Published in final edited form as:

AIDS Care. 2009 October ; 21(10): 1222–1229. doi:10.1080/09540120902730054.

We Never Thought This Would Happen: Transitioning Care of Adolescents with Perinatally-Acquired HIV Infection from Pediatrics to Internal Medicine

Tara Vijayan, MD, Andrea L. Benin, MD, Krystn Wagner, MD, PhD, Sostena Romano, APRN, and Warren A. Andiman, MD

From the Doris Duke Clinical Research Fellowship (TV), Department of Pediatrics and Yale New Haven Children's Hospital Pediatric AIDS Care Program (ALB, SR, WAA), Nathan Smith HIV Clinic at Yale New Haven Hospital (KW), Yale University School of Medicine; University of California-San Francisco (TV)

Abstract

Purpose—Transitioning the medical care of children with perinatally-acquired HIV from pediatric care to internal medicine practices has become increasingly important as newer therapies prolong survival. The study aims to describe challenges to caring for these adolescents and the potential barriers to transitioning them to internal medicine-based care.

Methods—Qualitative study in which data were gathered from open-ended interviews conducted from November 2005–April 2006 with 18 adolescents with HIV, 15 of their principal guardians, and 9 pediatric health care providers from the Yale Pediatric AIDS Care Program, New Haven, Connecticut.

Results—Issues of stigma played a prominent role in both the challenges to care and barriers to transitioning care. Challenges to care were: (1) poor adherence to medication regimens; (2) adolescent sexuality; and (3) disorganized social environments. Potential barriers to transitioning care were: (1) families' negative perceptions of and experiences with stigma of HIV disease--which undermined the desire to meet new providers; (2) perceived and actual lack of autonomy-- pediatric providers feared that staff in adult clinics would demand a level of independence that adolescents did not have; and (3) difficulty letting-go of relationships-- adolescents, guardians, and providers described a familial relationship and expressed anxiety about terminating their relationships.

Conclusion—Understanding these challenges and barriers can inform both pediatric and adult HIV care providers and enable them to create successful transition programs, with the goal of improving retention and follow-up to care.

Keywords

transition; adolescents; special health care needs; HIV/AIDS

Corresponding Author: Tara Vijayan, 1438 Oxford Street, Berkeley, CA 94709, Email: tara.vijayan@ucsf.edu, Fax: 203-785-3461, Phone: 201-838-2523.

The manuscript is being submitted only to *AIDS Care*; it has not been published elsewhere. It was presented in abstract form at the 2006 National Meeting of The Doris Duke Clinical Research Fellowship program in Bridgewater, NJ.

INTRODUCTION

Transitioning children with chronic diseases to adult-oriented healthcare systems has become increasingly important as newer therapies prolong survival into adulthood (American Academy of Pediatrics, American Academy of Family Physicians, & American College of Physicians-American Society of Internal Medicine, 2002; Rosen, Blum, Britto, Sawyer, & Siegel, 2003). In particular, the introduction of highly active anti-retroviral therapy has dramatically improved survival in children with perinatally-acquired HIV infection. Over 9000 children <13 years old live with HIV and/or AIDS in the United States (Centers for Disease Control and Prevention, 2006); and while prior studies of transitioning the care of children with chronic illness have focused on diseases such as cystic fibrosis and congenital heart disease, few have specifically focused on HIV (Anderson, Flume, Hardy, & Gray, 2002; Boyle, Farukhi, & Nosky, 2001; Fielden et al., 2006; Lotstein, McPherson, Strickland, & Newacheck, 2005; Miles, Edwards, & Clapson, 2004; Nasr, Campbell, & Howatt, 1992; Reid et al., 2004; Reiss, Gibson, & Walker, 2005; Scal & Ireland, 2005; U.S. Department of Health and Human Services, Health Resources and Services Administration, & Maternal and Child Health Bureau, 2001, 2004; Wojciechowski, Hurtig, & Dorn, 2002). Adolescents with perinatally-acquired HIV have unique characteristics that may complicate their transition into adult-oriented care settings (Battles & Wiener, 2002; Fielden et al., 2006; Gaughan et al., 2004; Grubman et al., 1995; Miles et al., 2004). We aimed to describe the challenges to caring for adolescents with perinatally-acquired HIV infection and the barriers to transitioning them to adult-oriented healthcare settings.

METHODS

Study design and sample

We used qualitative methods to conduct and to analyze individual, open-ended interviews of adolescents/young adults (ages 12–24 years), their parents and the pediatric providers at the Yale-New Haven Children's Hospital Pediatric AIDS Care Clinic between November 2005–April 2006. The clinic provides comprehensive, multidisciplinary health care services to children and adolescents who have HIV/AIDS.

We sampled using the qualitative technique of purposeful sampling, which is intended to select information-rich cases (Britten, 1995; Mays & Pope, 1995; Pope & Mays, 1995). Adolescents who came to the clinic during the study period and met the following criteria were eligible: 1) had vertically-transmitted HIV; 2) did not have a clinical diagnosis of substantial cognitive limitation; and 3) were 12 – 24 years old.

Data Collection

Interviews lasted 30–60 minutes, were conducted by a single investigator not affiliated with the clinic (TV), and were performed using open-ended questions and probes. Interview questions and probes were designed to elicit feelings and ideas related to transition-of-care and the course of questioning for each participant was guided by their responses. As is typical for qualitative research, the questions asked were modified as the study evolved and as themes, important relationships, and directions emerged from the ongoing analysis. The interviews were audio-taped and were transcribed by an independent transcriptionist.

We collected supplementary information from the adolescents using a confidential written questionnaire regarding history of sexual activity and drug use as well as a health literacy test, Rapid Estimate of Adult Literacy in Medicine (T. Davis, Crouch, & Long, 1998; T. C. Davis et al., 1993), which calculates a grade-equivalent. We used performance on the REALM as a proxy to suggest the level of each participant's potential self-efficacy and autonomy with regard

to healthcare. We chose to use the REALM in this way because if an adolescent is capable of reading at a high school grade-level, they will be able to read most patient-related educational materials and some authors have speculated that improving health literacy is a means to improve patient self-management (Levin-Zamir & Peterburg, 2001). These questionnaires were completed just after the open-ended interview was completed. For adolescents who had difficulty reading the questions on the survey, the interviewer read the questions aloud for them.

Data Analysis

We analyzed transcripts of interviews using common coding techniques and the constant comparative method of qualitative analysis (Glaser & Strauss, 1967). For this analysis, qualitative concepts were generated by the data of the interviews (Strauss & Corbin, 1998): 3 independent coders, ¹ read transcripts line-by-line, abstracted key ideas and themes, and organized the key ideas into a coding structure in an iterative fashion. Interviews were analyzed shortly after they were performed, and the coders came to consensus regarding the process and structure of the coding schema. All authors reviewed and agreed on the final coding schema. Data were organized using Microsoft Excel and HyperResearch software (2003 ResearchWare, Inc). Interviews were performed until thematic saturation was reached and no new information was being elicited from successive interviews. To confirm that we had reached saturation, we conducted additional interviews (with 2 adolescents, 3 guardians and 5 providers).

Human Subjects

For participants ≥ 18 years old, we obtained informed consent. For participants < 18 years old, we obtained consent from their guardians and assent from the adolescents. For adolescents who did not know their HIV diagnosis, we did not disclose it during the assent or interview processes. Participants received \$20 gift certificates. The study was approved by the Yale School of Medicine Human Investigation Committee.

RESULTS

We interviewed 42 participants: 18 adolescents ages 12–24 years, 15 guardians (12 adoptive parents), and 9 pediatric providers (5 attendings, 1 fellow, 1 nurse practitioner, 1 social worker and 1 research nurse) (Table 1). Among the adolescent participants, six were ≥ 18 years old. Three of the 18 adolescents did not know their diagnosis; they were 12, 13 and 15 years old respectively.

We identified themes in two major categories: (1) challenges to caring for adolescents with HIV infection (2) potential barriers to transitioning adolescents with HIV infection to adult medicine practices. Three subcategories of themes emerged in each of these categories (Table 2).

1. Challenges to Caring for Adolescents with HIV

Parents and pediatric providers described three subcategories of challenges to caring for adolescents: difficulties with adhering to medication regimens, with managing adolescent sexuality, and with negotiating disorganized social environments (Table 2). Underscoring each of these challenges was the theme of perceived stigma associated with having HIV. Specifically, fear of disclosure of HIV infection often prevented adolescents from taking their

¹The 3 independent coders were a Doris Duke Clinical Research Fellow, a pediatric infectious disease fellow and the medical director of the adult HIV clinic (TV, ALB, KW). The remaining two researchers (SR and WAA) were a nurse practitioner and attending physician at the Pediatric AIDS Care Clinic, respectively.

medication when they were with their peers, and from telling their sexual partners about their infection. Even providers experienced stigma:

This stigma was hard. I learned very quickly not to tell people what I did for a living. It used to stop conversations right in their tracks. People would not know what to say, I think, at church or at a party I used to tell people I did pediatric care and they'd go, "oh, isn't that sweet." But if I said HIV, that was the end of the conversation so I learned very much to keep it to myself.

1a. Challenges: Difficulty with Adherence to Medication Regimen—Adolescents, parents, and pediatric providers described poor adherence to antiretroviral therapy as one of the major challenges to care. Most adolescents either depended on their parents to help them take their medications or simply would not take them at all, especially when feeling well. As one patient said,

I was feeling fine so...why am I taking medicine? I feel... physically fine but...I don't really know what's going on inside of me. I can't see that. So that's what really was like a mental thing for me. (20 year old)

Adolescents also stated that the act of taking medication was a negative reminder of their disease state. As one said, "I don't like taking medicine because every time I take it, it makes me, it goes back to, oh you're taking the medicine because you've got this." (21 year old). Moreover, they reported that a significant reason for missing doses was discomfort about taking medicine when they were with their peers. As one young woman stated:

I don't really like taking [my medicine]... when I'm at my friends' houses, I can't really sleep there... I have all that medicine that I have to take, and they would ask me questions and I can't really tell them because it's none of their business. (16 year old)

Adolescents demonstrated variable knowledge about their medication regimens; while some could vividly describe the shape and color of pills, only 5 out of 18 adolescents could articulate the names of their medications.

1b. Challenges: Difficulty with Adolescent Sexuality—Adolescents acknowledged the difficulty of having intimate relationships and of disclosing their illness to their partners. On the written questionnaire, 12 adolescents confirmed that there was some pressure to have sex. Four reported having had sexual intercourse, and of those, none had disclosed their status to their last partner. One participant described her feelings around sex and dating:

I've had a lot of people... I was dating but just maybe 3 of them knew [about my status] out of all those people... those are the ones that I felt, kind of felt safe with. (21 year old)

Providers expressed concerns both about the lack of resources for sexual health care in the pediatric-oriented clinic (specifically gynecologic care) as well as about the issue of partner notification.

1c. Challenges: Disorganized Social Environments—Many of these adolescents have lived in disorganized environments. Twelve of 15 parents were adoptive parents; many children were taken away from their biological parents at a young age. As one provider recalled:

A few of the kids not only have HIV but they have a lot of damage from mothers drug use. This one...mother was extremely depressed and [her daughter] didn't get fed, and she had no meds, [and] she was sick the whole first year [of life]. She was so underweight that we removed her to a foster care where she thrived.

A few adolescents had witnessed the death of family members due to HIV, while others had witnessed drug abuse and incarceration. Providers also explained that living in such environments significantly affected many adolescents' emotional and psychological well-being, their perception of their HIV disease, and their adherence to their medication regimen. Children were prevented from benefiting from supportive social networks in part because their social environment was disrupted and in part because of the stigma conveyed by their disease and the subsequent social isolation.

Nobody wanted to touch him with a 10 foot pole...I will never forget the day I brought my nephew home and I was like a little proud mother...I took him over and showed him over to my mother and father... My niece came and picked him up...[and] my father...saw this baby in her arms and he yelled, "Put that baby down and get in there and wash your hands!" So, you know, I packed him up and took him home. It was... three years or longer before anybody would speak to me... (Adoptive parent of 13 year-old boy)

2. Barriers to transitioning adolescents to adult-oriented health care systems

Three subcategories of barriers to transitioning to adult-oriented health care systems emerged (Table 2): families' negative perceptions of and experience with HIV, perceived lack of autonomy, and difficulty letting-go. Again, stigma emerged as a theme that underscored each of the barriers to transitioning care. This experience of stigma in their social networks led adolescents to learn not to trust individuals outside of their immediate social circles and had led to some patients not knowing their diagnosis thereby impeding their ability to develop autonomy.

2a. Barriers: Families' Negative Perceptions of and Experiences with HIV

Disease—During interviews, adolescents often avoided the subject of HIV. Many did not even mention HIV as the primary reason for taking medication or for coming to the Pediatric AIDS Care Program clinic. Adolescents and parents often used "normalizing" language to diminish the disease:

It's not really anything to me, it's just something like a sickness that you just have.
It's not like anything depressing or something suicidal to do if you have it ...So to me it's really nothing. (16 year old)

Most adolescents had not disclosed their HIV status to their peers; some conveyed a sense of fear of stigma surrounding the disclosure of the disease and general lack of trust towards peer groups and other social networks (including health care clinics). As one 20-year old said, "No, nobody knows... [If I tell anybody] they won't like me no more, they will see me in a different way, they will just keep on going and not say a word to me." Most adoptive parents prohibited discussion of HIV outside the family unit, calling it a "family matter."

In school they tell you, "don't tell"...it's like a hidden thing, you know, because I've mentioned it a few times in school and they said, "please don't talk about [it]...don't tell anybody." (Adoptive parent of 15 year-old man)

Adolescents felt restricted in their daily activities, such as engaging in contact sports. Some adolescents also conveyed a sense of betrayal and anger towards their biological parents for living with the disease.

My daughter and I were sitting here looking at some pictures of her [mother] ...and we had called [her] over to look at the pictures ... and she didn't want to look at them. She said "no because she's the reason why I'm sick, she had AIDS." (Adoptive parent of 16 year-old woman)

Almost all of the adolescents and parents interviewed had also experienced stigma and discrimination within their social networks, including extended family, other clinics, and school settings.

They [the Pediatrician's office staff] seemed to be very prejudiced about the medical issues. One time, I never forget, my son had to have a shot and they were debating who should give the shot, "You give him the shot, I'm not giving it to him." "No, you give it to him." I think it was totally so unprofessional. (Adoptive parent of 12 year-old boy) Well he read a book at school about, like high school date rape, and the girl got AIDS...and he was kind of emotional about it. (Biological parent of 15 year-old boy)

2b. Barriers: Perceived Lack of Autonomy—Providers felt that because these adolescents had never been expected to live for very long, they were never taught the life skills needed to survive independently. As one provider said,

Their ability to read and write and... do the normal activities of daily living that are expected of adults, like using a bank, using transportation, making phone calls... things that we expect of adults in the health care system... [are] things that may be difficult activities for these kids. (Provider)

Regardless of their age, a number of adolescents were unable to state what kind of medication they took and with what frequency. Moreover, for those who did not know their diagnosis, it was especially difficult to encourage independence.

Well the biggest challenge is that I have to say is dealing with, dealing to the fact that she doesn't know her status and, and one of the challenges that I go through too is her medicine. She's still having a hard time taking the medicine so it's kind of hard for me to just tell her, you know, you need to take this and not telling her why. (Mother of 15 year old.)

One-third of the adolescents/young adults achieved their expected reading level on the REALM test. Of the 6 adolescents who were 18 years or older, two went to college, but would frequently take breaks in their education, largely secondary to depression. One had a part-time job, and the remaining 3 were still in high school. Some adolescents had neuropsychiatric co-morbidities, such as depression, attention deficit and hyperactivity disorder and learning disabilities which pediatric providers perceived as barriers to receiving care as an adult because it might impair their ability to live independently.

2c. Barriers: Difficulty Letting-go of Relationship between Pediatric Providers and Families—Parents, adolescents and providers all conveyed a sense of difficulty terminating their relationships because of a sense of a familial relationship within the Pediatric AIDS Care program. Relationships had been built on working together over many years in circumstances that were challenging, emotional, and even isolating because of the associated stigma.

Everything that came along was a big challenge. And children would get suddenly sick and die... I enjoyed my relationships with families and my colleagues very much. So that's what kept me going... You don't have patients that are going to be poster child...for cystic fibrosis or anything else...So you have to get your reward from your work and your relationships because you're not going to get rewards by having your picture in the paper. (Provider)

Familiarity, comfort and length of relationship with their provider were important features of this relationship for adolescents and guardians.

The people who... watch over him medically, that's my family...it's like starting your whole life over again you know. These people are going to be strangers to us.
(Adoptive parent of 14 year old)

Adolescents described positive attributes of their current providers which could not be naturally assumed in a new setting. In particular, they felt that their pediatric providers offered a non-pressured environment and feared that the adult clinics would not provide the same.

I'm just concerned about their personality... they might be like strict like concerned in a demanding way or something. I don't like people who demand me to do anything I don't want to do so maybe that's why I haven't [transitioned]. (21 year-old woman)

A few adolescents conveyed a fear of the different “language” used in the adult setting. Some adolescents suggested that they did not feel old enough to see an internist.

Given the familial relationship, providers expressed difficulty saying good-bye: I think all of us had been afraid [that] this moment in time would come, and I don't think we know how to deal with it. I don't think we have any sense of how tricky it's going to be and how sad it's going to be. (Provider)

Providers also conveyed a fear that the adult HIV clinic may be less welcoming than the pediatric HIV clinic and may not provide the same comprehensive, individualized care. Patrons of the adult clinic were also perceived to be a possibly frightening group with whom to share the waiting room.

I think it's very difficult for these kids to walk into an adult clinic... they see themselves as very different, they don't see themselves as, as those around them, who they may look at as being drug addicts... obviously I don't want to let them go.
(Provider)

As much as adolescents and their parents acknowledged the difficulty of transition, many also accepted this process and as a natural part of life.

Changing a doctor, finding a new doctor you know. You have to change to meet the needs and demands that you, you have. So what, what do you do? You meet those demands, you meet those challenges and you go forward. (Adoptive parent of 14 year-old)

DISCUSSION

Many providers and parents never expected that adolescents with perinatally-acquired HIV infection would survive to adulthood and, as such, delayed thinking about how to best transition this population to adult-oriented health care systems. Adult-oriented providers should be aware of the specific challenges regarding adolescents with HIV. In particular, stigma played a prominent role in both challenges to care and barriers to transition and is an aspect of the disease that may significantly impede access to health care (Fielden et al., 2006; Kinsler, Wong, Sayles, Davis, & Cunningham, 2007; Martinez et al., 2003; Wight, Aneshensel, Murphy, Miller-Martinez, & Beals, 2006).

One substantial challenge to care was non-compliance with medication regimen. We found that non-compliance often was due to fear of disclosure, as adolescents felt uncomfortable taking medicine around their peer groups. Many adolescents in our study were not comfortable with discussions about HIV and often were reluctant to even use the word HIV. Such behavior may prevent adolescents from fully developing a coping process and acceptance of their disease, which is thought to be critical to adherence (Belzer, Fuchs, Luftman, & Tucker, 1999; Hammami et al., 2004). Similarly, adolescents were often unable to disclose their HIV

status to their intimate partners, presenting a significant public health challenge to providers (Fielden et al., 2006).

As in other chronic diseases, two of the major barriers to transitioning adolescents to adult oriented health care systems was perceived autonomy and difficulty letting-go of relationships between providers and families (Anderson et al., 2002; Boyle et al., 2001; Flume, Anderson, Hardy, & Gray, 2001; Grubman et al., 1995; Kinsler et al., 2007; Lotstein et al., 2005; Nasr et al., 1992; Reid et al., 2004; Reiss et al., 2005; Rosen et al., 2003; Scal, Evans, Blozis, Okinow, & Blum, 1999; Scal & Ireland, 2005; Telfair, Myers, & Drezner, 1994; U.S. Department of Health and Human Services et al., 2001, 2004). Providers perceived that the adult clinic would necessitate a level of autonomy that their patients did not possess. Adolescents who do not know their HIV status are at the most risk; the strong undercurrent of denial by families may preclude adolescents from transferring the locus of control onto themselves. Most adolescents did not achieve their expected level of literacy, a proxy that we used to assess the ability of the adolescent to access their own health care (Levin-Zamir & Peterburg, 2001; Wolf et al., 2007). However, a fair percentage of the adult HIV-infected population may also struggle with literacy and autonomy (Kalichman et al., 2000); because of this background, providers of adult-based HIV care are likely to have experience with patients with low health literacy.

Providers had a difficult time letting-go of their relationships with families and feared that adult clinics would not provide as welcoming a setting as the pediatric clinic. In other studies, adolescents in various stages of transition acknowledged their surprise at the differences in the patients and environment of the adult-oriented clinic (Miles et al., 2004) and described an explicit dislike of HIV/AIDS-related material that decorated clinics (Dodds et al., 2003). Adolescents, like those in our study, who have been sheltered from such material may not know how to respond to it and may find it uncomfortable.

Despite having reluctance to let-go and a familial relationship with their pediatric providers, participants generally felt that they could easily adapt to transitioning to a new locus of health care. Having pediatric providers continue to be involved directly in the adult-oriented setting, by inviting adult providers to the pediatric setting, or by specifically creating transitional clinics for adolescents, may provide an effective bridge to transition (Miles et al., 2004)

The limitations of this study are those commonly found in qualitative research. With respect to generalizability, we chose a modest sample of adolescents with perinatally-acquired HIV disease, and we cannot be sure that our results would apply more broadly. To enrich validity, we used qualitative methodological techniques of grounded theory, coding by three researchers, and purposeful sampling (Britten, 1995; Mays & Pope, 1995; Pope & Mays, 1995; Strauss & Corbin, 1998).

Our results imply that adult-oriented care-providers need to be aware of the protected healthcare environment from which these children come and may have to tailor their language and approach to interacting with patients who have been followed in a pediatric HIV clinic. Providers should take care to address patients' limited autonomy by working with them to take control of their healthcare and find ways to help them manage the stigma that they face daily. Pediatric HIV care providers may need to be aware of their own reluctance to let-go; and they will need to address the issues of transition at earlier ages, ones that acknowledge the sexual precocity of many adolescents.

Successfully transitioning adolescents with HIV to adult-based settings of healthcare will depend on having ample dialogue between pediatric and adult HIV care teams, preparation of patients and their families via specific transition plans, and robust support structures that address stigma, limited autonomy, and the many other challenges to growing-up with HIV.

Acknowledgments

Supported by the Doris Duke Clinical Research Fellowship. Supported in part by a grant from the NIH (T32-AI07210-23).

Tara Vijayan is independent of any commercial funder and had full access to all of the data in the study and takes full responsibility for the integrity of the data and the accuracy of the data analysis.

We would like to thank Nancy Kim, MD, and Nora Groce, PhD for their thoughtful comments, and Anne Murphy and Leslie Hurst for their referrals of patients. We are grateful to the adolescents and their families who shared their experiences with us.

REFERENCES

- American Academy of Pediatrics, American Academy of Family Physicians, & American College of Physicians-American Society of Internal Medicine. A consensus statement on health care transitions for young adults with special health care needs. *Pediatrics* 2002;110(6):1304–1306. [PubMed: 12456949]
- Anderson DL, Flume PA, Hardy KK, Gray S. Transition programs in cystic fibrosis centers: perceptions of patients. *Pediatr Pulmonol* 2002;33(5):327–331. [PubMed: 11948976]
- Battles HB, Wiener LS. From adolescence through young adulthood: psychosocial adjustment associated with long-term survival of HIV. *J Adolesc Health* 2002;30(3):161–168. [PubMed: 11869922]
- Belzer ME, Fuchs DN, Luftman GS, Tucker DJ. Antiretroviral adherence issues among HIV-positive adolescents and young adults. *J Adolesc Health* 1999;25(5):316–319. [PubMed: 10551660]
- Boyle MP, Farukhi Z, Nosky ML. Strategies for improving transition to adult cystic fibrosis care, based on patient and parent views. *Pediatr Pulmonol* 2001;32(6):428–436. [PubMed: 11747245]
- Britten N. Qualitative interviews in medical research. *BMJ* 1995;311(6999):251–253. [PubMed: 7627048]
- Centers for Disease Control and Prevention. HIV/AIDS surveillance report: cases of HIV infection and AIDS in the United States and dependent areas, 2006. 2006. Retrieved 11/30/2008, 2008 from <http://www.cdc.gov/hiv/topics/surveillance/basic.htm>
- Davis, T.; Crouch, M.; Long, S. Rapid estimate of adult literacy in medicine (REALM) examiner's instruction sheet. 1998. Retrieved 11/30/2008, 2008 from http://www.medicalhome.alabama.gov/applications/documentlibrary/2.1.5.3%20PtEd_REALM_Instr.pdf
- Davis TC, Long SW, Jackson RH, Mayeaux EJ, George RB, Murphy PW, et al. Rapid estimate of adult literacy in medicine: a shortened screening instrument. *Fam Med* 1993;25(6):391–395. [PubMed: 8349060]
- Dodds S, Blakley T, Lizzotte JM, Friedman LB, Shaw K, Martinez J, et al. Retention, adherence, and compliance: special needs of HIV-infected adolescent girls and young women. *J Adolesc Health* 2003;33(2 Suppl):39–45. [PubMed: 12888286]
- Fielden SJ, Sheckter L, Chapman GE, Alimenti A, Forbes JC, Sheps S, et al. Growing up: perspectives of children, families and service providers regarding the needs of older children with perinatally-acquired HIV. *AIDS Care* 2006;18(8):1050–1053. [PubMed: 17012099]
- Flume PA, Anderson DL, Hardy KK, Gray S. Transition programs in cystic fibrosis centers: perceptions of pediatric and adult program directors. *Pediatr Pulmonol* 2001;31(6):443–450. [PubMed: 11389577]
- Gaughan DM, Hughes MD, Oleske JM, Malee K, Gore CA, Nachman S. Psychiatric hospitalizations among children and youths with human immunodeficiency virus infection. *Pediatrics* 2004;113(6):e544–e551. [PubMed: 15173535]
- Glaser, BG.; Strauss, AL. The discovery of grounded theory: strategies for qualitative research. New York: Aldine de Gruyter; 1967.
- Grubman S, Gross E, Lerner-Weiss N, Hernandez M, McSherry GD, Hoyt LG, et al. Older children and adolescents living with perinatally acquired human immunodeficiency virus infection. *Pediatrics* 1995;95(5):657–663. [PubMed: 7724299]

- Hammami N, Nostlinger C, Hoeree T, Lefevre P, Jonckheer T, Kolsteren P. Integrating adherence to highly active antiretroviral therapy into children's daily lives: a qualitative study. *Pediatrics* 2004;114(5):e591–e597. [PubMed: 15520091]
- Kalichman SC, Benotsch E, Suarez T, Catz S, Miller J, Rompa D. Health literacy and health-related knowledge among persons living with HIV/AIDS. *Am J Prev Med* 2000;18(4):325–331. [PubMed: 10788736]
- Kinsler JJ, Wong MD, Sayles JN, Davis C, Cunningham WE. The effect of perceived stigma from a health care provider on access to care among a low-income HIV-positive population. *AIDS Patient Care STDS* 2007;21(8):584–592. [PubMed: 17711383]
- Levin-Zamir D, Peterburg Y. Health literacy in health systems: perspectives on patient self-management in Israel. *Health Promot Int* 2001;16(1):87–94. [PubMed: 11257858]
- Lotstein DS, McPherson M, Strickland B, Newacheck PW. Transition planning for youth with special health care needs: results from the National Survey of Children with Special Health Care Needs. *Pediatrics* 2005;115(6):1562–1568. [PubMed: 15930217]
- Martinez J, Bell D, Dodds S, Shaw K, Siciliano C, Walker LE, et al. Transitioning youths into care: linking identified HIV-infected youth at outreach sites in the community to hospital-based clinics and or community-based health centers. *J Adolesc Health* 2003;33(2 Suppl):23–30. [PubMed: 12888284]
- Mays N, Pope C. Rigour and qualitative research. *BMJ* 1995;311(6997):109–112. [PubMed: 7613363]
- Miles K, Edwards S, Clapson M. Transition from paediatric to adult services: experiences of HIV-positive adolescents. *AIDS Care* 2004;16(3):305–314. [PubMed: 15203424]
- Nasr SZ, Campbell C, Howatt W. Transition program from pediatric to adult care for cystic fibrosis patients. *J Adolesc Health* 1992;13(8):682–685. [PubMed: 1290768]
- Pope C, Mays N. Reaching the parts other methods cannot reach: an introduction to qualitative methods in health and health services research. *BMJ* 1995;311(6996):42–45. [PubMed: 7613329]
- Reid GJ, Irvine MJ, McCrindle BW, Sananes R, Ritvo PG, Siu SC, et al. Prevalence and correlates of successful transfer from pediatric to adult health care among a cohort of young adults with complex congenital heart defects. *Pediatrics* 2004;113(3 Pt 1):e197–e205. [PubMed: 14993577]
- Reiss JG, Gibson RW, Walker LR. Health care transition: youth, family, and provider perspectives. *Pediatrics* 2005;115(1):112–120. [PubMed: 15629990]
- Rosen DS, Blum RW, Britto M, Sawyer SM, Siegel DM. Transition to adult health care for adolescents and young adults with chronic conditions: position paper of the Society for Adolescent Medicine. *J Adolesc Health* 2003;33(4):309–311. [PubMed: 14519573]
- Scal P, Evans T, Blozis S, Okinow N, Blum R. Trends in transition from pediatric to adult health care services for young adults with chronic conditions. *J Adolesc Health* 1999;24(4):259–264. [PubMed: 10227345]
- Scal P, Ireland M. Addressing transition to adult health care for adolescents with special health care needs. *Pediatrics* 2005;115(6):1607–1612. [PubMed: 15930223]
- Strauss, A.; Corbin, J. Basics of qualitative research. Vol. second ed.. Thousand Oaks, CA: SAGE publications; 1998.
- Telfair J, Myers J, Drezner S. Transfer as a component of the transition of adolescents with sickle cell disease to adult care: adolescent, adult, and parent perspectives. *J Adolesc Health* 1994;15(7):558–565. [PubMed: 7857954]
- U.S. Department of Health and Human Services. Health Resources and Services Administration, & Maternal and Child Health Bureau. All aboard the 2010 express: a 10 year action plan to achieving success for all children with special health care needs - to accompany Healthy People 2010. 2001. Retrieved 11/30/2008, 2008 from <http://cshcnleaders.ichp.edu/measuresachievingssuccess.htm>
- U.S. Department of Health and Human Services. Health Resources and Services Administration, & Maternal and Child Health Bureau. The National Survey of Children with Special Health Care Needs Chartbook 2001. 2004. Retrieved 11/30/2008, 2008 from <http://mchb.hrsa.gov/chscn/index.htm>
- Wight RG, Aneshensel CS, Murphy DA, Miller-Martinez D, Beals KP. Perceived HIV stigma in AIDS caregiving dyads. *Soc Sci Med* 2006;62(2):444–456. [PubMed: 16039763]

- Wojciechowski EA, Hurtig A, Dorn L. A natural history study of adolescents and young adults with sickle cell disease as they transfer to adult care: a need for case management services. *J Pediatr Nurs* 2002;17(1):18–27. [PubMed: 11891491]
- Wolf MS, Davis TC, Osborn CY, Skripkauskas S, Bennett CL, Makoul G. Literacy, self-efficacy, and HIV medication adherence. *Patient Educ Couns* 2007;65(2):253–260. [PubMed: 17118617]

Table 1

Characteristics of Participants

Characteristic	Adolescents	Guardians	Providers
Sex (n)			
Female	6	12	4
Male	12	3	5
Age (mean)	16 years		
Race (n)			
Black	8	5	1
White	1	6	7
Hispanic *	5	3	1
Other	4	1	0
Total	18	15	9

* Hispanic non-black

Table 2

Transitioning Care of Adolescents with HIV to Adult-Oriented Care Settings: Qualitative Themes, Categories and Subcategories

Category	Subcategory
Challenges to caring for adolescents with HIV infection	<ul style="list-style-type: none"> • Difficulty adhering to medication regimen • Adolescent sexuality • Disorganized social environments
Barriers to transitioning adolescents with HIV infection	<ul style="list-style-type: none"> • Negative perceptions of and experiences with HIV disease • Perceived and actual lack of autonomy of adolescent • Difficulty letting-go of relationship between pediatric providers and families