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Linkage to Care for HIV-Positive Adolescents: A Multisite Study of the Adolescent Medicine Trials Units of the Adolescent Trials Network

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ABSTRACT

Purpose: To understand linkage to care practices at sites providing clinical services to newly diagnosed HIV-positive adolescents.
Methods: Qualitative analysis of detailed interviews conducted with 28 personnel involved in linkage to care at 15 sites providing specialty care to HIV-positive adolescents.
Results: We showed that multiple models exist for linkage to care, and that both formal and informal community relationships are important for successful linkage to care. Stigma was seen as a universal issue, enhancing the importance of the balance of confidentiality and social support. Barriers to care, such as mental health issues, substance use, and transportation, are common.
Conclusions: We conclude that the complexity of linkage to care requires thought and planning as HIV testing is expanded to lower-risk populations.

IMPLICATIONS AND CONTRIBUTION

Linkage to care for HIV-positive youth is an essential element of contemporary treatment and prevention strategy. Successful linkage to care requires coordinated efforts at clinical and community levels.

Expanded population-based screening and treatment of positive cases is a centerpiece of HIV control efforts, especially in the United States [1]. However, treatment requires clinical care, and linkage to care fails for one-third or more of infected adults [2]. Linkage to care refers to a systematic process of initiation of HIV-related medical, psychological, and social services for newly diagnosed HIV-positive persons. Recently diagnosed patients who are not engaged in care are more likely to develop viral resistance and less likely to receive antiretroviral therapy or achieve viral suppression [3]. Viral suppression—especially early in the course of infection—preserves immune function and contributes to decreased HIV transmission [4,5]. In the United States, only about 28% of the more than one million HIV-positive persons achieve viral load suppression [6], in part owing to failure in linkage to care.

Newly diagnosed HIV-positive adolescents may be especially likely to fail in linkage to HIV care because of individual characteristics (e.g., stigma and shame, denial, low educational achievement, substance use, or psychiatric disorder), family characteristics (e.g., lack of health care insurance, family dysfunction, or past and current neglect/abuse), or perceptions of the HIV health care system (e.g., costs to patients, services available, access, and the degree of "youth-unfriendly" staff and services) [7–9]. Efforts to improve linkage to care for adults lead to modest improvements in linkage to care and care engagement [10,11], but linkage to care for adolescents has not been studied as extensively [12].

With few exceptions [13], research on linkage to care addresses the characteristics of patients but does not examine linkage to care from the perspective of persons providing linkage to care services. These perspectives are important because no single standard exists for linkage to care practices, although a multidisciplinary case management model is recommended [14]. Case management approaches recruit personnel to interact with adolescents, help adolescents meet the expectations

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of the care system, activate appropriate segments of the health care system, and identify barriers to entering and maintaining care [11].

This article focuses on HIV-positive youth from the perspective of those providing linkage to care services. We chose to study personnel associated with linkage to care and affiliated with the 15 Adolescent Medicine Trials Units (AMTU) in the Adolescent Medicine Trials Network for HIV/AIDS Interventions (ATN). We reasoned that because the AMTU focus expertise on provision of clinical HIV services for youth, these sites represent extensive practical experience with linkage to care for adolescents.

Methods

The research (conducted in 2008–2009) consisted of structured telephone interviews with personnel employed at all 15 AMTU and community partners associated with the linkage to care process. AMTU were created in 2001 to provide HIV-related services to youth aged 12–24 years, and to implement research protocols under the scientific auspices of the ATN [15,16]. The 15 AMTU are located in large urban areas throughout the continental United States, and Puerto Rico.

Personnel and community partners at each AMTU site were identified by the ATN principal investigator for that site. The principal investigators were asked to identify up to three personnel with direct responsibility for interactions with newly diagnosed HIV-positive youth. These personnel included social workers, case managers, physicians, and posttest counselors. Because linkage to care activities often involved personnel with varied professional backgrounds and job descriptions, each site nominated personnel most closely associated with linkage to care at their site. Interviews were arranged at the convenience of persons at each site, and not all nominated persons were interviewed owing to scheduling problems.

Semistructured interviews required 30–45 minutes and were conducted in either English or Spanish by a bilingual male interviewer with no affiliation to the AMTU. The interview guide consisted of items in four areas: site-specific organization of linkage to care, process of linkage to care, barriers to linkage to care, and coordination with community partners. Follow-up questions expanded and clarified initial responses. The interview guide was developed based on earlier research [7,12]. Interviews were digitally audiorecorded (after obtaining verbal permission from the interviewee) and transcribed verbatim, as well as translated from Spanish by a certified bilingual translator when necessary. The protocol was approved by the Institutional Review Board at Indiana University/Purdue University at Indianapolis, and each of the 15 participating AMTU sites.

Data analyses were conducted using a two-stage coding approach [17,18]. First, transcripts were indexed by broad themes that were conceptually mapped to domains derived from a widely used framework for health care access [19]. This framework addresses characteristics of the health care system, the social environment, and the community, as well as provider- and clinic-related domains, allowing us to conceptualize linkage to care as an issue associated with health care access. We chose this framework in recognition that contemporary models for HIV-related care for youth evolved from models of academically affiliated subspecialty pediatric and adolescent health care designed for the special challenges in health care access faced by adolescents [20,21].

This first stage of coding identified a tentative model of the organization and process of HIV-related linkage to care for youth, from the perspective of those who conduct linkage to care activities. Initial codes were reviewed and refined until consensus developed. In the second stage, transcripts were reread based on the initial codes. This reading was used to develop more detailed understandings of approaches to linkage to care, to generate theoretic memos based on this reading, and to link key concepts to specific illustrative quotes. ATLAS.ti (version 5.6.1; ATLAS.ti Scientific Software Development GmbH, Berlin, Germany) was used to organize and analyze codes. During this process, the tentative model for HIV linkage to care was revised to achieve consensus of the authors. We assessed validity by testing hypotheses against analysis of subsequent data and by assessing the theoretical consistency of results.

Results

Twenty-eight interviews were conducted across the 15 AMTU sites. Interviewed personnel were primarily physicians ($n = 4$) and case managers ($n = 20$). Four interviews were conducted with representatives of community partners who referred HIV-positive youth for care at the local AMTU. Three main components of HIV-related linkage to care were identified: the infrastructure and organization of linkage to care, the process of linkage to care, and the content of linkage to care activities.

Infrastructure and organization of linkage to care

Models for linkage to care. Three models represented approaches used to bridge the geographic and systems-level challenges of linking adolescents to care. The first model used passive referral, where the posttest counselor provided referral information that could include an appointment for initial evaluation at the AMTU site. Responsibility for appointment adherence rested with the adolescent. The second model involved an immediate introduction to a case manager who provided additional education, support, and coordinated initial intake evaluations, typically within 48–72 hours. In the third model, a case worker was introduced at the time of diagnosis who then accompanied the adolescent through the intake process of the initial HIV-related care visit. This model was used in a small minority of sites.

Relationships among networks of testing sites and HIV clinical care sites. The approach to linkage to care was associated with the quality of relationships of testing sites and the HIV clinical care site. These relationships were characterized by three subthemes: formal relationships, informal relationships, and education and training of test sites. *Formal relationships* were not explicitly described. Rather, respondents suggested that these were institutional relations of health authority, care financing, and mandated reporting. Formal relationships provided means by which patient information could be exchanged and the responsibility for a newly diagnosed HIV-positive person transferred to HIV clinical care sites. *Informal relationships* were an important aspect of linkage to care and were personal rather than institutional, forged though past professional interactions and shared commitments to youth. Informal relationships were often used to circumvent barriers to linkage to care. For example, sexual minority adolescents were often specifically referred to gay or lesbian staff members. *Training* of testing sites—by the clinical sites—about the process of linkage to care was seen as an ethical responsibility of testing. This type of training also helped forge the informal relationships around the linkage to care process and additionally established the clinical sites as members of the larger community.

Community membership. Membership in a network of community partners created a trusted identity for the HIV clinical care sites. “Community” referred in some instances to geographic situation within urban areas thought to be accepted and used by adolescents. This type of community membership facilitated linkage to care by placing testing and treatment sites in the same facility or by decreasing distance from test sites to treatment sites. Community membership also reflected a site’s capacity to respond to the cultural and linguistic needs of adolescents, particularly by employing multicultural and multilingual staff. In many instances, community membership referred to a site’s engagement with lesbian–gay–bisexual–transgender–queer (LGBTQ) communities in ways that transcended the geographic location of the clinical services.

Adolescent friendliness. Respondents noted that physical structures and services intended to be “adolescent friendly” were necessary. Infrastructural aspects of “adolescent friendliness” included clinic hours (including afternoon and evening hours) and separation of adolescents’ space from that of other pediatric and HIV-related clinical services.

The composition and attitudes of staff were important elements of adolescent friendliness. In fact, the quality of adolescent friendliness often referred explicitly to “LGBTQ friendliness” rather than age per se. This perspective of youth friendliness suggested that “mirroring” of relevant characteristics by staff (e.g., openly LGBTQ staff) was seen as an important element of youth friendliness.

The process of linkage to care

Readiness for HIV care. Respondents spoke of wide variation in youths’ readiness for care, emphasizing two key issues: stigma and social support. Stigma was seen as a ubiquitous barrier to readiness for care but was not uniformly conceptualized by all respondents. The various conceptualizations followed distinctions of “internal” and “external” stigma [22]. Internal stigma reflected a psychological loss of self-worth, presumably reflecting acceptance of negative societal attitudes about persons with HIV. By contrast, external stigma was seen as inherently social, something that was innate to the diagnosis and immediately attached to it. Internal stigma was seen as something amenable to intervention, but respondents’ perceptions of external stigma were more pessimistic.

Discussions of social support in linkage to care were marked by ambivalence. Enlisting social support—especially from family members—at the time of diagnosis was seen as a potential benefit worth the investment of energy during the linkage to care process. Other respondents were more cautious, noting that families were often uninvolved and could detract from linkage to care.

Crisis management. Respondents frequently discussed linkage to care within the context of response to a crisis. One respondent specifically identified Crisis Theory [23] as a structure for approaching linkage to care within the heightened emotional context of receipt of HIV test results. Thus, the linkage to care process represented the supporting structure for assisting youth in the dramatic reconceptualization of their lives, represented by an HIV diagnosis. Other respondents, however, emphasized the almost overwhelming complexity of issues associated with HIV: poverty, physical abuse and neglect by parents, substance abuse and addiction, mental health issues, suicidality, and homelessness. In this sense, linkage to care was an attempt to stabilize a deteriorated situation, ensure safety of the youth, and “buy time.”

Patient education and orientation. Respondents discussed the ways in which a linkage to care interaction with newly diagnosed youth involves numerous factors: education (details about HIV transmission and infection, treatment, prognosis), issues related to disclosure, and orientation to the immediate demands of becoming an HIV patient. Education constituted an iterative verbal interaction with youth, providing information while gauging a youth’s intellectual and emotional capacity to receive the information. Emotional coping capacity, particularly, was seen as limited in the context of the distress of an HIV diagnosis.

Respondents thought education provided early in the linkage to care process gave hope and motivation to adolescents. This was grounded in understanding of HIV as a serious, but treatable, disease, and adolescents’ responsibility to become “good patients” to maximize the lifelong benefits of modern HIV care. An extension of this perspective was emphasis on framing care in the context of training for “adolescent responsibility.” Focus on responsibility was seen as a developmentally appropriate orientation to expectations of clinicians and staff to issues such as appointment keeping, medication adherence, and abstinence from health-harming behaviors.

Linkage to care content

Case management. Case management served as a generic term for the content of linkage to care. Moreover, case management itself differed from site to site in terms of how the transition from diagnosis to care was tracked and how various services were coordinated. For example, some respondents discussed a very “hands-on” approach, with extensive efforts to solve problems in the linkage to care process and with follow-up for missed visits to the extent of making home visits, if necessary. Other sites made less detailed efforts, and not all respondents discussed a mechanism for identifying newly referred youth who missed initial appointments or who dropped out of care after only one to two visits.

Barriers to care. Respondents were asked to list the three most important barriers to linkage to care. Barriers such as stigma and readiness for care have already been addressed. Other commonly mentioned barriers included availability of services, eligibility requirements, consent, payment, housing instability and homelessness, transportation, and mental health/substance use. Within the context of service eligibility, respondents identified the often complex criteria, difficult application and documentation procedures, and involvement of multiple service providers.

Confidentiality. The theme of confidentiality touched on issues related to the involvement of family, friends, and partners. The routine separation of youth from family and others during a clinic visit was justified in part by commitment to confidentiality. The protection of confidentiality was also seen as a protection against stigma, and it influenced the pace and content of linkage to care. In these circumstances, case managers served as “disclosure intermediaries” by providing a single point of contact for the linkage to care process. Because HIV test sites and HIV care sites may be geographically separate, newly diagnosed adolescents often must physically relocate to receive care. In many circumstances, this means negotiation of separate “systems,” requiring negotiation of a new set of interviews, registrations, and eligibility requirements. Transitions from testing to care typically involves a progressive increase in the number of people who share the private information about a person’s HIV status, as a referral moves from one setting to another. Thus, linkage to care marks the first experiences of adolescents in disclosure of infection status.

Discussion

The National HIV/AIDS Strategy for the United States refers in several instances to the importance of “seamless” linkage to care for persons with HIV infection, with a target of linking 85% of people to care within 3 months of diagnosis (http://www.whitehouse.gov/sites/default/files/uploads/NHAS.pdf). The key finding from our data is demonstration of the complexity of linkage to care for newly identified HIV-positive youth. This complexity suggests that achievement of the linkage to care goals identified in the National Strategy—at least for HIV-positive youth—requires active planning and allocation of resources.

Our data suggest several key areas that could guide this planning and resource allocation process. First, the importance of formal community relationships and community membership in linkage to care means that organizations conducting HIV screening should focus some resources on linkage to care. This finding parallels linkage to care approaches described for adults: choose an appropriate partner, build and strengthen the essential partnerships, and communicate the importance of linkage to care to those partners [13]. The importance of centering linkage to care activities within a network of community relationships is that it helps confront the fragmentation of care when HIV testing, linkage to care, or HIV-related care is conducted by a complex blend of public and private service providers [24]. Providers for adults report marked improvements in the linkage to care process after recruitment of case managers and implementation of coordinated linkage to care services [25].

Our data suggest that many barriers to HIV-related care for youth are structural rather than related to individual characteristics of youth. Structural changes are often discussed in the context of HIV *prevention* for youth but much less frequently in terms of HIV *care* [26,27]. For example, co-location of testing and linkage to care services is associated with improved linkage to care success rates but was seen in a minority of the AMTU sites [13]. Transportation is another important barrier to linkage to care, and provision of free or low-cost transportation services is associated with improvements in HIV-related health outcomes [28,29]. However, systematic provision of transportation services requires shifting of responsibility for transportation from patients to the HIV care system itself. This type of structural change is akin to those labeled as “accessibility” structural change interventions [30]. Accessibility interventions are based on recognition that issues such as transportation are associated with the marginalization, unequal power, and differential resources that are hallmarks of health disparities [31,32].

Our data suggest the range of issues to be considered in implementation of youth-focused linkage to care practices, especially in areas without expertise in care of adolescents and youth. Particularly if posttest counseling for positive cases and linkage to care are provided by the same person, youth may form a relationship with that person for support through the crisis of diagnosis and guidance into care. This approach is similar to the brief intensive case management and patient navigator systems effectively used with adults [33,34].

An additional advantage of the intensive case management or patient navigator systems relates to what might be called “the paradox of confidentiality” in provision of HIV-related services. Linkage to care essentially involves an orchestrated HIV disclosure process, beginning with the posttest counselor and then many others: case managers, laboratory technicians, financial counselors, office personnel, nurses, physicians, pharmacists, psychologists, and social workers. Family and friends require a separate set of disclosures to be balanced against perceptions of acceptance, safety, and supportiveness. The linkage to care process is thus a transformation of self-held personal information to collectively held information shared among others [35]. Expansion of the set of persons sharing private information about a person’s HIV status has many potential risks, even if those receiving disclosure are professionally entitled to receive private information. Thus, successful linkage to care substantially depends on careful management of this staged disclosure, as many adolescents forego care if confidentiality is threatened [36]. One potentially fruitful area for new research could address adolescents’ perceptions of stigma and disclosure as new privacy rules, boundaries, and expectations are experienced during the linkage to care process [37].

These data should be evaluated in the context of the design of the study and approach to data analysis. We studied linkage to care at AMTU—members of a research and clinical network specializing in HIV prevention and treatment among adolescents [15]. The AMTU represent expertise and commitment to youth with HIV different from that generally available and likely set a high-quality standard in terms of linkage to care services. The study design relied on persons at each site to describe linkage to care for that site. We chose persons expected to be knowledgeable about linkage to care but made no attempt to integrate multiple perspectives into a common description of linkage to care for a specific site. We did not measure the effectiveness of linkage to care at each site and cannot address the relative effectiveness of different approaches to linkage to care. Finally, we note that linkage to care is only the beginning of lifelong “engagement in care.” This chronic disease perspective on HIV will become even more important as increasing numbers of youth transition into adulthood.

In summary, we found linkage to care to be variable in structure, process, and content. However, we found that several elements—especially working closely with key community partners and intensive case management—were common across sites. These structural and process elements are very similar to those described for implementing linkage to care programs for adults [13]. As routine HIV testing becomes more widely used by youth, a thoughtful, planned, and organized approach to linkage to care will be needed. Our data provide a starting place for such well-organized approaches to linkage to care for youth with newly diagnosed HIV.

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