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Linking HIV-positive adolescents to care in 15 different clinics across the United States: Creating solutions to address structural barriers for linkage to care

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Abstract

Linkage to care is a critical corollary to expanded HIV testing, but many adolescents are not successfully linked to care, in part due to fragmented care systems. Through a collaboration of the National Institutes of Health (NIH), Centers for Disease Control and Prevention (CDC) and the Adolescent Trials Network (ATN), a linkage to care outreach worker was provided to ATN clinics. Factors related to linkage were explored to better understand how to improve retention rates and health outcomes for HIV-positive adolescents. We conducted 124 interviews with staff at 15 Adolescent Trials Network clinics to better understand linkage to care processes, barriers, and facilitators. Content analysis was conducted focusing on structural barriers to care and potential solutions, specifically at the macro-, meso-, and micro-levels. Macro-level barriers included navigating health insurance policies, transportation to appointments, and ease of collecting and sharing client-level contact information between testing agencies, local health departments and clinics; meso-level barriers included lack of youth friendliness within clinic space and staff, and duplication of linkage services; micro-level barriers included adolescents' readiness for care and adolescent developmental capacity. Staff initiated solutions included providing transportation for appointments and funding clinic visits and tests with a range of grants and clinic funds while waiting for insurance approval. However, such solutions were often ad hoc and partial, using micro-level solutions to address macro-level barriers. Comprehensive initiatives to improve linkage to care are needed to address barriers to HIV-care for adolescents, whose unique

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developmental needs make accessing care particularly challenging. Matching the level of structural solution to the level of structural barriers (i.e., macro-level with macro-level), such as creating policy to address needed youth healthcare entitlements versus covering uninsured patients with clinic funds is imperative to achieving the goal of increasing linkage to care rates for newly diagnosed adolescents.

Keywords

adolescents; HIV/AIDS; linkage to care; structural barriers; qualitative methods

Introduction

Linkage to care (LTC) for newly diagnosed HIV-positive adolescents is an important consideration as the United States HIV epidemic shifts toward younger individuals; an estimated 26% of HIV infections occur among youth ages 13–24 (Centers for Disease Control and Prevention [CDC], 2013). Over 100,000 adolescents (13–24) are currently infected with HIV (CDC, 2013). Younger age is associated with lower rates of retention in care during the first two years following diagnosis (Ulett et al., 2009), and HIV-diagnosed persons under 35 years of age have more difficulty establishing, and being retained in care (Giordano et al., 2005). In general, not being engaged in care or having inconsistent medical visits is associated with higher mortality (Giordano et al., 2007; Metsch et al., 2008; Tripathi, Youmans, Gibson, & Duffus, 2011).

Barriers to care have individual and structural roots. Most LTC interventions have focused on the individual – e.g., strengths-based LTC and case management – with varying levels of success (Craw et al., 2010; Craw et al., 2008; Gardner et al., 2009). Less attention, however, has been given to “structural barriers” – factors impeding HIV-related care that originate in the social, economic and political disparities that shape and constrain individual health behaviors (Blankenship, Bray, & Merson, 2000). Structural barriers include HIV-related stigma and poverty (Cunningham et al., 1999; Kempf et al., 2010; McCoy, 2002), housing availability and homelessness (Gardner et al., 2009), unemployment or job instability (Stein et al., 2000), insurance policy/eligibility (Cook et al., 2002; Lillie-Blanton et al., 2010), and public transportation options (Kempf et al., 2010).

Structural barriers are particularly relevant for HIV-positive adolescents who often have difficulty navigating fragmented care systems (Chutuape et al., 2010). This structural fragmentation can occur when HIV testing sites fail to plan for LTC, when adolescents must negotiate transitions across multiple care systems, when legal or regulatory issues require disclosure to parents, and when providers are unprepared to care for HIV-positive adolescents (Mugavero, Norton, & Saag, 2011). Adolescents may be particularly likely to receive HIV testing in community-based rather than clinic-based venues, and given the fragmentation between diagnosis and care, rates of successful LTC are lower in community-based settings compared to clinic-based settings (CDC, 2013). Relatively few HIV-related health services are specifically designed for adolescents, even though adolescents differ from adults in their ongoing dependence on families for resources, health insurance, transportation, and access to clinics and pharmacies.

Methods

Data were obtained from a multimethod evaluation of the Strategic, Multisite, Initiative for the Identification, Linkage and Engagement in Care Program (hereafter called the Care Initiative). The care initiative originated in a formal partnership of the National Institutes of

Child Health and Human Development, Centers for Disease Control & Prevention, and The Adolescent Medicine Trials Network for HIV/AIDS Interventions (ATN). The care initiative was developed to improve LTC for HIV-positive adolescents by improving collaboration with local health departments and community partners, and by supporting outreach workers solely dedicated to facilitating adolescent linkage to care (Tanner et al., in press).

The data included 124 semi-structured qualitative interviews collected between February 2010 and October 2011 from 15 ATN clinics across 13 cities in the US that provide HIV-related care to adolescents (Straub et al., 2007). Two qualitatively trained researchers conducted interviews with ATN staff involved in linkage to care processes (e.g., physicians, nurses, linkage to care outreach workers, social workers, case managers, and program staff). Interviews lasted approximately one hour each. Interviews used a topic guide that focused on site-specific organization and LTC processes; facilitators and barriers to LTC; relationships with local health departments and community partners; and the scale-up of the care initiative LTC process. Specific inquiries addressed potential solutions to barriers to LTC. Interviews were conducted in personnel offices or a private space at the clinics, and informed consent was obtained prior to each interview. Interviews were digitally recorded, transcribed verbatim, and managed using Atlas ti 6.2 (Muhr, 2004). The Institutional Review Board at the Johns Hopkins Medical Institutions and each ATN site approved the study protocol.

We used a Dynamic Social Systems model (Latkin, Weeks, Glasman, Galletly, & Albarracin, 2010) to guide the identification of structural factors associated with linkage to care, specifically the influence of macro-, meso-, and micro-level structures (Latkin et al., 2010). This model emphasizes the social and dynamic qualities of structural factors that influence HIV programs, and postulates three key structural dimensions that affect care: resources; influence and control; and, contextual factors (Latkin et al., 2010). Within the current study, the macro-level structure refers to the sociopolitical, economic, and cultural context, as well as larger social institutions that shape linkage to care more broadly. The meso-level structural factors include systems that work within the more proximal institutions, within which individuals are involved (for example, clinic dynamics and physical space). Micro-level structural factors refer to the immediate social and physical context within which interactions among individuals take place (for example, between providers and patients; Latkin et al., 2010). Pairing this model with qualitative research has allowed us to explore issues related to adolescents and linkage to care, which have been missing in earlier studies.

To assess the barriers and facilitators to linkage to care at each of the 15 ATN clinics, transcripts were analyzed using the constant comparative method (Glaser & Strauss, 1967). A list of thematic codes was first created based on the existing linkage to care literature and interview guide; two team members read and coded each interview transcript to create an initial code dictionary. These team members cross-coded a random sample of 33% of transcripts to refine the code dictionary, which was subsequently reviewed by other team members. Final coding was conducted during a sequence of weekly meetings to develop additional codes and resolve discrepancies. We constructed analytical memos on these processes, discussed the memos, and refined the coding matrix based on these discussions of the data (Glaser & Strauss, 1967). Following the procedures of the constant comparative method, we searched for negative cases to explore potential exceptions to the themes surrounding barriers and facilitators to linkage to care, modified and developed the coding matrix as needed, and returned to the data for additional comparisons (Glaser & Strauss, 1967). A random sample of 20% of the interviews was again cross-coded to assess consistency; any discrepancies in coding were discussed among the investigators and resolved.

Results

Examining linkage to care barriers and solutions

Barriers and potential solutions to LTC emerged, and fell into three general headings corresponding to the Macro-, Meso-, and Micro-level structures identified in Dynamic Social Systems model, and resembling components of other models of structural barriers for HIV-related prevention (Latkin et al., 2010). These are described briefly below; quotes describing these barriers and potential solutions are presented in Table 1.

Macro-level structural barriers and solutions—Macro-level structural barriers to linkage to care coalesced around categories of insurance availability and maintenance; transportation; and system-wide relationships between clinics, local health departments, and testing organizations. Pragmatic insurance-related barriers were associated with the application process, possession of adequate documentation, and delays related to locating documentation that many youth did not possess (See Table 1 “Resources”). Eligibility-related insurance barriers were due to age, gender, or residence. In particular, youth aged 18 years and older had difficulty obtaining any form of health-care insurance. Some youth with insurance through a parent would delay care or refuse care in order to avoid disclosure of infection status.

Transportation-related barriers were identified in almost every interview, with an emphasis on lack of availability, complexity of public transport systems, and difficulty in accessing transportation support. Some clinics provided transportation, but these services were associated with considerable stigma (See Table 1 “Resources”). Relationships of clinic staff, health departments, and local agencies also affected adolescent linkage to care. Staff described challenges with information sharing and turf issues between the local health department, partnering agencies, and their program. Staff also described the unwillingness of both health departments and local HIV/AIDS agencies to provide information for fear of losing clients, and thus funding associated with service provision (See Table 1 “Influence and control”).

Solutions to macro-level barriers (See Table 1 Section on Solutions) often involved individualized, micro-level approaches to address the immediate needs of youth without contributing to changes in the macro-system barriers. Adolescents’ insurance issues were often resolved by workarounds that included use of other funding sources, or writing off costs until insurance was received. Grant funds were identified as potential sources of support for care, but this was acknowledged as a particularly unstable approach. Most clinics addressed transportation issues by providing vouchers or tokens for public transportation, usually in advance of appointments. For initial appointments, program staff frequently transported youth, which also allowed provision of emotional support during the first visit. Suggestions of how to improve relationships with partner agencies included assurance that, care initiative staff were actively participating in community coalitions to improve these relationships.

Meso-level structural barriers and solutions—Meso-level structural barriers focused on a clinic’s physical space, personnel issues (such as levels of acceptance and general personality), and procedural issues (such as when in the local collaboration care initiative staff can join the linkage to care process) (See Table 1, “Contextual Factors”). The geographic location of the clinic within a larger medical facility, as well as within a specific community, was discussed as a potential barrier, especially if the clinic was HIV-specific. Staff characteristics were identified as either a facilitator or a barrier toward linkage to care for adolescents. Discomfort with gender issues, implied heterosexual bias, and disapproval of the quirks of adolescent behaviors, all influenced the ease of linkage to care. These issues

were particularly relevant when the clinic served transgender youth, or both adolescent and pediatric patients.

A major issue in the care initiative implementation was a sense that the care initiative duplicated linkage to care services that were perceived to be sufficient. In turn, at some sites the program staff felt excluded from the LTC process, as they were only able to talk to adolescents once they had already been linked. This lack of inclusion limited the services that program staff could provide. The care initiative staff suggested that *had* the linkage to care coordinator or clinic director worked more closely with the clinic staff to explain the role of the program, and highlighted that they were not being introduced to assume other people's positions, but instead to support them, *the services would have been less duplicative*.

Solutions (Table 1) focused on organizing clinic spaces to adapt them to the adolescent population, conducting competency training with site personnel, and trying to engage the outreach worker earlier in the linkage to care process. Suggestions for increasing youth friendliness, including adapting multiple-use space to be specifically responsive to adolescent needs, was seen as especially challenging but important for improving outcomes. In terms of personnel-related barriers, specific staff training to raise awareness and sensitivity to youth was seen as important, especially in interactions with transgender and other sexual minority youth. This approach included sensitivity to access needs, sometimes outside of the clinic's usual working hours.

Micro-level structural barriers and solutions—Nearly all respondents mentioned micro-level barriers specific to the adolescents or their situation. These barriers included an adolescent's readiness for care or willingness to begin medication. Many staff described being an adolescent, or the period of adolescence itself, as a barrier to linkage to care (See Table 1 "Contextual Factors").

Solutions included continued contact (e.g., texting) with adolescents regardless of their readiness for care, and providing services that were non HIV-related. Program staff described linkage to care as a process that takes time, especially if the adolescent is in denial. Maintaining contact and providing incentives for contact was important, even when youth were not ready to be immediately linked to care. These solutions, to engage with the adolescents even if they are not ready to attend clinic and provide additional services, were suggested as ways to alleviate barriers to linkage to care, and increase eventual retention in the clinic.

Discussion

The results highlight macro-, meso-, and micro-levels of structural barriers – and solutions – to LTC for HIV positive adolescents. Although individually focused efforts are undoubtedly needed to support linkage to care, structural change is essential to achieve the goal of "seamless" care as described in the National HIV/AIDS Strategy (Office of National AIDS Policy [ONAP], 2012). The Affordable Care Act could cover HIV-positive individuals that are currently treated with Ryan White monies, which could allow these monies to be re-allocated for supplemental services like mental health, case manager and so on. As adolescents under 18 years have an easier time enrolling in Medicaid, however, it is uncertain that the Affordable Care Act will affect adolescents as much as adults. Care initiative process data show that solutions to structural barriers are frequently expedient and fragile. The solutions often represent "micro-level" responses to "macro-level" barriers. These discrepancies are particularly salient for adolescents who inhabit a unique developmental stage and are also reliant on other friends or family members for access to

resources and support. For example, an older adolescent without any dependents may have a more difficult time getting covered under Medicaid/Ryan White funding (macro-level barrier), but as a solution the clinic uses small pots of grant monies to cover the adolescent's health care (micro-level solution). Broadly, representative coalitions were described as necessary to ensure that important structural barriers are not masked by less efficient contingency solutions that might not be sustainable.

From a macro-level perspective of structural barriers, health-care insurance and transportation were significant issues. Adolescents and young adults –especially poor and minority – are over-represented in the approximately 10% of American children and adolescents without health-care insurance of any kind (Bethell et al., 2011). Lack of insurance also limits subsequent care engagement of newly diagnosed youth, especially if alternative means of payment are unavailable (Moore, 2011; Ulett et al., 2009). Our findings align with other research showing that transportation is uniformly cited as macro-level barrier to care (Fortenberry, Martinez, Rudy, & Monte, 2012; Kempf et al., 2010; Zaller et al., 2008), especially in areas with fragmented and limited public transportation systems. Reduced cost or free transportation services for HIV-positive patients have been shown to improve HIV-related health outcomes (Kissinger et al., 1995; Magnus et al., 2001; Sherer et al., 2002). However, our data demonstrate the difficulty of provision of transportation, particularly in a resource-limited time, that is associated with HIV-related care.

Clinic staff reported that the introduction of the care initiative was often met with indifference or even active resistance by health departments and community organizations providing HIV-related services for youth (Fortenberry et al., 2012; Straub et al., 2007; Ziff et al., 2006). Solutions required the investment of time, identification of common ground, and demonstration of the benefit of coordinated approaches to linkage to care. This highlights the importance of creating a network of community partnerships and relationships, and shows how linkage to care is a process that requires a complex blend of public and private service providers (Fortenberry et al., 2012; Mugavero et al., 2011).

Meso-level factors affecting linkage to care focused on physical space and the attitudes and behaviors of clinic personnel. Other studies have shown that staff attitudes often communicate larger social values of homophobia and HIV-related stigma (Kempf et al., 2010; Lichtenstein, 2003). The concept of adolescent friendliness reflects the importance of creating spaces where HIV-positive adolescents – many of whom are marginalized sexual minorities – feel secure and not judged (A. E. Hutton, 2003; N. Hutton, [personal interview, conducted by Morgan Philbin, March 15, 2006]; Macfarlane & Blum, 2001). However, few studies aside from results stemming from this program have directly assessed what constitutes adolescent friendly qualities of clinics providing HIV-related care (Tanner et al., 2012).

Micro-level level factors, such as individual readiness for care, have the potential to directly affect linkage to care. These data showed that LTC often required flexibility and persistence in maintaining contact with adolescents not yet ready to engage in HIV care. Though often seen as a structural issue, the stigma that results from an HIV-diagnosis, and fear of rejection by family, peers, and community has individual implications (Moore, 2011). Development of self- and social-identities during middle and late adolescence additionally affect the acceptance of the HIV diagnosis, which is associated with higher rates of depression, anxiety, social isolation, and stigma among HIV-positive adolescents (American Academy of Pediatrics [AAP], 1997; Blum, 1992; Futterman, Chabon, & Hoffman, 2000; Orr, Weller, Satterwhite, & Pless, 1984; Pao et al., 2000; Safren et al., 2004).

Strengths and limitations

These data represent an exploration of structural facilitators and barriers in the linkage to care process for adolescents from a wide geographic area (Straub et al., 2007). We relied on the perspectives of the care initiative clinical staff, without speaking directly to the adolescents, which could limit insight into how these factors affected adolescents' linkage to care processes, and how they interpret the barriers and potential solutions. Barriers were assessed at the beginning of the care initiative scale-up and we will continue to monitor how these have changed and how barriers continue to affect linkage to care processes for adolescents.

Conclusions

The federal government is increasingly requiring that HIV testing programs have linkage plans and partners in place in order to continue receiving funding (ONAP, 2012). Across the wide geographic implementation of the care initiative, there was agreement regarding certain barriers, as well as suggestions of how to address these barriers at multiple levels, such as restructuring of funding streams or insurance procedures to facilitate early entry into care and the wider provision of transportation services. At times the clinics may not have had control to change things at the macro-level (e.g., Ryan White funding eligibility), which suggests that creative thinking and responses are needed to change the local macro structure to complement the existing micro-level solutions. Our study shows that macro-level solutions are necessary to address macro-level barriers, and that meso-level solutions are best suited for meso-level barriers. Specifically, study findings suggest that it will likely be more effective and sustainable to address most barriers with macro-level solutions, and if that is not possible, to use higher order solutions (e.g., policy change) as opposed to lower order solutions (e.g., clinical funding).

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Table 1

Representative quotes on barriers and solutions for linking youth to care by structural dimension and barrier-solution type.

Structural dimensions	Barrier	Solution	Barrier-solution type
<i>Resources</i>			
Insurance	... And many times what the insurance company or Medicaid is asking for is a bill that comes to your house.... of course for a young person who is 16 years oldwhat bill do they probably have? Site R	And we have grants like children's medical services that go up to 21, will help support stuff. Kind of a variety of hodge-podge of grants and donations. And whatever billing we can do. Site H	Macro-Micro
Transportation	... we're dealing with youth who have no jobs so you can't even buy a bus pass, and if you need a bus pass it needs to be mailed to you so you have to get in contact with your case manager at least two weeks before your appointment. Site T	I think the biggest thing is the taxi, being able to taxi a kid from 40 miles away to get to a doctor's appointment just to make sure that he gets here Site S	Macro-Micro
	All my clients are like, "Please don't come to the house in a white [health department] van. Everybody going to see that white van." You don't want to ride what's free but you don't have money to ride. Site G	I usually try to go to the first appointment with them. I don't force it upon them but just a friendly, "Hey, if you want me to come, I'm more than willing to do that. Pick you up, drop you off and I can still give you bus cards afterwards." Site P	Meso-Micro
<i>Influence & control</i>			
Inter-agency communication and cooperation	Instead of the director saying, 'now we're not going to do it that way', she went on and said, "we support them" and then later said, "you're on your own" so that doesn't give us much. Site I	The outreach worker is interacting with [partner agencies] very frequently. Whenever they have testing events in the community, she's participating. And then we see them at the meetings, the Coalition on HIV/AIDS meetings. We participate with them because they are sitting on subcommittees. So we're always working together in some fashion. Site G	Meso-Meso
Personnel	Yeah, that's got to be tough and that I don't know how to help heterosexuals with that [transgender]. They're the same person. They're dressed differently.... The personality hasn't changed. They were feminine dressed as a boy and now they're feminine and comfortable, dressed how they want to be. Site T	We really are very gay friendly. And we've done some training around that specifically. We did it for the front desk.... we need everybody to be cool about our transgendered youth. Or our youth that are cross-dressing, or are very effeminate or whatever. Site G	Meso-Meso
<i>Contextual factors</i>			
Clinic location	The rooms have giraffes on the walls and monkeys juggling, and chalkboards at four-year-old level with chalk. So you're 19, you're HIV-positive, and you're a gay boy. You're like, "What the heck am I doing in here?" Site T	Making sure the boards have something that they will want to read about, what I might put on my board for adolescents is marijuana, drinking, yeah. Sociable things that could lead to unprotected sex.... Not having cartoons on the television when they come in. Site J	Meso-Meso
Integrating SMILE into existing programs	I think they only let me do that [complete insurance forms] because they have so many kids that they just don't physically have the time. [The social workers] are very protective of what they do. Site Q	The [site staff] were very standoffish and we sort of like let them just have that for a while, and get to know me and get more comfortable with me. Site Q	Meso-Micro
Accepting diagnosis	If you're not ready to accept your diagnosis, you're not going to come in for care. So usually by the time someone is coming in for care that has been addressed in some way, although it may not be, they may not really be completely accepting the diagnosis but they're coming in for care in some form of acceptance. Site N	A lot of times it's working with patients outside of the clinic so offering all of our supportive services but not pressuring them to have to come in for medical care. Site Q	Meso-Micro

Structural dimensions	Barrier	Solution	Barrier-solution type
Adolescence	A lot of them are still in that concrete operational phase. A lot of them are still just dealing with regular adolescence. Now you got to throw this diagnosis in there. Site I	So in the beginning I may call 50 times to get them to come in... we're also finding texting to be quite an effective way of communicating with kids. They actually respond better to texts, and I think texting is easier because it's immediate... Site N	Meso-Micro