

“Youth friendly” Clinics: Considerations for Linking and Engaging HIV-infected Adolescents into Care

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Abstract:

Linkage and engagement in care are critical corollaries to the health of HIV-infected adolescents. The adolescent HIV epidemic and adolescents' unique barriers to care necessitates innovation in the provision of care, including the consideration of the clinical experience. Little research has addressed how “youth friendly” clinics may influence care retention for HIV-infected youth. We conducted 124 interviews with providers, outreach workers, and case managers, at 15 Adolescent Medicine Trials Network clinics. Photographs of each clinic documented the characteristics of the physical space. Constant comparison and content and visual narrative methods were utilized for data analysis. Three elements of youth friendliness were identified for clinics serving HIV-infected youth, including: (1) role of target population (e.g., pediatric, adolescent, HIV); (2) clinics' physical environment; and (3) clinics' social environment. Working to create ‘youth friendly’ clinics through changes in physical (e.g., space, entertainment, and educational materials) and social (e.g., staff training related to development, gender, sexual orientation) environments may help reduce HIV-infected adolescents' unique barriers to care engagement. The integration of clinic design and staff training within the organization of a clinical program is helpful in meeting the specialized needs of HIV-infected youth.

Keywords: adolescents | HIV care | youth friendly | clinics | qualitative research

Article:

Introduction

Over 8000 individuals between the ages of 13–24 in the USA were diagnosed with HIV in 2009 (CDC, 2011). Younger HIV-infected individuals have more difficulty establishing linkages with, and being retained in, care (Giordano et al., 2005), which is associated with higher morbidity and mortality (Giordano et al., 2007; Metsch et al., 2008). Furthermore, HIV-infected adolescents have high rates of associated comorbidities (e.g., substance use, mental health issues; CDC, 2011). Therefore, access to and engagement in HIV care is particularly relevant for adolescents.

Adolescents' potential lack of experience with clinics and healthcare providers may complicate their ability to navigate the healthcare system. Access and retention in care may be challenging as clinics are conceptualized as places that require “adult” skills or an adult companion. Adolescents, however, occupy the clinical fringes and do not embody either adult or pediatric space (Abbott-Chapman & Robertson, 2009; Malone, 1999). Adolescents may also lack the skills necessary to negotiate clinical policies and procedures (e.g., insurance, residency documentation). The way in which clinics approach “youth friendly” has implications for adolescents' abilities to access and engage with HIV care.

The term “youth friendly” is widely used but poorly defined. The term may include how/whether a clinic provides: nonrestrictive services based on age (and potentially gender, disability, religion); easily negotiated access; support staff oriented toward adolescents; appealing facilities with convenient hours; adolescent involvement; and comprehensive services (World Health Organization [WHO], 2002).

Research has focused on the way in which healthcare space affects adolescents' experiences (Hutton, 2002, 2007, 2010). For instance, adolescent-specific ward space allows for more privacy and the delivery of comprehensive services by staff trained to meet adolescents' developmental needs (Fisher, 1994; Hoffman, Becker, & Gabriel, 1976; Hutton, 2010). These spaces increase adolescents' participation in their own care (Hutton, 2010). Little attention, however, has focused on outpatient clinical settings and how a clinic's “youth-friendliness” affects adolescents' HIV-related care engagement.

The primary patient population of clinics (e.g., adolescent-only, HIV-only) may affect adolescents' healthcare outcomes (Hutton, Rudge, & Barnes, 2009). HIV-only clinics, for instance, may increase the chance of passive HIV disclosure, yet, may also have providers with increased skill and experience in addressing illness-related issues. Providers in adolescent-specific clinics, in contrast, may have skills in addressing adolescents' developmental needs but some providers may lack comfort in treating the sometimes-complex HIV-related comorbidities.

The high rates of adolescent HIV and adolescent-specific barriers to accessing HIV-related medical care (CDC, 2011; Philbin et al., 2013a) require innovative approaches, including the consideration of the role of the clinical environment. “The richness or poverty of environmental affordance to which young people are exposed ... is only part of the equation – the degree of

access and engagement with clinics is also important” (Abbott-Chapman & Robertson, 2009, p. 421). The way in which clinical space is labeled can shape how adolescents behave and interact with the environment. Accordingly, this paper presents data – verbal and visual – that examined the elements and approaches to clinical “youth friendliness” with the primary objective to assess how staff constructed the notion of, and worked to improve, youth friendliness within clinics serving HIV-infected adolescents.

Methods

Data were obtained from a multimethod evaluation of the Strategic, Multisite, Initiative for the Identification, Linkage and Engagement in Care of Youth with Undiagnosed HIV Infection 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 care retention for HIV-infected adolescents by facilitating collaboration with local health departments and community partners, and by supporting outreach workers solely dedicated to adolescent care linkage (Tanner et al., 2013).

We conducted semi-structured interviews with staff affiliated with the Care Initiative at 15 ATN clinics, including outreach workers, nurses, and physicians (124 interviews [Baseline $n = 64$, Year 1 $n = 60$]). Interviews explored ways in which clinics were currently youth friendly, changes in youth friendliness across time, and recommendations for improving youth friendliness. Interviews were digitally recorded, transcribed verbatim, and managed using Atlas ti 6.2 (Muhr, 2004). Average interview length was 68 minutes (range = 32–118 minutes). Researchers took photographs of each site to systematically document clinic space. The goal of photo-documentation was to capture the essence of the space while not recording people or individual identifying information. The Institutional Review Boards at the Johns Hopkins Medical Institutions and all ATN sites approved the study protocol.

The verbal and visual data sources were analyzed using the constant comparative method and content and visual narrative analysis (Glaser & Strauss, 1967; Morse, 1994). Data were inductively analyzed with particular attention given to formal discussions of “youth friendliness,” and guided by the WHO’s (2002) definition of youth friendliness and associated clinical characteristics.

The study team created a coding dictionary based on the literature and preliminary transcript readings to analyze the interview data. We wrote analytical memos to summarize and refine codes (Glaser & Strauss, 1967). Researchers cross-coded a random sample of 33% of transcripts to confirm the initial coding structure. Following constant comparison methodology, transcripts were searched for negative cases to identify exceptions to the initial themes (Glaser & Strauss, 1967). The finalized coding structure was applied to all transcripts by two researchers;

independent codings were compared and indicated high consistency among raters (87%). To assess changes over time, three researchers reviewed all of the transcripts at each site and created a comparison matrix; discrepancies were resolved by discussion. After analyzing the verbal data, the coding structure was applied to the photographs. We identified photographs that were both consistent and inconsistent with conceptualizations of youth friendliness.

Results

Youth friendliness included three primary elements: (1) how the clinic labels its primary population, (2) the clinic's physical environment, and (3) the clinic's social environment. Some sites described development of “youth friendly” spaces; at others, the creation of a youth friendly clinic was a work in progress with increased attention to improving youth friendliness between Baseline and Year 1.

Primary population of the clinic

A clinic's target population affected the ways it addressed the creation of a youth friendly space. It affected the ways in which staff was able to utilize space and provide specific services and materials; it also had implications for passive disclosure.

About half ($n = 6$) of the clinics were shared spaces, and served pediatric and adolescent patients across sub-specialties. Shared space limited providers' control of the physical space:

The problem is we're not just—we're a teen clinic, but then we have dermatology clinics, so it's not just adolescents that come here. It's little kids, which is part of the reason why I think it's kind of hard to be neutral about it, because it's one extreme to the next, adolescents or babies. [Site_F]

Some of the mixed-use clinics carved out a specific adolescent-only section to develop a more inviting space (Figure 1). Despite these efforts, the centrality of the pediatric space remained:

We're nurturing and we're kind ... but I don't know that I would want to come in those doors to come and get my own care here if I was HIV-positive. I think I would feel like this is for little kids and what the hell am I doing here? [Site_C]



Figure 1. Adolescent-specific space in shared clinic.

The seven adolescent-only clinics reported more control over their space and staff. Staff frequently catered to adolescents' needs, for instance allowed walk-in and texted appointment reminders.

Both shared and adolescent-only clinics had stated advantages over the two HIV-only clinics (which also served adult patients). Participants discussed adolescents' fear of passive disclosure (e.g., everyone in waiting area is known/perceived to be positive), and preference for a clinic that is not HIV-specific “because this isn't necessarily known as an HIV clinic, so they can come here and feel safe. No one's going to figure out why they're coming here” [Site_G]. Furthermore, the waiting areas for clinics serving adults are often filled with people who are older and sicker, and there is a potential for unsolicited sexual advances:

The building is basically HIV-only so people don't always like that idea ... Also it's very hectic, it's not touchy-feely like pediatrics [and adolescents]. You sit in a lobby with 200–300 other people. [Site_N]

Responsiveness to adolescents' needs: physical and social environment

Being responsive to patient characteristics (e.g., age, gender, sexual orientation, and language), to create a more youth friendly clinic was presented in two specific ways – clinical space (physical environment) and staff-specific (social environment).

Physical environment

In summarizing how clinics' physical environments can be responsive to adolescents, one participant stated:

I feel like it needs to be space where they [adolescents] can come in and just feel comfortable right off the bat ... So I'd like to see more ... things that they're actually interested in. [Site_F]

Participants described adolescent-specific décor and materials as important elements of youth friendliness. Some clinics incorporated adolescent-oriented décor and youth-designed art (Figure 2). One participant described that the ideal space would be one “that's more modern, kind of funky, like IKEA-y meets Manhattan or something” [Site_E] (Figure 3). This style could then balance the child-like décor of shared pediatric spaces:

The rooms have giraffes and monkeys juggling, and chalkboards at four-year-old level. 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_E]



Figure 2. Youth friendly art.



Figure 3. Adolescent-specific decor.

Print material, including pamphlets on STIs, transgender health, and drugs allowed staff to use clinic areas as communication mechanisms for prevention messages (Figure 4). Even when youth did not engage with the material it served as a way to define the space as welcoming to adolescents. The use of peer educators and interactive spaces was also helpful for engaging adolescents, “We have a youth table ... we've got young people who are trained to do secondary prevention education and so we have a little candy and condoms and lube available” [Site_A].



Figure 4. Adolescent-specific materials.

Participants discussed making other types of adolescent-specific entertainment materials available including magazines and TV programs:

So just give them [adolescents] something to watch while they're in the room, not necessarily in the waiting room because that caters to zero to 24, but in the room ... along with the magazines or books that are friendly to them. [Site_E]

When clinics shared space with or worked with other departments (e.g., diabetes and emergency room) they were more limited in information presentation; “because so many different practices use that space, I guess if everybody wanted to put up something that was unique to their practice, it might get a little overwhelming.” In some sites, there was movement to enhance the shared space:

[Adolescents] leave because [the ER] waiting room is scary and it's in a hospital and it's like no place that anybody wants to ever hang out. So they talked to us about how to redo their waiting room ... they redid the floors and they put a computer lab in there and that really kind of helped. [Site_B]

Social environment

Sites described more control over the social than the physical environment. Specific issues included: staff comfort with adolescents (e.g., development, gender and sexual orientation), specific clinic policies, and targeted programming. Adolescents' progression through their clinical experience requires interactions with a variety of clinical staff and policies highlighting how the social environment can impact clinical youth friendliness. “If you don't have the people,

behind the desk greeting them ... [if] they're nasty, the [physical] environment doesn't even matter" [Site_M].

The first point of interaction within the clinic was with the registration staff. Providers worried, however, that these staff, particularly in shared clinics, might judge the youth. For example, when addressing transgender youth, one participant noted that "It's other departments that aren't really used to that, that deal with little kids We need everybody to be cool about our transgendered youth" [Site_X]. Accordingly, most sites had training related to sexual minority youth: "We've done some training ... Because while I may be really open to whatever it doesn't help if the front desk was like 'What are you wearing today?'" [Site_X]. After registration, adolescents interacted directly with program staff and providers. The way these relationships developed were described as important for keeping youth connected to care: "The youth bond with the doctor and nurses, they love all the attention" [Site_N].

Specific policies were also deemed important for youth friendliness, including having convenient hours and walk-in appointments:

There are flexible hours for those in school, they aren't waiting for forever to be seen. They don't want to wake up early. Clinics that adapt themselves to the needs of the participant, Saturday clinics [are youth friendly]. [Site_L]

One site created an adolescent clinic day with delayed hours to support adolescents:

I thought youth would come after school and so I pushed administration to allow us to work late on Thursdays, and it works really well ... from 3:30 until we close [8pm] it's packed ... we've been seeing about 20 on those evenings. [Site_C]

Finally, clinic programming affected youth friendliness. Two sites had child life specialists who assisted with adolescent events (e.g., hospital prom and open mic night). There were also adolescent activities in waiting areas (e.g., Wii, computer) and one site, with a high transgender youth population, created a program to be responsive to their specific needs and strengthen the relationship to the clinic. Formal and informal programming also worked to improve connection to space:

So they can come up here, they can talk and hang out until they're ready to be seen ... we'll let them get on the computer, you know, while you're waiting, come, let's take a look at your resume. Let's talk about this; let's talk about that. [Site_I]

Discussion

The adolescent HIV epidemic in the US (CDC, 2011) necessitates innovation in the provision of adolescent HIV-related care, including the consideration of the clinical experience. In order to be retained in care, HIV-infected adolescents must navigate a complex healthcare system and engage with physical and social environments that differ from their everyday lives. The results

highlight different elements of clinical youth friendliness that expand the WHO's (2002) conceptualization to meet the specialized needs of adolescents living with HIV. These elements can be helpful in maintaining HIV-infected adolescents in care (see Philbin et al., 2012, 2013b) despite limitations related to changing space and target population(s) of the clinic.

The clinic's target population has implications for the control staff has over the physical environment, the ability to provide targeted materials, and potentially the process of disclosure. Sites that were adolescent-only had more control over the physical environment than shared clinics, which required more creativity to be responsive to adolescents needs. For instance, creating an adolescent-only space and using adolescent-specific print materials to aid in creating a designated and inviting environment for adolescents (Hutton, 2002; Hutton et al., 2009).

HIV-specific clinics afforded adolescents quality care but also had implications for passive disclosure. As many of the HIV clinics were also adult facilities, there are issues of the space being “scary” (e.g., emergency room) and adolescents being surrounded by older and often sicker patients. This exposure can be intimidating and may affect the way adolescents think about their disease and mortality and influence their desire to stay in care. The clinic, then, is not only a geographical space that holds physical designation of space (e.g., monkeys on the wall) but also the place where adolescents enter at specific points in disease trajectory (i.e., diagnosis, transition to adult care) that shapes their understanding of, and experience with, the disease.

The clinic's social environment shapes how adolescents behave within the physical space. For instance, clinic staff expects adolescents to adhere to specific routines (e.g., check-in, stay in waiting area), so staff knows where adolescents are located which facilitates efficient movement through their appointment. The adolescent–adult relationships that develop in clinical environments help support adolescents meeting these behavioral expectations. The management of these relationships may be particularly important for the way in which adolescents build trust and disclose information (Abbott-Chapman & Robertson, 2009; Goffman, 1971) suggesting that staff training related to specific needs of the adolescents (e.g., developmental, sexual minorities) may be crucial for getting adolescents to return to the clinic. Finally, how clinical policies and programs respond to adolescents needs – in terms of policies, hours, and targeted programs – may affect adolescents' care-seeking behaviors.

Strengths & limitations

These data should be evaluated in the context of particular limitations of the research. The defining characteristics of youth friendliness came through interviews with staff, not with adolescents. Lefebvre (1991) would argue that the multiplicity of social meanings that the staff and youth may have created around the clinical experience make the data “suggestive rather than conclusive” and more research is warranted. However, several recent studies (e.g., Fortenberry, Martinez, Rudy, Monte, & the Adolescent Trials Network for HIV/AIDS Interventions, 2012; Magnus et al., 2013) have elucidated the importance of the provider perspective. Future research

should explore youth friendliness directly with adolescents and its affect on the transitioning to adult HIV process (Blanchet-Cohen & Salazar, 2009).

Conclusion

Linkage and engagement in care are critical corollaries to the long-term health of HIV-infected adolescents. The consideration of how clinical environments can be youth friendly is important as we conceptualize ways of increasing efficiency from diagnosis to care (Tylee et al., 2007). Our data suggest some common elements of “youth friendliness” that could guide the integration of clinic architecture, interior design, staff training, and programming to meet the specialized needs of HIV-infected youth. Youth friendly clinical environments may reduce the unique barriers to care faced by HIV-infected adolescents (Philbin et al., 2013a), especially as we work toward a test and treat model of HIV prevention and treatment (Blanchet-Cohen & Salazar, 2009; Mugavero et al., 2012).

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