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Transition of Adolescents With HIV to Adult Care: Characteristics and Current Practices of the Adolescent Trials Network for HIV/AIDS Interventions

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Abstract

The transition process from pediatric to adult health care for adolescents with chronic diseases is always challenging and can be even more so for adolescents with HIV disease. The purpose of this study was to describe characteristics and current practices surrounding the transition of adolescents from the clinics of the Adolescent Trials Network for HIV/AIDS Interventions to adult medical care. This report focuses on the processes of transition, perceived barriers and facilitators, and anecdotal reports of successes and failures. Practice models used to assist adolescents during transition to adult medical care are described. Interviews were conducted with 19 key informants from 14 Adolescent Trials Network clinics. Findings revealed no consistent definition of "successful" transition, little consensus among the sites regarding specific elements of a transition program, and a lack of mechanisms to assess outcomes. Sites that viewed transition as a process rather than an event consistently described more structured program elements.

Keywords

adolescent; AIDS; developmental; HIV; transition

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According to the most recent Centers for Disease Control and Prevention (CDC) surveillance data, there were 56,300 new HIV infections per year in the United States from 2003 to 2006 (Hall et al., 2008). An estimated 10% to 15% of these new infections occurred in individuals ages 13–24 (CDC, 2008). Currently, an estimated 19,979 adolescents of the same age group are living with HIV infection (CDC, 2008). The majority of HIV-infected adolescents receive their medical care in a pediatric or adolescent medical setting. These individuals will soon reach an age when transition to adult-centered medical services is expected.

Health care transition (HCT) is defined as the purposeful planned movement of adolescents and young adults with special health care needs from child-centered to adult-centered health care (Blum, Garrell, Hodgman, & Slap, 1993). Adolescents with special health care needs and chronic medical conditions typically transition from the care of their pediatric or adolescent care providers between the ages of 18 and 24 years. Historically, the transition of adolescents with disabilities and special health care needs from child-centered health care to adult-centered health care has been challenging (Blum et al., 1993; Reiss, Gibson, & Walker, 2005; Rosen, Blum, Britto, Sawyer, & Siegal, 2003). Obstacles to transition include poor access to health insurance (Futerman, 2005; Reiss et al., 2005), minimal case management in adult medical practices (Wojciechowski, Hurtig, & Dorn, 2002), and a lack of communication between pediatric and adult providers (Reiss et al., 2005). Additionally, adult providers may be reticent to accept responsibility for the care of these adolescents with multifaceted medical and psychosocial needs (McDonagh, 2005; Peter, Forke, Ginsburg, & Schwarz, 2009; Reiss et al., 2005). Peter et al. (2009) identified additional concerns of adult providers related to a lack of adolescent training, lack of family involvement and difficulty meeting families' expectations, difficulty facing disability and end-of-life issues early in the provider–patient relationship, and financial pressures limiting visit time.

Adolescents with a chronic disease often have concurrent developmental difficulties, psychosocial delays, and concerns about separating from their pediatric providers, which may further complicate the transition process (Rosen et al., 2003). The HCT for HIV-infected adolescents may also be complicated by stigma, discrimination, marginalization, and social isolation that may hinder adolescents from seeking the support of unfamiliar providers (AIDS Education and Training Centers National Resource Center [AETC NRC], 2006; HIV/AIDS Bureau, Health Resources and Services Administration, 1999). In addition, adolescents with HIV may have experienced parental illness and loss that, combined with other psychosocial stressors, can make HCT an even more complex process (Brown, Lourie, & Pao, 2000).

Several professional medical associations, including the Society of Adolescent Medicine, the American Academy of Pediatrics, American Academy of Family Physicians, American College of Physicians, and American Society of Internal Medicine, have addressed the need for evidence-based practice models of transition for young adults with special health care needs (Blum, Hirsch, Kastner, Quint, & Sandler, 2002; Rosen et al., 2003). These position papers call for programs that are family-centered, continuous, comprehensive, coordinated, compassionate, culturally competent, and developmentally appropriate, terms that are now consistently seen throughout the HCT literature.

Before beginning our project, we identified only one study in the United States that analyzed transition from child-centered care to adult care for HIV-infected adolescents (Weiner, Zobel, Battles, & Ryder, 2007). Weiner et al. (2007) described an intervention study with a sample of HIV-infected adolescents enrolled in a National Institutes of Health Clinical Research Program that planned to close within the year. Readiness to transition and level of

anxiety associated with transition were measured in a sample of adolescents before and after an individually designed intervention. A clinic social worker or medical provider delivered the interventions. Interviews were also conducted with transitioning adolescents and family representatives to identify barriers to transition. Commonly reported barriers were identified as follows: (a) the need for a physician, social worker, and pharmacy in the home community; (b) a lack of health insurance; (c) insufficient funds to cover out-of-pocket expenses; and (d) knowledge deficits related to HIV disease and medications. As hypothesized, poor readiness scores were associated with increased anxiety levels. After the individualized intervention, all participants improved their readiness to transition scores and their levels of anxiety decreased. It was suggested that social workers were well suited to address the psychosocial needs, emotional barriers, and resistance to transition, as well as to assist in resource acquisition for this unique population (Weiner et al., 2007).

Recently, two additional publications were identified that focused on the transition of adolescents with HIV disease from child-centered care to adult care. Vijayan, Benin, Wagner, Romano, and Andiman (2008) described the transition experience from the perspective of a group of perinatally infected patients, their parents, and the pediatric providers. Their purposive sample included 18 adolescent patients (ages 12–24 years), 15 of their principal guardians, and nine pediatric health care providers from the Yale Pediatric AIDS Care Program in New Haven, Connecticut. Open-ended interviews were conducted with all participants between November 2005 and April 2006. Data were organized around the challenges of caring for adolescents with HIV and potential barriers to transitioning adolescents to internal medicine-based care. Challenges to care were identified as poor adherence to medication regimens, adolescent sexuality, and disorganized social environments. Potential barriers to transitioning these adolescents included families' negative perceptions of and experiences with stigma of HIV disease, perceived and actual lack of autonomy, and difficulty letting go of relationships that were frequently described as familial. Stigma associated with an HIV diagnosis was identified as a component of adherence to medications, sexuality, disclosure of HIV status, and difficulty trusting a new health care provider. The authors suggested that increased dialogue between pediatric and adult HIV care providers, individualized transition plans for patients and families, and mechanisms to address stigma and autonomy would ultimately improve outcomes after transition to adult care.

A second recent publication described the development of a protocol for transitioning adolescents with HIV infection to adult care (Maturo et al., 2010). The protocol was developed by a multidisciplinary team of adolescent HIV-care providers at a university-based clinic in Miami that traditionally serves low-income and underserved populations. The Specialty Adolescent Clinic (SAC) provides specialty and primary care to patients ages 15 to 25 years who have been diagnosed with HIV disease, both perinatally and behaviorally. The SAC is an Adolescent Trials Network (ATN) clinic and was one of the sites included in our study.

Maturo et al. (2010) described their "Movin' Out" transition model. Their model addressed two primary issues: (a) the number of adolescents currently in care with pediatric or adolescent providers at SAC admitted to adult units when hospitalized, and (b) the high attrition rate for adolescents after they transferred to adult services. The need to develop an original protocol was identified after a search of the literature that revealed no transition models specific to adolescents with HIV infection. The development of this protocol was an iterative process, which now consists of five phases: (a) discussing transition with clients at age 23 who were pre-identified during team meetings, (b) introducing the client at age 24 to the adult infectious disease physician at SAC, (c) making the next 3-month routine clinic appointment with the adult infectious disease physician at SAC, (d) having a SAC social

worker or peer educator accompany the client to the first appointment at the adult clinic with the adult infectious disease physician, and (e) providing a follow-up session at 1 year between the client and SAC psychosocial team. Follow-up revealed certain barriers to transition that continued to exist. Adult providers lack knowledge about public assistance programs for adolescents. The barriers that were more directly related to adolescent clients included transportation, employment, family support, food, and housing.

One explanation for the lack of evidence-based transition models is that the need to prepare and transfer perinatally infected children and adolescents to adult care is a relatively new phenomenon. Before the mid-1990s, when multidrug antiretroviral therapy (ART) emerged as the standard of care, perinatally infected children usually did not survive to adulthood. A retrospective study of 1,142 perinatally infected children born between November 1980 and December 1997 in the Italian Register of HIV Infection in Children and the Italian National AIDS registry calculated risk of death from HIV-related illnesses according to the type of drug therapy received (de Martino et al., 2000). The researchers reported that the adjusted risk of death decreased by 70% in a group receiving triple-drug therapy after 1996 compared with that receiving single-drug therapy before 1996. A recent report from the Antiretroviral Therapy Cohort Collaboration (2008) presented the results of a meta-analysis of 14 cohorts of HIV-infected adolescents in the United States, Canada, and Europe. Considering adolescents who began initial treatment regimens between the years 2003 and 2005, a 20-year-old starting ART could expect to live an additional 43 years.

The need to address this phenomenon was recognized by the Department of Health and Human Services (DHHS). The November 2008 DHHS *Guidelines for the Use of Antiretroviral Agents in HIV-1-Infected Adults and Adolescents* contained the first discussion of transitioning adolescents with HIV to the adult care setting (Panel on Antiretroviral Guidelines for Adults and Adolescents, 2008). The DHHS recommendations to promote successful transition are listed in Table 1.

The paucity of research examining the transition of perinatally infected adolescents combined with increasing numbers of behaviorally infected adolescents magnifies the need to examine the transition process in these populations. Further understanding about how HCT affects both perinatally infected and behaviorally infected adolescents may ultimately allow providers to improve care for this vulnerable population. The aim of this research was to begin a process to ensure that HCT is a purposeful, well planned, and expected experience for adolescents with HIV disease. The purpose of this qualitative study was to describe the characteristics and current practices of the ATN for HIV/AIDS Interventions clinics related to transition of HIV-infected adolescents to adult medical care.

Methods

Participants and Procedure

The ATN for HIV/AIDS Interventions is a multi-center collaborative network funded by the NIH to study the HIV/AIDS epidemic in adolescents. Relevant leadership groups within the ATN and respective site leadership agreed to this research collaboration, and internal review board approval was obtained from the University of South Florida. Site representatives were recruited from eligible ATN clinic sites, and all eligible sites participated. Puerto Rico and Tulane clinic in New Orleans were considered ineligible to participate because of language and transcription problems in the former and severe disruption of services resulting from Hurricane Katrina in the latter. The principal investigator at each site was asked to identify one to three individuals who were considered the most knowledgeable and experienced in their clinic's transition program. This purposeful sample was then contacted for participation in the study.

Measures

A multidisciplinary team of researchers experienced in HIV care developed a 39-item semi-structured interview tool. Questions were designed to elicit information about perceived barriers and facilitators to transition and case reports of successful and failed transition. Demographic and frequency data were collected, and open-ended questions were used to encourage site representatives to elaborate on their views of transitions as well as specifics about their current practices. The interview schedule and instructions for participation were e-mailed to each site representative before the interview. The interviews were conducted between January 2007 and July 2007 by telephone, with each site's representatives interviewed as a group. The average length of 10 of the 14 interviews was 54 minutes (range, 40–64 minutes) and the remaining four interviews lasted 76, 83, 100, and 145 minutes, respectively. These lengthier interviews resulted from additional discussions that were tangentially related to topics of transition. Verbal informed consent for both participation and digital recording of the interviews was obtained. All interviews were conducted by a single member of the research team, and were audio-taped and professionally transcribed. The interviewer was a credentialed HIV-specialty nurse practitioner and PhD candidate. Copies of the transcribed interviews were stored by two members of the research team in an electronic format. Written policies and procedures as well as other documents specifically related to transition were requested for review.

Methods of Analysis

An *a priori* list of content and contextual topics referred to in the interview tool was developed as a preliminary code list. The list included theory or theoretical constructs, decision points, professional disciplines, facilitators, and barriers. A coding matrix was then developed according to the methods described by Miles and Huberman (1994). Data were organized using Microsoft Excel (Redmond, WA) and ATLAS.ti (ATLAS.ti Scientific Software Development GmbH, Berlin, Germany).

The verbatim transcripts were independently analyzed by two members of the research team, using content analysis. Any text passage considered particularly rich or representing ideas, thoughts, and feelings that addressed a previously identified or unique theme was copied and exported to a Word document for later review and consideration. All submitted clinic documents were similarly reviewed and coded. The transcripts and clinic documents were then reviewed and coded by an independent experienced qualitative researcher. Coding discrepancies were discussed among the independent reviewer and the two research team analysts until consensus was reached.

Rigor in the summary and reporting of the interview data was achieved through triangulation of both method and analysts. Triangulation of methods included use of both the interview transcripts and supporting documents supplied by the clinics. Analyst triangulation was accomplished through independent analysis by two members of the research team and analysis by an independent researcher.

Results

Demographics

The 14 ATN sites represented in this study were located in Chicago (2), New York (2), and one each in Boston, Philadelphia, Washington DC, Baltimore, Memphis, Tampa, Ft. Lauderdale, Miami, Los Angeles, and San Francisco. At the time of this study, these 14 clinics managed a total of 1,775 patients ages 13 to 25 years. There were 31–266 patients at each site in this age group.

The clinic populations were described by a variety of demographic variables that were not mutually exclusive. The overlapping demographic variables included adolescents who were perinatally infected; behaviorally infected; of gay, bisexual, transsexual, or heterosexual orientation; and intravenous drug users. None of the ATN clinics exclusively managed perinatally infected adolescents. Five clinics managed patients from infancy to age 25, and eight clinics exclusively managed adolescents from 12 or 13 years to age 25. One clinic managed patients of all ages (infancy to adulthood), with different providers managing specific age groups. The number of patients transitioned to adult care per clinic ranged from four to 16 per year looking retrospectively over the previous 3 to 4 years, depending on data collection practices.

A total of 19 site representatives representing 14 ATN clinic sites were interviewed between March and December 2007. The site representatives included social workers ($n = 7$), nurse practitioners ($n = 7$), physicians ($n = 3$), one registered nurse, and one health educator. Six were males, four were social workers, and two were physicians. In three of the sites, a nurse practitioner and a social worker had collaborated to develop and implement their clinic's transition practice guidelines.

Research Questions

How do ATN health care team members view transition?—All key informants agreed that transition to adult care was an important issue that was increasing in urgency as perinatally-infected adolescents approached the age of 24. Representatives from seven of the clinics concluded that transition to adult care should occur between 22 and 24 years of age. Representatives from five clinics had not established a specific age at which to transition, preferring to individualize the experience on the basis of levels of maturity and responsibility. One clinic preferred to transition patients between 24 and 25 years of age. Interestingly, this clinic representative was a nurse practitioner who worked at both the adolescent and adult clinics. The nurse practitioner cared for transitioning adolescents during their final 2 years in the adolescent clinic and became their provider when they transferred to the adult clinic at age 25. The remaining clinic preferred to transition adolescents to adult care between 20 and 22 years of age. This clinic managed patients of all ages, birth to adulthood, within the same physical site. All sites proposed a multidisciplinary team approach to the process of transition.

Several providers noted that within their clinical settings, there could be different views related to HCT. At one end of the continuum, providers viewed preparing for transition as simply setting up an appointment with an adult provider. Other providers considered transition to be a time to provide education and skill development to promote independent functioning as an adult. This dichotomy of opinions was most apparent when examining those clinics with structured transition programs compared with those without structured programs. The major difference in the two groups was whether transition was viewed as an *event* or a *process*. A participant reported that "... people have different ideas of what transition even means and we probably spent, let's say 2 years, just talking, trying to teach the difference between transfer and transition."

Site representatives who described transition as a *process* reported beginning the discussion of transition when patients were in their mid-to-late teenage years. One representative reported beginning transition discussion as early as age 16 and another reported beginning the discussion on "the first day they enter care at this clinic." These clinics had outlined specific developmental tasks and learning objectives that were to be accomplished during the process of transition.

Alternatively, those sites that viewed transition more as an *event* or simple *transfer* of care began to prepare adolescents during the final one or two clinic visits before transferring to an adult care provider. When queried about the length of their clinic's transition process, key informants from clinics without a formal transition process provided responses such as: "Once we've identified that we are going to transition the patient, it'll be done at their next visit," or "We begin discussing transition at their 24th birthday."

Several key informants described how their views had changed over time as the younger patients matured through their programs. One informant said:

Our method of providing support in the pediatric environment was really protecting them, but yet not teaching them the skills of independence... so we had to address our own interactions with our young people. I am probably admittedly the world's worst because as long as the patient is here in my mind they are still 16 when they are really 24. So really, making sure that we are supporting each other to recognize that they are not our babies anymore and really [trying to] promote that independence. I think that has been one of the issues across the board that we have had to address is how we view our patients.

Another perspective when viewing this population related to the fact that transition to adult care for perinatally infected children was a relatively new phenomenon beginning in the mid-1990s with combination of ART. One key informant explained:

We actually find it to be really exciting because, when you think about it, before, we were working really hard to engage people in care, but we were engaging them with the idea that they were going to die. That's the truth. So for us, transition is, like, such a hopeful thing because the idea behind it is that young people have a future. So we actually find it to be really exciting.

Six of the 14 ATN clinics had written guidelines or written procedures that detailed a transition model. Key informants from these clinics provided a much more comprehensive and expansive view of transition. This group also described a philosophy that incorporated ideas such as beginning the transition process early, individualizing the process, using developmental theory, and a holistic approach that incorporated patients' psychosocial and medical needs.

What do ATN health care team members perceive as facilitators to a successful transition to adult care?—Several interview questions focused on the annual number of adolescents transitioned to adult care and the number of successes or failures of these transitions. Answers to these questions were admitted to be estimates and often incomplete. During the early interviews, it became apparent there was no consistent definition of "successful" transition. One informant asked, "Are you talking about transition as the actual physical transition, going from here to there, or just the process?" After this problem was acknowledged, the informants responded with descriptions of ideal transitions but were unable to accurately report an outcome. Anecdotal comments during the interviews led the authors to conclude that another cause for the lack of outcome data was the absence of tracking mechanisms after transfer from the adolescent site. Only three clinics were able to track patients by appointment schedules or laboratory results through an intra-agency computer network. The remaining clinics relied on informal methods of tracking patients after they transferred out of the adolescent clinics. These informal methods consisted of feedback from the adolescents themselves or through follow-up by a clinic staff member, usually acting in the role of a case manager. Several key informants expressed concerns of Health Insurance Portability and Accountability Act compliance with this informal follow-up.

Characteristics identified as facilitators to a successful transition were listed by the respondents and extracted from their anecdotal reports of successful transitions. These characteristics can be distinctly categorized as intrinsic or extrinsic to the adolescent. The intrinsic characteristics included emotional maturity along with the ability and motivation to function independently. External factors perceived to facilitate a successful transition included a strong social support system, uninterrupted health insurance benefits, available transportation system, and stable housing.

Key informants were asked several questions about preferred adult referral sites. As these questions were answered, a picture of the ideal adult clinic began to emerge. Characteristics of an adult clinic that were reported as desirable and perceived to facilitate successful transition are listed in Table 2.

What do ATN health care team members perceive as barriers to a successful transition to adult care?—The most commonly reported barriers to successful transition to adult care included system issues, such as health insurance, and the inability to track patients after transfer to adult care. Barriers categorized as patient issues included adherence problems, medically complex patients, drug use, and mental health problems. These problems are emphasized in the following statement:

I would say that all of the dually diagnosed – and by dually diagnosed, I mean they had HIV and either substance abuse or serious mental health issues – have been lost to regular care during the transition. I think it is part of their way of avoiding it.

Key informants described several psychological issues that were thought to be barriers to a successful transition, including the difficulty of letting-go of long-standing relationships, stigma, and perceptions that the adult clinic was the “AIDS place.” Site representatives reported that the adolescents’ perceptions and fears of the adult clinics were an important barrier to HCT. Because adult HIV clinics are known in many communities, adolescents worried about the lack of confidentiality and feared being recognized as having HIV. One site representative described how adolescents felt in adult clinic waiting rooms:

One of the scariest things for the kids is that the adult clinics sound scary... The adult patients look so sick and that...you know, [that is] what they’re going to look like some day. And they [the patients] are afraid of that.

One key informant described a constellation of issues that could individually or collectively be a barrier to successful transition:

Doing the chart review is what gave us the view ...[we] did not recognize the importance of, you know, such as issues as abandonment, disenfranchised from society, and things that are talked about...learning disability, amount of education, how they viewed a system or structure. The ones who did not remain in care or did not go to school after eighth grade have very little structure in their lives so here we are expecting them to go into adult care and they do not even know how to have a daily routine so a lot of it was re-looking at where they had come from and the fact that we were going to have to parent them in a way to promote independence... We are helping them do those steps of independence. It has really guided our, now looking back, it has really guided our practice.

Another set of issues that could potentially interrupt the continuity of care for older adolescents were reported, including medical emergencies and hospital admissions. Specific examples mentioned were age restrictions at specific hospitals and scope of practice concerns for pediatric, adolescent, and adult providers. Medical settings mentioned as problematic were children’s hospitals and emergency departments. Concerns were voiced about the inconsistent application of age restrictions among adolescents with congenital

illnesses when compared with adolescents with HIV disease. An informant from a major teaching institution reported:

There isn't a firm age cutoff that's consistent across the hospital. And the kid who is told when she's admitted for PCP at 24, that she can't get admitted here anymore, she's too old, by the resident who admits her, when she's in a bed next to a 40-year-old with cystic fibrosis, it feels to them inconsistent.

Informants reported that during an emergency hospitalization to an adult hospital unit, it was common for a transitioning adolescent or one that had been lost to follow-up during transition to provide the name of a previous pediatric or adolescent provider as their medical contact, not knowing that pediatricians did not have privileges at these adult facilities and could not participate in the care of these adolescents.

What strategies have ATN health care teams developed to assist patients to make a successful transition to adult medical care?—All sites proposed a

multidisciplinary approach to the process of transition. Six of the 14 clinics had written policies and procedures that addressed such things as the age at which transition would be initiated; the ages by which certain behaviors were expected and accomplished; and staff assignments for transition objectives, responsibilities, and activities. The staff members involved in transition most often included a care manager, social worker, health care provider, and a youth advocate or peer partner. Five of the clinics with written policies and procedures credited nurse practitioners, social workers, or a combination of both working together as either the formal or informal transition team leaders.

Two clinics reported using a written test of HIV self-care knowledge that included disease-specific information, transmission, secondary prevention information, and treatment information. Both of these clinics include a follow-up phone call at 3 months after the transfer of care.

Three clinics reported using documentation and charting tools that were specific to transition, including a checklist of knowledge and skills for management of HIV and a transition-specific plan of care. Topics addressed in the knowledge or skills checklist and plan of care are listed in Table 3. Two clinics described the use of a Transition Workbook developed by the Adolescent HIV/AIDS Workgroup (AETC NRC, 2006), which uses a developmental approach to teach and reinforce various life-skills and health information.

A site informant who began to develop her clinic's transition program more than 8 years ago described how the process had evolved.

What we've learned is that we really need to teach them [the adolescents] life skills, responsibility, skills around their medical issues... how to advocate for themselves within an adult care system because they are not going to get the coddling and the enabling [the way] they've had here.... Children and adolescents are treated differently than adults and when they get to an adult facility, it's on them. They will not be called every week to remind them to take their meds, not going to be called for their appointments, so there is a lot that they have to learn and those are the things that we have really learned ourselves in terms of what we need to [do to] prepare these kids to move to adult care... So we've really learned from our mistakes and they've taught us a lot about what we did wrong in the beginning. So learning from them and moving forward we continue to learn.

Six ATN clinics have developed structured transition programs. Some elements were common among the programs such as a mechanism that provided introductions or gradual exposure of the adolescent to the prospective adult provider as well as a tour of potential

adult clinics during the transition process. A case manager or peer educator and a member of the adolescent's family or support group accompanied the patient on these visits, as well as to first appointments. Representatives from four sites commented on the benefits of continued contact between the adolescent and his or her adolescent case manager during the first year after transfer to the adult clinic.

Two sites employed an adult nurse practitioner to manage the care of transitioning patients during the last year or two before transfer to the adult clinic. This adult provider would continue as the adolescent's provider after the transfer to the adult clinic. One site employed a psychiatrist who managed patients at both the adolescent and adult sites.

Are there differences in the transition of a patient who has developmental delays or cognitive limitations (an adolescent who cannot make age-appropriate health decisions); is a member of a sexual minority or is gay; is a member of a gender minority or transgender; is medically complex; becomes pregnant; or has a long-standing therapeutic relationship with the team?—No differences in transition were found for patients who were members of a sexual or gender minority. Attempts were made to identify and match patients to adult clinics that were considered culturally competent as well as gay, lesbian, bisexual, and transgender friendly. Informants from 13 of the 14 sites reported that more attention and time devoted to skill development would be provided to adolescents with developmental or cognitive delays. Informants from 12 of the 14 sites described a difference in planning and more extensive communication between the adolescent provider and adult provider if the patient was considered to be medically complex. Six of the informants specifically mentioned that transition would be delayed during a medical or social crisis and not attempted if the adolescent's prognosis was poor.

It was noted by informants from seven sites that pregnant adolescents seemed to experience an easier transition to adult care. This information was of interest because the explanations for this phenomenon may be instructive in planning transition interventions for other adolescent groups. Pregnant adolescents were frequently referred to OB/GYN providers during the pregnancy. Several respondents hypothesized that women could have an easier transition to adult care because they had interacted with a provider outside the adolescent clinic setting during the pregnancy. A unique feature to this group was that they received Medicaid benefits and other entitlements because of their pregnancies. This would not only increase the number of available adult providers but might also assist with other expenses necessary to stay in care, such as money for transportation, co-pays, and stable housing.

Discussion

Despite the absence of a standard definition of transition, we did find some trends across sites that suggested positive outcomes after transition. Six of the ATN sites had developed formalized approaches to HCT. All of the sites that used a formalized approach reported using collaborative transition teams, a developmental approach, and planned activities to facilitate patient education and skill building. These activities were initiated early and reinforced frequently. Each of these sites reported some type of organized events for the patient and adult provider that served as an introduction to begin a therapeutic relationship before actual transfer to the adult site. There was also considerable agreement in terms of factors that served as facilitators and barriers to transition. Finally, representatives from clinics both with and without established transition programs recognized a continued need to improve practice related to transition.

Our research demonstrates how difficult the process of transition, especially among HIV-infected adolescents, really is. Barriers such as poverty, stigma, and marginalization are deeply rooted in our society and are not unique to individuals with HIV disease. The notion that experienced clinicians and researchers all struggle with this problem suggests that it is one not easily solved. Although objective evidence relating to outcomes after transition was lacking, our study seems to suggest that those site representatives who described their programs as more “successful” were those with the most experience in designing and implementing a transition program, those that used a developmental approach, and those that included an iterative process of evaluation and revision to produce individualized patient transition plans.

Strengths and Limitations

The strengths of our study include a high rate of voluntary participation from the clinics, which included representatives from several professional disciplines. The clinics were geographically diverse and cared for adolescents from all subpopulations living with HIV. As previously noted, the clinics had all successfully competed for National Institutes of Health funding in this area and were likely representative of the most experienced academic programs in the United States.

Limitations to the study include the lack of site anonymity so it may have been difficult to be candid regarding less-than-ideal practices. There was also the possibility of interviewer bias, selection bias, and social desirability bias.

Suggestion for Future Research

When the criteria for successful transition have been defined and the ability to accurately measure these criteria is established, it will be important to determine predictors of success. Future studies could include young adults who had recently transitioned or were currently in the process of transition. Additional factors that positively or negatively affect the transition experience could be identified. These potentially important phenomena could then be explored systematically in future intervention studies. From these and other data, clinical care-based delivery systems could be designed, implemented, and evaluated, and an evidence base could be established to address the transition needs of this unique population.

Clinical Considerations

- Providers who care for adult patients with HIV disease may need additional training in the requisite set of knowledge and skills required to successfully manage adolescents and young adults with HIV disease.
- Adolescent providers, adult providers, and patients and their families/social units are invested in the success of transition programs. These stakeholders must collaborate to determine the basic components of transition programs.
- Transition programs need acceptable and measurable criteria to assess transition successes and failures.
- Nurses have communication, patient education, health promotion, and patient advocacy skills that can be used to contribute to all phases of transition programs.

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Table 1**Department of Health and Human Services Recommendations to Promote Successful Transition**

Optimizing provider communication between adolescent and adult clinics
Addressing patient/family resistance caused by knowledge deficits, stigma, or disclosure concerns, and differences in practice styles
Preparing youth for life-skills development, including counseling them on the appropriate use of a primary care provider, appointment management, the importance of prompt symptom recognition and reporting, and of the importance of self-efficacy with medication management, insurance, and entitlements
Identifying an optimal clinic model for a given setting (i.e., simultaneous transition of mental health and/or case management vs. a gradual phase-in)
Implementing ongoing evaluation to measure the success of a selected model
Engaging in regular multidisciplinary case conferences between adult and adolescent care providers
Implementing interventions that may be associated with improved outcomes, such as support groups and mental health consultation
Incorporating a family planning component into clinical care

SOURCE: Panel on Antiretroviral Guidelines for Adults and Adolescents. (2008). *Guidelines for the use of antiretroviral agents in HIV-1-infected adults and adolescents*, p. 75. Retrieved from <http://www.aidsinfo.nih.gov/Guidelines/GuidelineDetail.aspx?MenuItem=Guidelines&Search=Off&GuidelineID=7&ClassID=1>

Table 2

Desirable Characteristics for an Adult Clinic

A single contact person assists the adolescent in transition
The new provider is introduced to the adolescent as the preparation and process of transition begins
Comprehensive services are provided that include primary care, dental care, and on-site pharmacy services
Psychosocial services such as case management, mental health, and support groups are provided
The staff is culturally competent and lesbian, gay, bisexual, and transgender friendly
Follow-up is provided by a case manager from the pediatric clinic
Adult providers deliver age- and developmentally-appropriate care for the adolescent
Communication occurs between adolescent and adult providers during the transition process

Table 3**Knowledge/Skills Checklist and Plan for Transition to Adult Care Topics**

Knowledge and Skills Required for Self-Care
Knowledge of health condition
Medication management
Preventive health behaviors
Responsible sexual activity and family planning
Community resources
Education vocation and career plans
Family support
Housing or goals for independent living
Transportation
Funding sources