interviews were digitally recorded, transcribed, and uploaded into Atlas.ti 6.2 for data management and to assist with coding, analysis and interpretation. All interviewees provided verbal consent; Institutional Review Boards at the University of North Carolina Greensboro and all participating sites approved the study protocol.

Data were analyzed using a constant comparative method to identify differences and similarities in providers' descriptions and approaches toward care linkage and engagement (Buetow, 2010; Glaser & Strauss, 1967). Two team members independently read and coded each transcript using a line-by-line method to create an initial code dictionary. We then created a list of thematic codes based on the existing literature and integrated it to the initial code dictionary to ensure that both theory-based and emergent concepts were included. Team members then independently cross-coded a random sample of 33% of transcripts to refine the code dictionary, which was subsequently reviewed by other team members (MacQueen, McLellan, Kay, & Milstein, 1998). Next, we created a data table to summarize and refine codes, (Glaser & Strauss, 1967) and a site matrix to compare site similarities and variations in descriptions of linkage and engagement. As final coding occurred, the research team conducted a sequence of weekly meetings to develop additional codes and resolve discrepancies. Researchers applied the finalized structure to all transcripts and there was high consistency between raters. Any discrepancies were resolved through discussion involving the coders and, when needed, the primary investigators.

Results

Care Linkage versus Engagement

Respondents positioned the relationship between adolescents and care systems differently for care linkage and care engagement. Care linkage was viewed as a procedure performed on an adolescent; engagement was adapted based on a patient's actions: *"…when I link something that means I'm actually doing a physical act…"* whereas an engaged patient *"…showed up at the clinic on his own"* (Linkage coordinator; Site C). Linkage was also described as a relatively uniform process regardless of patient characteristics, whereas engagement was a personalized process tailored to a patient's needs. A social worker noted:

> *Linking is more action oriented, there's a process of steps in making things happen and engagement really has to do a lot with relationship building and figuring out the needs of each patient and being able to do that over a period of time* (Site L).

While clinic staff worked to support youth and to be an advocate, linkage was primarily about *"…getting kids to an appointment…"* (Outreach Worker; Site P), providing information, and arranging blood draws. There was often little patient-client interaction prior to linkage, though some social service providers described a 'touch' rate where they tried to send text messages before the first clinic visit. For some respondents, care linkage was described as a counter-measure for what they attributed to a patients' perceived incapacity: *"Hey, I need some kind of assistance, because I'm not going to access this. I'm still in denial"* (Linkage Coordinator; Site D).

In contrast to linkage that was defined by an action (i.e., a clinic visit or labs), practitioners defined engagement as youth taking responsibility and actively participating in their own care, showing up without prodding, and accepting their diagnosis. In addition, staff often depicted engagement as a process that involved not only presenting at the clinic, but as *"having it together"* (Outreach Worker; Site C) more broadly in terms of housing, employment, and self-care. A few providers supplemented this definition by noting that engagement was only achieved once an appropriate clinical plan existed and the adolescent had, *"actually gotten the clinical services that they need"* (Outreach Worker; Site P).

Differences in duration

While descriptions of linkage were typically precise and short, engagement often led to lengthy discussions to articulate what one nurse summarized as '*just messy'* (Site E). Many respondents noted ways in which engagement contradicted the assumption of a linear care continuum, "*engagement is a continuum of care…engagement is a continuum of linkage, but it's continued over a period of time*" (Care Coordinator; Site M). Indeed, engagement itself was a cycle of recurrent entry, dropout, and re-entry; providers never described youth as 'dropping out' of linkage activities.

Participants' perceptions of the timeframes for linkage and engagement also differed: linkage was described as a rapid event that should occur within a week of referral; in contrast, engagement was a potentially prolonged process, in which the pace was determined by the adolescent. As a social worker noted:

> *A lot of young people get linked quickly but I would think engagement would take a couple of years, which sounds kind of crazy, but just to kind of get used to coming to the clinic and dealing with that* (Site K).

Acceptance of HIV

An adolescent's acceptance of the HIV diagnosis was considered vital because it forced an acknowledgment of the potential challenges to medical linkage and engagement. This involved not only an awareness of social barriers that come with being HIV-infected, but also that one's life will continually include interactions with a clinical setting. For example, whereas stigma was not reported as a barrier to care linkage *"…because in most clinical sites you can just walk the adolescent over"* (Outreach Worker; Site M), providers described stigma as a consistent problem for care engagement. Clinicians described adolescents who were *"…scared and not ready to deal with it or in denial and they have to hide it from family and friends…"* (Social Worker; Site L) which often required offering solutions outside of the clinic until adolescents were ready to engage in medical care. Respondents frequently discussed the challenges of working with adolescents who struggled to accept their diagnoses:

> *It's a process, it's not—they're accepting and that's okay. There is grief and there's anger and everything else…Most of them come. They tell us, "I'm not ready to start medications yet." We tell them, "it's no problem. We can give you a break until you're ready"* (Psychologist; Site N).

One physician described the acceptance portion of engagement as “an internal process for the patient, engagement in care is a process where the person understands that they need to go to a healthcare facility for the rest of their life. And sometimes that process doesn’t happen immediately” (Site N). Providers talked about adolescents who attended clinic visits for a period of time, and then grew tired of the work required to be consistently engaged. Providers struggled with this, and with the chronic nature of HIV infection and its treatment. A staff member stressed how engagement differed from linkage in that “…engagement is cyclical. I think it’s a whole ‘nother animal, you know the long-term willingness to deal with a chronic illness…” (Linkage Coordinator; Site J).

Building relationships

Respondents repeatedly stressed the importance of building relationships between adolescents and clinic personnel, whether a physician, receptionist or security guard, for care engagement. While this could happen in one visit, staff said it frequently took months or even years. A nurse stated that having personal relationships was important, “*above all else*” (Site J) and an Outreach Worker noted that *“…a consistent relationship with one medical provider is more than, well, not more important than getting your labs done, but as important as getting your labs done at least…”* (Site B). Although important, adolescent-staff relationships were described as particularly challenging. Many adolescents lacked stable relationships with adults, and previous experiences with healthcare or social service providers often involved child protective services or social workers. As one Care Coordinator noted, *“To assume that a young person is just going to instantly develop a relationship with a physician is ridiculous”* (Site B). Respondents also believed these relationships facilitated a safe space in which adolescents could voice their own needs, ask questions, and share relevant challenges. Indeed, providers also associated engagement with how well they knew an adolescent and whether an adolescent would tell them the truth (e.g., about drug use).

Becoming a ‘good’ patient

Another aspect of effective engagement was the process through which adolescents became ‘good’ patients who took care of themselves, and who would grow into healthy and successful adults. Staff frequently used words like ‘knowledgeable,’ ‘cooperating’ and ‘not complaining’ to describe those who were ‘good’ engaged patients. A Case Manager described what would ideally occur for a youth to be considered engaged:

> *They are keeping appointments, taking their medications and not just because someone’s telling them to. If they don’t, they’re calling us to reschedule or to acknowledge that they missed an appointment. They’re having productive conversations with people related to their healthcare. They want to stay healthy and they want to start to educate others around them* (Site M).

Getting youth engaged helped prepare them for transition; this was particularly important because of a perception that adult HIV care providers were much less tolerant of missed or canceled appointments.

The concept of the ‘good patient’ was also discussed by participants who noted the importance of wanting to stay mentally and physically healthy, being adherent, eliminating the behaviors that put an adolescent at risk for HIV (e.g., not using condoms or avoiding sex during treatment for a sexually transmitted infection (STI)), and actively contributing to care-related decisions. Specifically, this meant knowing the names and doses of medications, understanding viral loads and CD4 cell counts, and asking relevant questions about their condition. One Outreach Worker summarized this perspective as “*Engagement means you’re going to your appointments; you’re involved in your care; you’re asking questions; you’re taking your medicine*” (Site I).

Involvement in ancillary services

Respondents described patient involvement with ancillary services (e.g., vocational, educational, or housing support) as a vital component of care behaviors since the acceptance of an HIV diagnosis often required adolescents to address the social and structural factors that facilitated their HIV acquisition and challenge medical engagement. Respondents believed that participation in ancillary services helped to engage adolescents in the clinic more broadly, *“You know, not just them attending that first and second medical appointment but being able to help them get the resources that they need: housing, food stamps, ID, etc.”* (Outreach Worker; Site C) Involvement in these ancillary services was seen as important to help adolescents address the issues that would allow them to fully engage in HIV care, particularly for groups who were vulnerable based on race/ethnicity, sexual orientation, or economic status:

> *A lot of the youth are African American and they’re coming out of the closet and they’re also testing positive…I mean if you feel like you’re bad, or evil, or wrong, or deserving of the HIV because of your sexuality that’s a huge impact on readiness. You got to work with that with the youth before you can even attempt to begin to address their medical care* (Nurse; Site I).

Discussion

These data produced three key findings that can help inform the structure of HIV-related healthcare services for adolescents. First, care linkage was consistently described as a finite procedure with a specific goal–achieving a first medical appointment–whereas engagement was a process of learning and experience, often marked by periods of less than optimal adherence to clinical and treatment regimens, or by complete interruption of engagement followed by re-entry into care. The perception of linkage as a relatively straightforward procedure may reflect recent developments of adolescent linkage-related infrastructure and skill enhancement, as earlier work suggests a fragile and complex process often ending in failure (Fortenberry, Martinez, Rudy, & Monte, 2012; Hosek et al., 2008). This perception may also reflect the fact that it is a stage over which providers have more control: staff can bring an adolescent to a clinic and then linkage is complete; engagement is primarily an adolescent’s responsibility. Even though care linkage was described as relatively straightforward, studies suggest that only two-thirds of newly diagnosed adolescents are successfully linked (Philbin et al., 2014b). In addition to personal characteristics, youth are more likely to link if they are stably housed, have health insurance, and are referred to a clinic that is adolescent specific; youth linked more quickly are also more likely to become engaged (Philbin et al., 2016). This demonstrates the importance of creating integrated systems of care to ensure that regardless of where a young person tests—e.g., clinic, community organization or health festival—that they will be rapidly referred to a clinic where they will feel comfortable (Tanner et al., 2014). Then, once at the clinic, even if a young person does not want to be linked to medical care, social service providers can work with them address other factors that could facilitate linkage, and later engagement (e.g., housing, education, health insurance).

A second key observation is the need to "become a good patient" for engagement to be deemed successful. This emphasis certainly has practical overtones in that proactive engagement in self-care, adoption of healthier lifestyles, clinic appointment keeping, and therapeutic adherence are relevant to reasonable clinical care objectives such as long-term viral suppression, prevention of HIV disease morbidity, and reduction in HIV transmission risk (Hoffmann & Gallant, 2014). However, "becoming a good patient" suggests the imposition of social and behavioral standards often targeted toward disadvantaged youth and sexual or racial/ethnic minorities. It emphasizes the work patients must do to achieve the expectations that result from HIV being seen as chronic, namely to remain virally suppressed and healthy. Similar themes have emerged in transplantation studies where patients must demonstrate that they are worthy of receiving an organ for which many people are on a waitlist (Cass et al., 2007; Furnham, Ariffin, & McClelland, 2007). With adolescent patients, it also seems suggestive of "transitional paternalism" as an appropriate stance for adults (in this case, health professionals) and adolescents with social, developmental, and legal boundaries on behavioral autonomy (Manson, 2015). Social service and medical providers can facilitate a youth's transition into a "good patient" by moving away from the provider-centered model that is common in pediatric medicine and developing a collaborative model that includes direct patient input. Such a model allows youth to describe how they envision being a "good patient," and to design their own treatment goals, realistically assess barriers, and practice skills needed to reach the jointly decided goals.

A third key observation was that care engagement, and thus, retention, is a process rather than a definitive event. This means that assessments of engagement based on number of clinic visits cannot adequately represent the complex issues faced by adolescents (e.g., social barriers and need for specific ancillary services) (Mugavero et al., 2013; Mugavero et al., 2009; Mugavero et al., 2012). Engagement is most commonly defined as a second HIV-related visit within a given time period after an initial visit, (Fleishman, Yehia, Moore, Korthuis, & Gebo, 2012; Giordano et al., 2007) though details vary to include the number of missed visits, the proportion of kept visits to scheduled visits, the number of 3-month intervals with at least one attended medical visit, the existence of a 6-month gap in care, and whether a person kept two visits separated by at least 90 days (Fleishman et al., 2012; Giordano et al., 2007; Mugavero et al., 2013; Mugavero et al., 2012). The U.S. National HIV/AIDS Strategy differentiates linkage and engagement only by time and the number of clinic visits (Office of National AIDS Policy, 2015). The ways our respondents described the engagement process differed from the timelines and straightforward definitions offered by the Centers for Disease Control and Prevention (CDC) (Centers for Disease Control and Prevention, 2016; Mugavero et al., 2012). Engagement, in particular, takes incredible energy and time. It includes overcoming social barriers and developing relationships with clinical staff. Even if an adolescent attended sufficient visits to meet the CDC's definition of engaged, it frequently takes much longer for him/her to embrace the characteristics that would cause a provider to label him/her as engaged. This framing of care engagement as a cyclical and multi-phase process has been demonstrated by other research on youth living with chronic illness (e.g., diabetes, cystic fibrosis) (Lotstein et al., 2013; Sobota et al., 2014). This suggests that providers should place additional weight on building relationships to ensure that youth remain connected to the clinic, even if they are not taking their medication or engaging in care.

Adolescent providers' extended approach to engagement made it almost impossible for them to achieve the benchmarks outlined by the CDC and listed in the U.S. National HIV/AIDS Strategy. This suggests the importance of considering whether there is a need to develop alternative national-level benchmarks that match the realities of adolescents' day-to-day life in HIV clinics. Future research should work with newly diagnosed youth to explore how they conceptualize linkage and engagement. Then, findings from youth could be integrated into provider-focused research to inform interventions that will help increase rates of linkage and engagement for this vulnerable population.

Limitations

These data examine how adolescent providers across a wide geographic area understand care linkage and engagement. Geographic variability in the availability of ancillary services and support may facilitate linkage and engagement, and thus how staff came to understand them. Adolescent Trials Network sites are all located in major urban centers where the HIV epidemic is concentrated for youth, and may not be generalizable to other settings in the US. While this study relied on the perspectives of staff, future studies could enhance our understanding of the adolescent-specific HIV care continuum by interviewing adolescents to see how they understand and experience differences in care linkage and engagement.

Conclusions

Linkage and engagement are related but distinct aspects of care that require different resources and provider orientation toward youth. The implementation of seamless linkage and engagement services require a nuanced understanding of the similarities and differences, and what each involves. Successful care linkage and engagement, particularly for adolescents, will only be possible if the system of care is designed in an accessible and sustainable way. These findings can help inform the development of comprehensive clinical services for adolescents living with HIV. Integrating an understanding of these differences into future interventions will allow healthcare and social service providers to help retain youth in the clinic to begin antiretroviral medication, improve their engagement in care and maintain viral suppression for the long-term.

Acknowledgments

This work was supported by grants to the Adolescent Medicine Trials Network for HIV/AIDS Interventions (ATN): 5 U01 HD 40533 and 5 U01 HD 40474 from the National Institutes of Health through the National Institute of Child Health and Human Development (Bill Kapogiannis, MD; Sonia Lee, PhD) with supplemental funding from the National Institutes on Drug Abuse (Shoshana Kahana, PhD) and Mental Health (Susannah Allison, PhD; Pim Brouwers, PhD). Additional support was provided by an administrative supplement, 3 U01 HD 040533-09S1, awarded through funds from the American Recovery and Reinvestment Act (ARRA) of 2009. The comments and views of the authors do not necessarily represent the views of the Eunice Kennedy Shriver National Institute of Child Health and Human Development.

We acknowledge the contribution of the investigators and staff at the following sites that participated in this study: University of South Florida, Tampa (Emmanuel, Straub, McKinney), Children's Hospital of Los Angeles (Belzer, Brown), Children's National Medical Center (D'Angelo, Fawehinmi, Hoyte), Children's Hospital of Philadelphia (Douglas, Tanney, Kerfren, Louis), John H. Stroger Jr. Hospital of Cook County and the Ruth M. Rothstein CORE Center (Martinez, Henry-Reid, McFadden), University of Puerto Rico (Febo, Cruz), Montefiore Medical Center (Futterman, Jackson), Mount Sinai Medical Center (Steever, Maxwell), University of California-San Francisco (Moscicki, Auerswald, Bowman), Tulane University Health Sciences Center (Abdalian, McFarlane, Jeanjacques), University of Maryland (Peralta, Bishop), University of Miami School of Medicine (Friedman, Mills), Children's Diagnostic and Treatment Center (Puga, Archibald), St. Jude's Children's Research Hospital (Flynn, Askew), Children's Memorial Hospital (Garofalo, Vulpas, Heine)

The study was scientifically reviewed by the ATN Community Prevention Leadership Group. Network, scientific, and logistical support was provided by the ATN Coordinating Center (Craig Wilson, MD; Cynthia Partlow, MEd). Project support and coordination was provided by the ATN Data and Operations Center at Westat, Inc. (Jim Korelitz, PhD; Barbara Driver RN, MS). Dr. Philbin was supported by a NIDA-funded K01 (K01DA039804A)

Sources of Funding: 5 U01 HD 40533, 5 U01 HD 40474, 3 U01 HD 040533-09S1 (NICHD, NIDA, NIMH)

References

Buetow S. Thematic analysis and its reconceptualization as 'saliency analysis'. Journal of Health Services Research & Policy. 2010; 15(2):123–125. [PubMed: 19762883]

Cass A, Cunningham J, Anderson K, Snelling P, Colman S, Devitt J, Eris J. Decision-making about suitability for kidney transplantation: Results of a national survey of Australian nephrologists. Nephrology. 2007; 12(3):299–304. [PubMed: 17498127]

Castle PE, Rodriguez AC, Burk RD, Herrero R, Wacholder S, Hildesheim A, Proyecto Epidemiologico Guanacaste, G. Long-term persistence of prevalently detected human papillomavirus infections in the absence of detectable cervical precancer and cancer. Journal of Infectious Diseases. 2011; 203(6):814–822. [PubMed: 21343148]

Centers for Disease Control and Prevention. Linkage to and Retention in HIV Medical Care. 2016.

Centers for Disease Prevention and Control. HIV Surveillance report: Rates of diagnoses of HIV infection among adults and adolescents, by area of residence, 2011–United States and 6 dependent areas. 2011. Retrieved from https://www.cdc.gov/hiv/pdf/statistics_2011_HIV_Surveillance_Report_vol_23.pdf

Centers for Disease Prevention and Control. HIV in the United States: The stages of care. 2013. Retrieved from http://www.cdc.gov/nchhstp/newsroom/docs/2012/stages-of-CareFactSheet-508.pdf:

Centers for Disease Prevention and Control. HIV Surveillance–Adolescents and Young Adults. 2015. Retrieved from http://www.cdc.gov/hiv/library/slideSets/index.html:

Das M, Christopoulos KA, Geckeler D, Huriaux E, Cohen SE, Philip S, Charlebois ED. Linkage to HIV care in San Francisco: implications of measure selection. Journal of Acquired Immune Deficiency Syndromes. 2013; 64(Suppl 1):S27–32. [PubMed: 24126446]

Fleishman JA, Yehia BR, Moore RD, Korthuis PT, Gebo KA. Establishment, Retention, and Loss to Follow-Up in Outpatient HIV Care. Journal of Acquired Immune Deficiency Syndromes. 2012; 60(3):249–259. [PubMed: 22531758]

Fortenberry JD, Martinez J, Rudy BJ, Monte D. Linkage to care for HIV-positive adolescents: A multisite study of the Adolescent Medicine Trials Units of the Adolescent Trials Network. Journal of Adolescent Health. 2012; 51:551–556. [PubMed: 23174464]

Furnham A, Ariffin A, McClelland A. Factors Affecting Allocation of Scarce Medical Resources Across Life-Threatening Medical Conditions. Journal of Applied Social Psychology. 2007; 37(12): 2903–2921.

Gardner E, McLees M, Steiner J, del Rio C, Burman W. The spectrum of engagement in HIV care and its relevance to test-and-treat strategies for prevention of HIV infection. Clinical Infectious Diseases. 2011; 52(6):793. [PubMed: 21367734]

Gardner L, Marks G, Craw J, Metsch L, Strathdee S, Anderson P, del Rio C. Demographic, psychological, and behavioral modifiers of the Antiretroviral Treatment Access Study (ARTAS) intervention. AIDS Patient Care and STDs. 2009; 23(9):735–742. [PubMed: 19645619]

Giordano T, Gifford A, Suarez-Almazor M, Rabeneck L, Hartman C, Backus L, Morgan R. Retention in care: a challenge to survival with HIV infection. Clinical Infectious Diseases. 2007; 44(11): 1493–1499. [PubMed: 17479948]

Glaser, BG., Strauss, AL. The discovery of grounded theory: Strategies for qualitative research. Aldine de Gruyter; 1967.

Grant AM, Jamieson DJ, Elam-Evans LD, Beck-Sague C, Duerr A, Henderson SL. Reasons for testing and clinical and demographic profile of adolescents with non-perinatally acquired HIV infection. Pediatrics. 2006; 117:468–475.

Greenberg AE, Purcell DW, Gordon CM, Barasky RJ, del Rio C. Addressing the Challenges of the HIV Continuum of Care in High-Prevalence Cities in the United States. Journal of Acquired Immune Deficiency Syndromes. 2015; 69:S1–S7. [PubMed: 25867773]

Hall HI, Gray KM, Tang T, Li J, Shouse L, Mermin J. Retention in care of adults and adolescents living with HIV in 13 US areas. Journal of Acquired Immune Deficiency Syndromes. 2012; 60(1): 77. [PubMed: 22267016]

Hoffmann CJ, Gallant JE. Rationale and evidence for human immunodeficiency virus treatment as prevention at the individual and population levels. Infectious Disease Clinics of North America. 2014; 28(4):549–561. doi:http://dx.doi.org/10.1016/j.idc.2014.08.003. [PubMed: 25287588]

Hosek SG, Harper GW, Lemos D, Martinez J, the Adolescent Medicine Trials Network for H. I. V. A. I. An Ecological Model of Stressors Experienced by Youth Newly Diagnosed with HIV. Journal of HIV/AIDS Prevention in Children & Youth. 2008; 9:192–218. [PubMed: 20216916]

Kapogiannis BG, Legins KE, Chandan U, Lee S. Evidence-Based Programming for Adolescent HIV Prevention and Care: Operational Research to Inform Best Practices. JAIDS Journal of Acquired Immune Deficiency Syndromes. 2014; 66:S228–S235. [PubMed: 24918600]

Kasedde S, Kapogiannis BG, McClure C, Luo C. Executive Summary: Opportunities for Action and Impact to Address HIV and AIDS in Adolescents. Journal of Acquired Immune Deficiency Syndromes. 2014; 66:S139–S143. [PubMed: 24918589]

Kendall CE, Taljaard M, Younger J, Hogg W, Glazier RH, Manuel DG. A population-based study comparing patterns of care delivery on the quality of care for persons living with HIV in Ontario. BMJ Open. 2015; 5(5):e007428.

Kurth AE, Lally MA, Choko AT, Inwani IW, Fortenberry JD. HIV Testing and Linkage to Services for Youth. Journal of the International AIDS Society. 2015; 18(1):23–28.

Lotstein DS, Seid M, Klingensmith G, Case D, Lawrence JM, Pihoker C, Corathers S. Transition from pediatric to adult care for youth diagnosed with type 1 diabetes in adolescence. Pediatrics. 2013; 131(4):e1062–e1070. [PubMed: 23530167]

MacQueen KM, McLellan E, Kay K, Milstein B. Codebook development for team-based qualitative analysis. Cultural Anthropology Methods. 1998; 10(2):31–36.

Manson NC. Transitional paternalism: how shared normative powers give rise to the asymmetry of adolescent consent and refusal. Bioethics. 2015; 29(2):66–73. [PubMed: 24547962]

Minniear TD, Gaur AH, Thridandapani A, Sinnock C, Tolley EA, Flynn PM. Delayed Entry into and Failure to Remain in HIV Care Among HIV-Infected Adolescents. AIDS Research and Human Retroviruses. 2012

Mugavero M, Amico K, Horn, Thompson M. The state of engagement in HIV care in the United States: from cascade to continuum to control. Clinical Infectious Diseases. 2013; 57(8):1164–1171. [PubMed: 23797289]

Mugavero M, Lin H, Willig J, Westfall A, Ulett K, Routman J, Allison J. Missed Visits and Mortality in Patients Establishing Initial Outpatient HIV Treatment. Clinical Infectious Diseases. 2009; 48(2):248. [PubMed: 19072715]

Mugavero M, Westfall A, Zinski A, Davila J, Drainoni M, Gardner L, Metsch L. Measuring retention in HIV care: the elusive gold standard. Journal of acquired immune deficiency syndromes. 2012; 61(5):574–580. [PubMed: 23011397]

Office of National AIDS Policy. National HIV/AIDS Strategy for the United States, Updated to 2020, July 2015. 2015. Retrieved from https://www.aids.gov/federal-resources/national-hiv-aids-strategy/nhas-update/index.html:

Oni T, McGrath N, BeLue R, Roderick P, Colagiuri S, May CR, Levitt NS. Chronic diseases and multi-morbidity–a conceptual modification to the WHO ICCC model for countries in health transition. BMC Public Health. 2014; 14:575. [PubMed: 24912531]

Philbin MM, Tanner AE, Duval A, Ellen J, Kapogiannis B, Fortenberry JD. Linking HIV-positive adolescents to care in 15 different clinics across the United States: creating solutions to address structural barriers for linkage to care. AIDS Care. 2014a; 26(1):12–19. [PubMed: 23777542]

Philbin MM, Tanner A, DuVal A, Ellen J, Xu J, Kapogiannis B, Fortenberry J. 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 and Behavior. 2014b; 18(8):1501–1510. [PubMed: 24682848]

Philbin MM, Tanner A, DuVal A, Ellen JM, Xu J, Kapogiannis B, Fortenberry J. HIV Testing, Care Referral, and Linkage to Care Intervals Affect Time to Engagement in Care for Newly Diagnosed HIV-Infected Adolescents in 15 Adolescent Medicine Clinics in the United States. Journal of Acquired Immune Deficiency Syndromes. 2016; 72(2):222–229. [PubMed: 26885804]

Ryscavage PA, Anderson EJ, Sutton SH, Reddy S, Taiwo B. Clinical outcomes of adolescents and young adults in adult HIV care. Journal of Acquired Immune Deficiency Syndromes. 2011; 58(2):193–197. [PubMed: 21826014]

Sobota A, Akinlonu A, Champigny M, Eldridge M, McMahon L, Telfair J, Sprinz P. Self-reported transition readiness among young adults with sickle cell disease. Journal of Pediatric Hematology/oncology. 2014; 36(5):389. [PubMed: 24517960]

Swenson RR, Hadley WS, Houck CD, Dance SK, Brown LK. Who Accepts a Rapid HIV Antibody Test? The Role of Race/Ethnicity and HIV Risk Behavior Among Community Adolescents. Journal of Adolescent Health. 2011; 48(5):527–529. [PubMed: 21501815]

Tanner A, Philbin M, Ott M, Duval A, Ellen J, Kapogiannis B, Fortenberry J. Linking HIV-positive adolescents into care: The effects of relationships between local health departments and adolescent medicine clinics. Journal of HIV/AIDS & Social Services. 2013; 12(3–4):424–436.

Tanner A, Philbin M, Duval A, Ellen J, Kapogiannis B, Fortenberry J. “Youth friendly” clinics: Considerations for linking and engaging HIV-infected adolescents into care. AIDS Care. 2014; 26(2):199–205. [PubMed: 23782040]

Tanner A, Philbin M, DuVal A, Ellen J, Kapogiannis B, Fortenberry J. Transitioning HIV-positive Adolescents to Adult Care: Lessons Learned from Twelve Adolescent Medicine Clinics. Journal of Pediatric Nursing. 2016; 31(5):537–543. [PubMed: 27133767]

Whiteside YO, Cohen SM, Bradley H, Skarbinski J, Hall HI, Lansky A, Prevention. Progress along the continuum of HIV care among blacks with diagnosed HIV- United States, 2010. Morbidity & Mortality Weekly Report. 2014; 63(5):85–89. [PubMed: 24500286]

Zanoni BC, Mayer KH. The adolescent and young adult HIV cascade of care in the US: Exaggerated health disparities. AIDS Patient Care and STDs. 2014; 28(3):128–13. [PubMed: 24601734]