Transition to Adult Services among Behaviorally Infected Adolescents with HIV—A Qualitative Study

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Objectives The present study aimed to describe the experiences of youth with behaviorally acquired HIV who transitioned to adult care, to identify difficulties encountered, and to explore areas for improvement.

Methods Semi-structured interviews were conducted with 10 young adults ranging from 24 to 29 years old. Themes were derived from coding participant interviews.

Results Participants experienced adolescent care providers as an important source of support, felt anxiety about transition, provided recommendations for improving the process, and described significant changes associated with adult HIV care.

Conclusions Findings support the development of a clear and structured transition process to address patients’ fears and worries through early communication, planning, and coordination for adult healthcare, highlighting the need for future research in this area.

Key words adolescence; HIV; transition; qualitative.

With the increasing number of new HIV infections each year among adolescents (CDC, 2008), more individuals than ever will transition from adolescent to adult HIV services. However, there is little consensus as to what HIV transition services are needed or how best to evaluate outcomes (Gilliam, Ellen, Leonard, Kinsman, & Straub, 2008). The growing literature on transition to adult services among youth with disabilities and chronic illnesses has only recently begun to examine issues related to transition among youth with HIV, despite its uniqueness as a chronic illness (Donnenberg & Pao, 2005). Transition requires managing and adjusting to significant changes in the organization of care, family involvement in care, and patient–physician communication (Reiss, Gibson, & Walker, 2005; Soanes & Timmons, 2004). Population-based studies indicate that a large proportion of parents of youth between 13 and 17 years of age with special health-care needs are not prepared for these changes (Lotstein, McPherson, Strickland, & Newacheck, 2005; Scal & Ireland, 2005). A recent Society for Adolescent Medicine (2003) position paper on transition highlights the importance of developmentally appropriate care. In addition, some researchers advocate that disease-specific transition guidelines will improve transition care (Weissberg-Benchell, Wolpert, & Anderson, 2007), and there is evidence that transition programs lead to improved disease control and patient satisfaction (Bolton-Maggs, 2007).

Prior research on transition among youth with HIV has addressed transition needs only among perinatally infected youth with HIV, who acquired HIV at birth from a parent (Miles, Edwards, & Clapson, 2004; Wiener, Zobel, Battles, & Ryder, 2007). Miles and colleagues (2004) reported unique concerns among transitioning youth with HIV in the United Kingdom, including fear of attending a clinic with adults infected through injection drug use or adults with secondary illnesses. In the United States, Wiener and colleagues (2007) studied...
51 parents and largely perinatally infected children and adolescents who were transitioning to care outside a clinical research setting. After participating in a transition intervention, parental and child anxiety decreased, and transition readiness improved. Although there were positive changes in physician and social-work linkages, and disease/medication knowledge, smaller changes were made in reducing barriers related to health insurance, funds for out-of-pocket expenses, confidence in the new physician, and pharmacy availability. While these studies begin to address transition in youth with perinatal infection, youth with “behaviorally acquired” HIV, or HIV transmitted primarily through risky sexual behavior, may have unique characteristics (e.g., acquired primarily through teen’s own risky behaviors; primarily affects ethnic minorities; carries stigma within the larger community; threat of infection to others) that impact transition.

Studies of HIV-positive behaviorally infected youth have identified some potentially important characteristics that might affect transition. For example, REACH (Reaching for Excellence in Adolescent Care and Health), a multisite observational study of adolescents with behaviorally acquired HIV, has provided representative sociodemographic and behavioral data on a large cohort of teens (Wilson et al., 2000). HIV-positive teens in the REACH cohort were predominantly female, largely from racial/ethnic minority groups, and had acquired HIV primarily through risky sexual behavior. A quarter of the youth had been homeless at some point, a quarter had spent at least two nights in a detention facility, and almost half of the female participants had children of their own or were pregnant at the time of the study. More recently, Radcliffe and others (2007) have provided evidence that youth with behaviorally acquired HIV experience disproportionately frequent abuse and traumatic event histories, including family and personal violence, neglect, and sexual abuse. Lastly, at least one study has found that one-third of youth with behaviorally acquired HIV did not disclose their status to their mother, or closest mother figure, and rates are thought to be lower for paternal figures (Stanford et al., 2003). Youth who choose not to disclose their status may navigate the transition to adult HIV care without the support and guidance of family.

This study is the first to our knowledge that has attempted to study the transition experience for behaviorally infected youth with HIV. The purpose of the study was to better describe the experiences of behaviorally infected youth with regard to their perception of adolescent HIV care, the transition process, and their experience of adult HIV care, as well as their recommendations for improving the transition experience for other youth with HIV. This information will help to develop hypotheses and test HIV-specific intervention strategies for clinical practice.

Methods
Participants and Study Design

Permission to conduct this study was granted by the Human Subjects Committee of the Institutional Review Board. Study inclusion criteria were: (1) older than 18 years of age, (2) previously treated at the adolescent clinic for at least 1 year, within the prior 5 years, (3) now receiving HIV care by an adult health-care provider, and (4) available by telephone. Exclusion criteria were: (1) perinatal HIV and (2) cognitive or health difficulties that would have limited study participation (although no participants were subsequently excluded for cognitive or health difficulties). Eligible participants were contacted by the lead case manager of the adolescent clinic by phone. If they were interested in considering study participation, they provided phone numbers so the first or second author (who had not provided any of their past care) could schedule a time to obtain informed consent and conduct the interview. Of the 19 eligible patients, 6 could not be reached by phone, 2 did not keep scheduled visits, and 1 declined participation due to ongoing life stressors. The 9 non-participants were 66.7% female. Participants included 10 behaviorally infected HIV-positive adults, ranging in age from 24.50 to 29.33 years old (M = 26.69, SD = 2.17); seven were female. Seven participants identified as African American, two Caucasian, and one Biracial. Seven participants identified as heterosexual and three as homosexual. The age at diagnosis ranged from 14.92 years to 21.50 years (M = 17.19, SD = 2.00). Time since transition to adult care ranged from 2 months to 5 years (M = 1.46, SD = 1.83). The age at transition ranged from 24.00 to 27.67 years (M = 25.21, SD = 1.38). The length of time treated by adolescent care providers ranged from 2.67 years to 11.33 years (M = 7.96, SD = 2.52). All participants had previously been treated at the same HIV clinic in a northeastern pediatric hospital with interdisciplinary primary and HIV specialty care for adolescents. A team of physicians, nurse practitioners, nurses, social workers, and mental health professionals provided comprehensive care for HIV-positive youth, including individualized transition preparation. At the time of their interview for this study, all participants had attended at least one visit with an adult HIV provider across multiple adult settings in the city and region. Adult care settings included hospital-based and
community practice-based settings, with care from nurse practitioners and HIV physician specialists.

Interviews (by first and second authors, predoctoral students in clinical psychology), were conducted in a private room at an outpatient hospital clinic away from patient exam rooms, and were, on average, 60 min in length. Interview questions were derived from discussions with pediatric team members and modeled after findings published by Miles et al. (2004). Questions were open-ended to avoid bias and permit participants to describe experiences from their own perspective. The interview protocol included the following semi-structured questions: (1) How does your adult HIV care experience compare to your previous pediatric experience? (2) What helped you during your transition? (3) What are some things that made it harder to transition from pediatric to adult HIV care? (4) What changes would you like to see in place in order to create the ideal transition experience for other young adults with HIV? Additional follow-up questions were added to clarify participants’ specific experiences.

All interviews were tape-recorded and transcribed to ensure accuracy. Field notes indicated the location, length, and behavioral observations. Following each study interview, participants received $20 as compensation for their time.

Data Analysis

Data were systematically analyzed using Atlas.ti software according to the principles of thematic analysis (Braun & Clarke, 2006). The first phase of data analysis involved reviewing transcripts. The first and second authors coded the transcripts and field notes independently for emerging concepts and themes that fit with the research questions and participant responses. Emerging themes in each interview were checked iteratively against all other interviews and examined for overall trends, patterns, clusters, relationships, exceptions, and alternative explanations (Maxwell, 1996). No additional coders were trained; the first and second author coded all data using a standard definition for each theme derived from the data. Disagreements in coding were resolved collaboratively and resulted in adjustments made to the theme definitions, until both coders agreed on all codes through an iterative process. After data analysis was completed, a subsample of participants attended a member-checking event, held in a conference room at the hospital, which gave them an opportunity to amend or expand on the themes derived from the interviews. All participants were invited to attend the event through telephone calls and mailed invitations. Although a majority of the participants indicated that they would attend this event, only 3 participants actually attended (M age = 24.58, SD = 0.14; 2 males, 1 female). All indicated strong agreement with the themes and sub-themes presented.

Results

Findings are organized by phase of experience: adolescent care, transition, and adult care. Six broad themes emerged, two in each phase. For adolescent care, the major themes were “providers as family” and “adolescent care as a time of disease-related learning and growth.” The broad themes of transition were “a time of multiple challenges to navigate” and “recommendations for improving the transition process.” In adult care, the two major themes were “a significant change in the experience of care” and “opportunities for personal growth.” Several sub-themes emerged within these broad themes.

Adolescent Care

When asked to compare their adolescent and current care, every participant chose to characterize their relationship with adolescent care providers, and almost all indicated a strong connection with the adolescent care team (n = 8). For example, 7 participants specifically used the terms “family” and/or “love” to describe the relationship. One participant explained, “It felt more like a family then. I went to jail for a while and my social worker came to see me. So, it was more than just that they were my doctors.” Strong feelings were particularly evident among participants who reported having disclosed their status to few of their family and friends (n = 4). Several participants indicated that they developed “trust” or “faith” in adolescent team members over time; 1 participant said that she shared things with these doctors that she “wouldn’t tell other doctors.” In addition, participants reported that they continued to communicate with adolescent team members about disease-related concerns as well as life events and stressors (n = 5). For example, 1 participant said, “Still to this day, if I don’t understand something or if something is confusing, I can call and ask her (adolescent provider) and if she don’t know the answer she will find out the answer and call me. So, I left the clinic but I didn’t leave them.”

The second most common description of adolescent care was as a time of “learning and growth” (n = 7). Individuals emphasized that they learned about their disease and how to both care for themselves and cope with their diagnosis. For example, 1 participant said, “They helped me to realize that it’s not going to go away
of the clinic that say “infectious disease”); still others wanted to attend a clinic providing childcare or care to both mothers and children with HIV. In addition to preferences for different kinds of health-care settings, participants indicated that options for care providers were important. One participant tried three different adult care providers before settling on her current care setting; her first provider “never talked directly to (her)” and spoke in “medical jargon” that she did not understand. Another participant reported difficulty reaching his new provider; “there was always some kind of conflict where I couldn’t get in contact with the doctor and I wasn’t satisfied.” Finally, all participants recommended that patients receive assistance coordinating the transition process (n = 10). This included help enrolling in mental health support and case management, and assistance with the transfer of information between providers. For example, when counseling services were not offered as part of adult care, 2 participants reported that they discontinued those services. Another participant reported that transition was improved by having her adolescent and adult care providers know one another; “the fact that they knew each other was helpful. Basically, if they needed medical information and I wasn’t sure offhand, it wasn’t that hard for my doctors to get it. My adolescent care nurse pretty much filled her in with everything about me. That helped a lot because I didn’t have to re-discuss my whole life story.” Similarly, 1 participant shared that retelling “her story” was one of the most difficult parts of transition: “Telling how it happened. I don’t know how, when or where, I got it. It is here now and there is nothing that I can do about it (rolls eyes). (I) had to go through the whole scenario all over again!” However, it is important to note that 1 participant highlighted the importance of boundaries in the communication between adolescent and adult providers. She said, “I tried to separate my two lives: my child life from going to be an adult in an adult hospital. They have my medical record. They know everything about me. That helped a lot. That’s one thing. But, as I get older, I don’t need (my adult doctor) to discuss anything (personal) that is going on with me with my adolescent doctors…”

**Adult Care**

In general, descriptions of adult care centered on differences in both the health-care setting and the health-care system. Young adults described increased concerns related to dealing more independently with insurance requirements, longer waits, and/or less time with providers (n = 6). One participant said, “Now you gotta worry about referrals; you gotta worry about co-pays” and another noted that her insurance referral system was
a barrier. She said she had been “delaying (her) doctor’s appointment because they want (her) to see one doctor, in order to see (her) own doctor.” Two participants disliked that their adult care clinics displayed indications of infectious disease care. One said, “I’m still dealing with this myself, let alone announcing it to the world,” and another felt uneasy because she could not take her daughter, who was not aware of her status, to the doctor with her. In addition, 4 participants observed that other patients were generally older and varied in disease severity. This impacted participants in different ways: 2 participants clearly expressed that it was a “scary” experience because “you are actually going to see what might happen to you.” However, another participant felt that seeing “older people” made her “realize that you can fight this and you can beat this.” In addition to these changes in the health-care setting, a number of participants also noted that care was “fragmented” in comparison to their previous experience in adolescent care (n = 3). In fact, 1 participant described adult care as “everything sort of broken up so you have to go to different places to get things.” Another remarked that they now “have to make separate appointments for everything.” As noted previously, counseling services were discontinued for 2 participants upon entering adult care. In contrast, there was 1 participant who attended an adult community practice center where she was able to see multiple providers including a nutritionist, psychiatrist, and social worker in the same setting as her primary and HIV comprehensive care. She was very satisfied with her care, and reported benefiting from the additional services available at her place of care, including a therapy group with other patients.

Participants also experienced adult care as marking a change in provider expectations and interactions. Many felt that they were expected to be more responsible with making their appointments, arriving on time, and making medical decisions, as compared to adolescent care (n = 7). One participant remarked that, “(In adolescent care) they were kind of all ‘I’ll do everything for you’. It was a shock when (in adult care) they say, ‘Here is the number, do it yourself.’” Adult care providers spoke more bluntly (“no nonsense”) about their disease, lifestyle, and treatment (n = 5). They were described as less paternal and less flexible. One participant’s adult provider told her that her children would be alone if she got sick or died; she stated, “I guess I needed that more harsh reality more than I needed to be babied.” One of the positive aspects of this change in expectations was described in the following way, “Basically they are pushing me, but they are letting me take the steps. It’s helping me see that I’m helping myself and it is not only them helping me.” Another participant called this change “a little boost of confidence” because it made her think, “Okay, I’m an adult now. I can do this!”

Of note, participants who were particularly satisfied with adult HIV care focused on the positive relationship that they had developed with their adult providers (n = 4). For example, 1 participant said of her adult provider, “He makes me feel good when he takes my blood work and it’s really low and my counts are good. He makes me feel proud about having them low… That’s really special to me.” Another said, “They don’t let other people’s business out so I can trust them… She will call and make sure that I am ok if she hasn’t heard from me. They make me feel wanted. Like they want to see me come back… They made me feel welcome.” Likewise, participants who were dissatisfied with the provider-patient relationship often transferred to another adult care provider or mentioned considering transferring care in the future (n = 5). One participant who mentioned that she was “thinking about changing (her) doctor” indicated that she felt her doctor “works more with people who actually have AIDS.” She said that her doctor spends more time with patients who are more ill, but treats her like she is “just going to be in and out.”

Lastly, many of those interviewed felt that as adults, they were making healthier choices (n = 6) and/or had a more positive attitude about their health than when they were younger (n = 7). Each had a different motivation for these changes; 1 participant said that she takes better care of herself now because of her daughter, while another reported that being “sick” helped him understand the importance of his medications. Two participants mentioned no longer abusing substances, and at least 1 participant felt her regimen adherence had improved. Overall, participants felt that both adolescent and adult care were helpful preparation for managing their HIV. In addition, a few participants spontaneously spoke of their wish to “give back” to others (n = 4), such as by encouraging safe-sex practices among peers, volunteering to tell their story to others, and participating in research.

**Discussion**

This study, the first to examine transition among behaviorally infected youth with HIV, identified distinct themes in the experience of adolescent care, adult care, and the transition process, as well as important recommendations for improving transition in this population. Participants described adolescent care as a place where they grew in their acceptance of their status, knowledge about HIV, and
how to care for themselves, consistent with literature on the importance of adolescent care targeting coping and illness management skills to promote transition (Wiener et al., 2007). In contrast, participants described adult care as a period where they developed skills for increased independence (i.e., making healthier choices, taking a more positive attitude, and giving back in their community or previous clinics).

Consistent with earlier research, the young adults in this study had strong attachments to adolescent healthcare providers. Our findings suggest that this relationship is very important during the initial transition process, to help youth “test the waters” with adult providers and not to give up on finding helpful care if transition does not go smoothly at the first adult care setting attended. Other themes consistent with the transition literature were youths’ worries and anxiety around transition; need for significant preparation time; and adjustment to increased provider expectations and demands in an adult care setting (Miles et al., 2004; Wiener, 2007). However, despite prior literature indicating that the transition process involves decreasing family involvement in care (Reiss et al., 2003), this theme was absent in the present study. This may be due to limited disclosure of status to family members, and possibly reflects the fact that families are less involved in healthcare for youth with behaviorally acquired HIV. Since this finding is unique within the transition literature, further research is needed to examine the role of limited family support and involvement in care and transition planning for this population. Furthermore, some participants in this study reported difficulty in retelling their medical history to new providers. The reasons for this may be unique to this population (i.e., trauma associated with the HIV infection and diagnosis) and should be assessed prior to transition (Radcliffe et al., 2007). These challenges highlight the likely benefit of care systems where the adolescent and adult care systems are more integrated and allow for youth to develop relationships with adult providers before a formal transition occurs (Scal, Evans, Blozis, Okinow, & Blum, 1999).

There is considerable evidence in the literature that transition planning is absent in most settings (Hauser & Dorn, 1999; Scal & Ireland, 2005). Participants in this study recommend a clearer transition process, with collaborative planning among youth and health-care teams, more time to prepare for transition, more options for individualized services, and more help coordinating and linking services, especially since adult services were described as fragmented and difficult to access. Mental health services were especially challenging to arrange. However, these services are particularly important, given that youth with HIV show higher rates of psychiatric disorders and posttraumatic stress (Mellins, Brackis-Cott, Dolezal, & Abrams, 2006; Radcliffe et al., 2007).

Following study completion, results were presented to the members of the treating adolescent HIV clinic team, who subsequently adjusted their practices around transition. There is now a clearly defined age of transition (24); and transition is discussed with all patients at multiple time points during their care (yearly from the ages of 14–21; at each clinic visit after the age of 21). In addition, team conferences address transition plans for each patient, clarifying roles of involved team members in the process, and collaborative planning with patients. This allows for an ongoing evaluation of needs, consultation around patients’ anxiety surrounding transition, and a consistent message from team members. Patients are given the opportunity to visit multiple adult care settings accompanied by a team social worker before choosing a setting. All patients are linked with adult HIV case managers, and patients receiving adolescent mental health services are linked to community providers prior to their transition. In addition to these clinic-specific changes, the staff has also developed relationships with adult HIV providers to discuss the needs of youth transitioning into adult care settings and the expectations of the adult clinics.

While qualitative interviews provided the present study with rich data about the transition experience of an understudied population, it should be noted that this study is limited by the use of a small, predominantly female, convenience sample and its retrospective nature. In addition, the young adults in the present study had successfully transitioned to adult care from a specialty pediatric clinic in an urban setting. Therefore, these findings may not be applicable to those who do not transition to adult care. Youth who fail to transition to adult HIV care may be more vulnerable than our current sample in terms of financial status, homelessness, health status, or their relationship to providers. Larger studies with multiple sites will allow future researchers to more fully describe transition experiences among youth with HIV in an effort to determine optimal practices for programs serving HIV-infected youth. In addition, longitudinal research on the transition process will illustrate the continuum of adjustment to living with HIV and inform efforts to prepare youth for successful transition to adult HIV care.

Conflict of interest: None declared.

Received January 12, 2009; revisions received May 15, 2009; accepted May 18, 2009
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