

2009

# Transitional care for adolescents with HIV: Characteristics and current practices of the adolescent trials network systems of care

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Transitional Care for Adolescents with HIV:  
Characteristics and Current Practices of  
the Adolescent Trials Network Systems of Care

by

Patricia Gilliam

A dissertation submitted in partial fulfillment  
of the requirements for the degree of  
Doctor of Philosophy  
College of Nursing  
University of South Florida

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Date of Approval:  
March 4, 2009

Keywords: child-centered, transition, HIV/AIDS, developmental, life skills

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### Dedication

I would like to dedicate this dissertation to two young women, L.P. and L.H., both in their early 20's, who lost their lives to AIDS when all the resources available to them could not prevent their untimely deaths.

Let us help them to grow up...they are going to live.

## Acknowledgments

I thank the members of my doctoral supervisory committee, colleagues and friends for their expertise, guidance and support during the development of this dissertation. I would also like to also thank Dr. Gail Powell-Cope for her assistance and encouragement during the beginning semesters of my doctoral studies. I would also like to thank Dr. Lois Gonzalez for her contributions during the preliminary stages of this dissertation project. Her assistance with the qualitative design and ATLAS.ti analysis were invaluable.

I thank my husband, Bill Willoughby, for all that and everything else.

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Transitional Care for Adolescents with HIV:  
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ABSTRACT

**Background:** Advances in antiretroviral therapy have resulted in a significant increase in life expectancy for HIV-infected individuals, with more pediatric patients transitioning to adult care. The transition process from pediatric to adult care for adolescents with chronic diseases, such as HIV, is always a challenge.

**Purpose:** The purpose of this secondary data analysis was to describe the characteristics, processes and practice models used by the Adolescent Trials Network (ATN) systems of care that assist adolescents with HIV disease to transition from child-centered care to adult-centered care.

**Method:** This study used health care providers affiliated with the Adolescent Trials Network of HIV/AIDS Interventions (ATN) as key informants. One to three representatives from each site considered to be the most knowledgeable staff member(s) involved with their clinic's transition practice were interviewed.

**Analysis:** The data set consisted of fourteen audio-taped interviews with nineteen key informants, as well as clinic documents that were submitted for review. An a priori



coding framework was prepared prior to the initial preliminary analysis based on the study research questions and the interview questions. This initial coding framework was refined using the constant comparative method and subsequent coding discrepancies in the remaining analysis were resolved by consensus. Transcripts and clinic documents were analyzed using content analysis within an ATLAS.ti data management system.

Results: Interviews were conducted with 19 staff members (7 social workers, 7 nurse practitioners, 3 physicians, 1 registered nurse, and 1 health educator) from 14 ATN clinics. There was a general consensus from site representatives as they described perceived facilitators of a successful transition and barriers to a successful transition. Descriptions of practice models were provided.

Conclusion/Discussion: Two unanticipated findings were the lack of a consensus on the definition of “transition” and what constitutes a “successful” transition. Anecdotal evidence seemed to provide a consensus of opinions from the key informants when asked to describe facilitators and barriers to a successful transition. Examples of practice models that were used in several clinics with a structured transition program were described. Ideas for future research were suggested. A definition of health care transition is proposed.

## Chapter One: Background

### *Introduction*

This dissertation is a secondary data analysis of qualitative data collected to describe the characteristics, structured processes and practice models used in the transition of HIV-infected adolescents from child-centered medical care to adult-centered medical care from the viewpoint of providers in a unique network of pediatric HIV clinics in the United States. The data was originally collected and analyzed manually by this researcher. This secondary data analysis used ATLAS.ti, a qualitative data management software program (Muhr, 2004).

The population of interest is adolescents with HIV disease who are or soon will be transitioning from child-centered medical care to adult-centered care. This study used health care providers affiliated with the Adolescent Trials Network of HIV/AIDS Interventions (ATN) as key informants who were most familiar with the transition phenomenon in this population. These key informants were selected because the ATN is a national, collaborative clinical trials network established by the Pediatric, Adolescent, and Maternal AIDS Branch of the National Institute of Child Health and Human Development in 2001. This group of clinics is affiliated with some of the most prestigious academic medical universities in the United States and represents the largest cohort of HIV-infected adolescents in the U.S. The characteristics, formal processes and practice models were identified through interviews with these ATN key informants and

by examination of written clinic policies and other documents used during the transition process.

### *Problem Statement*

Improving the process of transitioning adolescents with special needs and chronic medical problems from child-centered medical care to adult-centered care has been recognized as a priority by numerous medical, social service and government agencies that include the American Academy of Pediatrics, the American Academy of Family Physicians, the American College of Physicians-American Society of Internal Medicine (Blum, Hirsch, Kastner, Quint & Sandler, 2002), the Society for Adolescent Medicine (Rosen, Blum, Britto, Sawyer, & Siegel, 2003); and the Maternal and Child Health Bureau (n.d.). One of the goals of Healthy People 2010 is that all young people with special health care needs will receive the services needed to make necessary transitions to all aspects of adult life, including health care, work, and independent living (Maternal and Child Health Bureau, n.d.). New treatments of HIV disease have resulted in more HIV-infected children and adolescents living well into their adult years. Researchers with the Antiretroviral Therapy Cohort Collaboration (2008) recently published a meta-analysis of 14 cohorts in the United States, Canada and Europe. Considering those adolescents that began their initial treatment regimen between the years 2003 and 2005, a 20-year-old starting antiretroviral therapy (ART) could expect to live an additional 43 years. As these young adults age out of their current medical insurance coverage and need the expertise of a health care provider in adult HIV care, they will soon be making the transition from child-centered medical care to an adult care setting. There are no

reports that describe current transition processes and practices used in adolescent HIV clinics in the United States.

*Transition of Adolescents with Chronic Illnesses*

Research in the area of health care transition from child-centered care to adult-centered care began in the mid-1980s as advances in health care resulted in more children with chronic illnesses living well into their adult years (Blum, et al., 1993, Koop, 1989). Young adults with cystic fibrosis, cerebral palsy, epilepsy, sickle cell disease, juvenile arthritis, juvenile diabetes and spina bifida were some of the first populations to be studied (Reis & Gibson, 2002; Sawin, Cox & Metzger, 1999).

According to the most recent Centers for Disease Control surveillance data, there were 56,300 new HIV infections per year in the United States from 2003-2006 (Hall et al., 2008). In that same surveillance period, the CDC estimated that half of new infections occurred in individuals between the ages of 13 and 24 years (Futterman, 2005). The same surveillance data reported an increase in the estimated number of HIV/AIDS cases among several young adult age groups that included persons aged 15 to 19 years and 20 to 24 years (CDC, 2008). A reported 19,979 individuals between the ages of 13 and 24 years are currently living with HIV or AIDS (CDC, 2008).

The majority of HIV infected youth receives their medical care in a pediatric or child-centered medical setting (Adolescent Trials Network, 2006). These individuals will soon reach the age when transition must occur from child-centered medical services to adult-centered medical services. Adolescents with special health care needs and chronic medical conditions typically transition from the care of their pediatric or adolescent provider between the ages of 18 and 24 years with variations in timing attributed to

health insurance coverage, clinic policies, availability of adult providers to care for young adults with complex care needs and the challenges of terminating relationships with pediatric providers and institutions (Reiss & Gibson, 2002).

### *Research Gap*

Extensive gaps in knowledge exist for all groups of young adults with chronic health problems due to the paucity of empirical data to help understand and explain the difficulties associated with transition to adult care (Betz, 2008; Reiss, Gibson & Walker, 2005; Viner, 2008). Stigma, discrimination, marginalization, and social isolation are common in HIV-infected adolescents (AIDS Education and Training National Resource Center, 2006; HIV/AIDS Bureau, 1999). This combination of additional concerns suggests that information related to the transition of other patient populations cannot be transferred to adolescents with HIV disease. Currently, there is no information that describes the process of transitioning adolescents with HIV from child-centered to adult-centered care for HIV patients receiving care in the United States.

### *Purpose Statement*

The purpose of this study was to identify and describe the characteristics, structured processes and practice models currently being used in the transition of HIV-infected adolescents from child-centered medical care to adult-centered medical care within the ATN systems of care.

### *Research Questions*

1. How do ATN health care team members view transition?
2. What do ATN health care team members perceive as facilitators to a successful transition to adult care?

3. What do ATN health care team members perceive as barriers to a successful transition to adult care?
4. What are the similarities and differences among the clinics that have a structured transition program and those that do not?
5. What strategies have ATN health care teams developed to assist patients to make a successful transition to adult medical care?

#### *Significance to Nursing*

Research in the domain of transition of adolescents with special health care needs has historically been of interest to nurses. In a review 43 research studies conducted from 1982 through 2003 in this domain, almost 30% ( 27.9%) were conducted by nurses (Betz, 2004). This project contributes to the profession of nursing by expanding our understanding of the complex issues involved in planning and implementing a program to facilitate transition of HIV-infected adolescents from child-centered medical care to adult care. The insights gained from this understanding may be applicable in other stigmatized and severely marginalized populations.

Nurses are known for their ability to successfully function in multiple roles within complex healthcare environments. Strengths in communication, patient education, health promotion, and patient advocacy combine to make nurses ideal project directors for transition programs. This body of work provides insights for nurses who are challenged with these projects.

## Chapter Two: Review of the Literature

### *Introduction*

Patton (2002) suggests that reviewing the literature prior to data collection “may bias the researcher’s thinking and reduce openness to whatever emerges in the field” (p. 226). He suggests that literature reviews for a qualitative research project may not be appropriate until after the data collection and analysis. This final review of the literature incorporates both the preliminary review used to identify knowledge gaps in the domain as well as the more comprehensive review of the literature that was performed following the data collection and analysis. Following the preliminary review of the literature, preconceptions were identified and bracketed to prevent bias during both the data collection and analysis phases.

It is instructive to discuss the origins of the domain of health care transition (HCT) because the need to transition adolescents with chronic disease from child-centered care to adult-centered care is a relatively new phenomenon. The need to develop processes that would facilitate a smooth transition to adult care was first identified in a public forum in 1984 (Blum, 2002; Koop, 1989). Advances in health care had begun to increase life expectancy for many children with congenital anomalies and chronic illnesses (Blum, et al., 1993; Koop, 1989). The late 1980s was also noteworthy within the HIV/AIDS community. The rate of perinatal infection with the HIV virus had increased exponentially due to the emergence of HIV disease in the female population. There were an estimated 6,000 to 7,000 infants born to women with HIV disease between 1989 and

1994 (Lindegren et al., 1999). The phenomenon of HCT for adolescents with HIV has emerged even more recently and is related to advances in antiretroviral drug therapy that occurred in the mid-1990s. The literature related to the transition of adolescents with HIV disease began to emerge in the early 2000s as the population of perinatally infected adolescents with HIV disease began to survive to reach young adulthood. Concurrently, the incidence of teenagers infected through high-risk sexual or drug use behaviors was also increasing (Valleroy, MacKellar, Karon, Janssen, & Hayman, 1998, Futterman, 2004). There are distinct as well as shared clinical and psychosocial characteristics of these two groups of adolescents. These characteristics must be considered in efforts to study the transition of adolescents with HIV disease to adult care.

Historical and sentinel publications dating back to 1989 are included in this review. This chapter is organized into sections that include the logic of the literature search, the origins of the domain of health care transition (HCT), policy and positions statements addressing the transition of adolescents with special health care needs from child-centered health care to adult-centered care, HCT of adolescents with chronic illnesses, HCT of adolescents with HIV disease, and the current state of the science of HCT.

#### *Logic of the Literature Search and Discussion*

A literature search was performed to retrieve published information from 1989 to 2009. Only sentinel publications that address the global domain of transition of adolescents with special health care needs and chronic disease have been included in this review. The domain of HCT for adolescents with HIV disease addresses a unique adolescent population with a distinct set of needs. There are concerns within the HIV



professional community that information related to the transition of other patient populations cannot be transferred to the HIV-infected adolescent population (AIDS Education and Training National Resource Center, 2006; HIV/AIDS Bureau, 1999). These concerns surround the stigma and discrimination associated with HIV/AIDS and how this might affect adolescents' efforts to establish care in an adult HIV/AIDS specialty clinic. The impact of stigma, social isolation, mental health issues, and frequent parental illness and death combine to form a unique set of factors that may affect the success of transition to adult care.

The majority of published research in the global area of transition of adolescents with special health care needs and chronic disease was generated not only by health care professionals but also policy, public health, and social work professionals. These publications were located in a variety of social science journals. Publications in the more focused area of transition of adolescents with HIV were produced by professionals working with this unique population and were published in HIV/AIDS specialty journals. Databases used in the literature search included the Cumulative Index to Nursing and Allied Health Literature (CINAHL), PubMed, AIDSinfo, AIDS Education Global Information System (AEGIS) and the Cochrane Database. A cursory review was done of the references cited in each publication. The search terms (key words) used included child, adolescent, youth, HIV, transition, child-centered, and adult-centered care. Search terms were combined using Boolean operators to maximize the yield and minimize duplication.

*Origins of the Domain: Transition of Adolescents with Chronic Diseases*

Research in the area of health care transition from child-centered care to adult-centered care began in the 1980s as the life expectancy of children with cystic fibrosis, cerebral palsy, spina bifida, and sickle cell disease began to reach into adulthood (Blum, et al., 1993). The first major public event to introduce the issue of transition of adolescents with chronic disease to adulthood occurred in 1984 at a conference co hosted by U.S. Surgeon General C. Everett Koop and Undersecretary of Education Madeline Will (Koop, 1989). As the population of adolescents and young adults living with chronic and disabling diseases increased, their issues of transition to adulthood became more urgent. Dr. Koop designated his Surgeon General's Conference in 1989 to discuss the phenomenon of adolescents with disabilities, special health care needs and chronic diseases. The conference was entitled, "Growing Up and Getting Medical Care: Youth with Special Health Care Needs". The following excerpt from Dr. Koop's keynote address succinctly identifies the problem:

I would like to recall one major issue in the care of special children which has not been adequately addressed and which is a significant barrier to our adolescent and young adult population as they pursue independence. I refer to the obstacles they encounter and must surmount if the provision and quality of medical care is to continue from childhood through the transition to adulthood....A basic underlying defect in the system has to do with the lack of a transition protocol for healthy adolescents from pediatric to adult services....How much more difficult for the youngsters with special needs when his/her acute illness demands entry to the

adult system. Adolescents are having more trouble than they need with this aspect of growing up (pp. 3-4, 1989).

Also in 1989 the Maternal and Child Health Bureau within the Health Resources Service Administration (HRSA) created a mandate that served as the foundation of State Title V programs for Children with Special Health Care Needs (CSHCN). This mandate outlined the need to develop systems of care for CSHCN that are family-centered, community-based, coordinated and culturally competent. An extension of this idea was included as a long-term national goal in the Healthy People 2010: National Health Promotion and Disease Prevention program. This goal outlined the need for available services to facilitate transition to all aspects of adult life, including health care, work, and independent living (CDC, 2000; Maternal and Child Health Bureau, n.d.). One of the six critical indicators of progress toward this goal addressed the expectation of good health care, employment with benefits, and independence. Available health care options in local communities that are family-centered and developmentally appropriate are expected. Programs should prepare individuals to take charge of their own health care and to lead an optimally independent and productive life. A broad definition of CSHCN is included in the language of this critical indicator. Those are the CSHCN who have or are at increased risk for chronic physical, developmental, behavioral, or emotional conditions and who require health and related services of a type or amount beyond that required by children generally (Maternal and Child Health Bureau, n.d.).

### *Policy and Position Statements*

Policy and position statements have been issued by various professional organizations addressing the need for transition services for these adolescents. They include the Society for Adolescent Medicine (Blum et al., 1993; Rosen, et al., 2003), American Academy of Pediatrics, (2000); and the American Academy of Pediatrics in collaboration with the American Academy of Family Physicians and the American College of Physicians-American Society of Internal Medicine (Blum, et al., 2002).

Blum et al. (1993) are credited with the definition of transition as “the purposeful planned movement of adolescents and young adults with chronic conditions from child-centered care to adult-centered care” (p. 572). This original position paper issued by the Society for Adolescent Medicine described a duality of opinions related to the need for such transition programs. Some pediatric providers believed the young adults with chronic illnesses should continue to be cared for by their pediatrician and the opposing school of thought suggested that these adolescents should be given the opportunity to mature into adulthood in a gradual and purposeful fashion. Blum et al., (1993) suggest that the majority of health professionals were either unsure of the issue or are only peripherally involved. In 1993, there were few model programs of transition. Blum et al. (1993) acknowledge the need for and lack of controlled studies of transition models and the lack of criteria to evaluate success. They propose that the success of adolescents with chronic diseases transitioning into adulthood must include a variety of measures such as disease-specific measures, functional status and sense of well-being.

Almost a decade passed before any professional organization again addressed the HCT of adolescents with special health care needs (ASHCN). The American Academy of

Pediatrics (2000) addressed the role of the pediatrician in transitioning children and adolescents with developmental disabilities and chronic illnesses from school to work or college. The responsibilities of the pediatrician are described as providing anticipatory guidance and promoting self-advocacy and self-determination for these children and adolescents. Although this statement primarily focuses on educational and training opportunities, there is mention of a transition plan mandated by the Individuals with Disabilities Education Act Amendments of 1997 that includes discussion of a medical home. The medical home model is introduced as a center that promotes “accessible, continuous, comprehensive, family-centered, coordinated and compassionate care” (p. 855) while partnering with the adolescent, the family, and other community health and human services professionals.

A consortium of professional groups that included the American Academy of Pediatrics, the American Academy of Family Physicians and the American College of Physicians-American Society of Internal Medicine (Blum, et al., 2002) jointly presented a consensus statement that was approved as policy by the boards of each of the organizations. They concurred with previous policy statements and added the caveat that developmentally appropriate healthcare services should continue uninterrupted as the individual moves from adolescence to adulthood. The groups identified six critical first steps to ensuring successful transitioning to adult-oriented health care. These steps are summarized in Table 1.

Table 1

*Critical Steps to Ensure a Successful Transition*

---

- Ensure that all ASHCN have an identified health care professional who attends to the unique challenges of transition and assumes responsibility for current health care, care coordination, and future health care planning.
- Identify the core knowledge and skills required to provide developmentally appropriate health care transition services to ASHCN and include them in training and certification requirements for primary care residents and physicians in practice.
- Prepare and maintain an up-to-date medical summary that is portable and accessible.
- Create a written health care transition plan by age 14 with the young person and family. The plan should be updated annually and include what services are needed, who will provide them, and how they will be financed.
- Apply the same guidelines for primary and preventive care for all adolescents and young adults, acknowledging that those with special health care needs may require more resources.
- Ensure affordable, continuous health insurance benefits for all ASHCN. The insurance should cover compensation for transition planning and core coordination.

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*Note.* ASHCN= adolescents with special health care needs.

The Society for Adolescent Medicine revisited the issue of HCT for adolescents and young adults in a second position paper (Rosen et al., 2003). Questions persisted related to effective strategies to assist adolescents while engaging in the adult health care system. During the ten years from 1993 to 2003, models had been proposed and some implemented, but outcome data was still lacking and no evidence-based

recommendations were made. They acknowledged the “paucity of meaningful data” (p. 309) but presented several fundamental principles of transition. These principles emphasized the need for health care transition services to be delivered at the level of both the adolescent’s chronological and developmental age. Emphasis was also placed on issues of growth and development; sexuality; mood and mental health disorders; substance abuse; and other health promoting or health damaging behaviors that are similar to both healthy adolescents and those with a chronic illness. At the same time, they acknowledged that many adolescents with chronic conditions are at higher risk than their peers for dependency, developmental difficulties and psychosocial delays. Rosen et al. (2003) posited that a successful transition experience might prevent some of these difficulties and delays by promoting autonomy, personal responsibility and self-reliance. They stressed the importance of designating a single professional to act as coordinator and advocate, who would take responsibility for the transition process. This designated professional would work in partnership with the patient and the family to facilitate and streamline the transition experience. This idea of a designated professional responsible for coordinating HCT was also included in the consensus statement from the American Academy of Pediatrics, the American Academy of Family Physicians and the American College of Physicians-American Society of Internal Medicine (Blum, et al., 2002). These organizations identified the first “critical step” in HCT is ensuring that all ASHCN have an identified health care professional who “assumes responsibility for current health care, care coordination, and future health care planning” (p. 1385).

These position papers used visionary phrases such as family-centered, continuous, comprehensive, coordinated, compassionate, culturally competent, and developmentally appropriate. These phrases are now consistently seen throughout the HCT literature.

*Transition of Adolescents with Chronic Illness and Special Health Care Needs*

Young adults with cystic fibrosis, cerebral palsy, epilepsy, sickle cell disease, juvenile arthritis, juvenile diabetes and spina bifida were some of the first populations to be studied (Reis & Gibson, 2002; Sawin, Cox & Metzger, 1999). Historically, the transition of youth and young adults with disabilities and special health care needs from child-centered health care to adult-centered health care has been problematic (Blum, 1993; Reiss, Gibson, & Walker, 2005; Rosen, et al., 2003) and often unsuccessful (Reiss et al., 2005). Adolescents with chronic conditions often exhibit dependency, developmental difficulties, and psychosocial delays (Pumariega, Shugart, & Pumariega, 2006; Rosen, et al., 2003). Blum (1995) described the higher than average prevalence of depression and suicide attempts in adolescents with chronic illnesses. He suggested that these problems were grounded in social isolation and loneliness which would often result in delayed social maturation. He reported lower self-esteem, higher anxiety, lower self-perceived popularity and greater self-consciousness in patients that felt overprotected by their parents.

As the formative research surrounding the transition of adolescents with chronic illness and special health care needs began to emerge, the studies were primarily descriptive, qualitative designs. The transition needs of the adolescents and families, their perceptions and expectations were explored in anticipation of transition program development.



Adolescents, families, pediatric and adult providers have provided insights into the transition process from their own unique perspectives. Numerous studies have attempted to identify potential challenges and barriers to the process. A common theme expressed by all participant groups addressed the scarcity of adult providers interested and skilled in the care required by chronically ill young adults ( Houser & Dorn, 1999; McDonough, Foster, Hall, & Chamberlain, 2000; Reiss et al., 2005; Scal, Evans, Blozis, Okinow & Blum, 1999; Scal, 2002; Schidlow & Fiel, 1990; Sinnema, Bonarilus, Laag, & Stoop, 1988). Both adolescent and adult providers expressed concern about their lack of expertise in providing transition services as well as and a lack of available training and resources (O’Connell, Bailey, & Pearce, 2003; Patterson & Lanier, 1999; Peter, Forke, Ginsburg, & Schwarz, 2009). Additional barriers were identified related to time restrictions and inadequate reimbursement for transition program development and the requisite interaction between adolescent and adult providers (Callahan, Winitzer, & Keenan, 2001; Geenen, Power, & Sells 2003; Peter, Forke, Ginsburg, & Schwarz, 2009; Reiss et al., 2005; Scal, 2002).

A second commonly expressed area of concern was the difficulty terminating the long-standing relationship between the adolescent, his or her family and the pediatric health care providers (Houser & Dorn, 1999; Schidlow & Fiel, 1990; Sinnema, Bonarilus, Laag, & Stoop, 1988). This problem with “letting go” was described from both the pediatric provider and the patient-family perspective.

Another frequently mentioned concern was related to perceived differences between the pediatric care model and the adult care model (Callahan et al., 2001; Houser & Dorn, 1999; Schidlow & Fiel, 1990; Sinnema, Bonarilus, Laag, & Stoop, 1988; Rosen

1995). Pediatric providers routinely rely on and include input from the patient's family while adult providers are more likely to communicate directly with their patient. Rosen (1995) suggested that adult providers may be viewed by their pediatric counterparts as being cold, distant and inattentive to global patient needs. He suggests that these perceptions may unintentionally be communicated to both the adolescent and their family which would increase their reluctance to transition. Notably, one study suggested that adult providers were better and more comfortable discussing sex, drug and alcohol issues and topic surrounding reproduction. Nasr (1992) and Geenen et al. (2003) presented similar findings through a different lens. They described the discomfort expressed by pediatricians when talking about sex, drugs and alcohol.

There have been attempts to identify the most appropriate professional to facilitate an adolescent transition experience. Several groups have suggested that physicians trained in Medicine-Pediatrics (med-peds) are best suited for transitional care (Callahan, et al., 2001; Melgar, Brands, & Sharma, 2005). Flum, Taylor, Anderson, Gray and Turner (2004) suggest that transition efforts are more successful when coordinated by someone other than a physician. Telfair, Alexander, Loosier, Alleman-Velez, and Simmons (2004) while comparing providers who care for patients with sickle cell disease found that nurse practitioners were more likely than other health care professionals to provide transitioning care. Several noted authorities in the domain of HCT suggest that nurses are in the best position to successfully coordinate transition efforts (Betz, 1998; Flume et al., 2004; Hauser and Dorn, 1999; Viner, 2000). Betz (1998) proposed models of HCT that used the school nurse, the nurse in traditional health care settings or the nurse practitioner functioning in key roles within the transition team. She described the

school nurse serving as a member of the transition team involved in developing the Individualized Transition Plan required by federal law in the Individuals with Disabilities Education Act [IDEA] of 1997. The school nurse could provide an assessment of the actual and potential impact of the student's health status on future education and training efforts. She discussed how the skills of nurses in traditional health care settings could be used to facilitate an improved collaboration between the schools and the health care team members. She described nurse practitioners as the primary care provider who would act as the coordinator of transition services and could advocate for accessible services for the adolescents and their families. The nurse practitioner would provide information and suggestions concerning adult providers and community services while working with the adolescents to assure the development of competencies necessary to become self-sufficient in managing their own health care as an adult.

Betz (1998) also explained how the nursing process could serve as a useful framework to develop a plan of care that addressed the adolescent's preventive, primary and long-term health considerations in a manner congruent with the values and culture of the adolescent and their family. It would begin with an assessment of the adolescent's skills and knowledge necessary to assume responsibility for his or her self-care and the adolescent's developmental readiness to assume this responsibility.

#### *Transition of Adolescents with HIV disease*

The Society for Adolescent Medicine has more specifically addressed the topic of transition for adolescents with HIV infection and AIDS in two position papers (D'Angelo, Brown, English, Hein, & Remafedi, 1994; D'Angelo, Samples, Rogers, Peralta, & Friedman, 2006). It is reasonable that the original position paper in 1994 did

not address the issue of transition to adult medical care because at that time a child or adolescent with HIV disease or AIDS was not expected to survive until adulthood. The life expectancy of a 20 year old that is diagnosed with HIV disease is now estimated to be greater than 60 years of age (Antiretroviral Therapy Cohort Collaboration, 2008). This improved prognosis is the direct result of triple drug therapy protocols that were introduced in 1996. It is interesting to note that 10 years after the introduction of triple drug therapy for HIV disease that transition to adult care was not thoughtfully addressed in the 2006 position paper.

Health care transition for HIV-infected adolescents may also be complicated by stigma, discrimination, forced disclosure and social isolation and may hinder adolescents from seeking the support of unfamiliar providers (AIDS Education and Training National Resource Center, 2006; Brown, Laurie, & Pao, 2000; HIV/AIDS Bureau, 1999; Weiner, Zobel, Battles and Ryder, 2007). An adolescent, when asked to list the three greatest problems in his life with HIV stated, “Stigma, side effects and transition-absolutely. It’s an extremely difficult process” (Vazquez, 2006). In addition, adolescents with HIV may have experienced parental illness and loss, depression and behavioral issues such as truancy, school drop-out, and drug use (Brown et al., 2000; Pumariega, 2006). The psychosocial stressors that come with having HIV disease can make HCT a complex process. This combination of unique characteristics and additional stressors suggests the need to determine if information related to the transition of other patient populations can be transferred to the HIV-infected adolescent population.

Five studies have been identified that address the HCT of adolescents with HIV disease and AIDS from child-centered care to adult care. One of the studies was set in the

United Kingdom, one in British Columbia and three in the United States. Only one of the U.S. studies has been published (Weiner et al., 2007). Another has been submitted for publication (Vijayan, Benin, Wagner, Romano, and Andiman, 2008) and the last was presented in a poster presentation at the 2008 International AIDS Conference in Mexico City. (Wagner, Murphy, Holmes, and Romano, 2008, August).

Miles, Edwards and Clapson (2004) are credited with the first study that addressed the experiences of adolescents with HIV following transition to an adult HIV/AIDS clinic. The adolescents had been transferred from a clinic that manages the largest cohort (n=142) of HIV-infected adolescents in the United Kingdom to an adult HIV clinic that provides care for >2000 adults with HIV/AIDS. Seven adolescents were interviewed in this qualitative study that explored their experiences of transition between the two clinics. The participants included five males and two females, ranging in age from 16 to 22 years. Four were perinatally infected with HIV and three were infected from blood products. The median number of years in care at the pediatric clinic was 16 years. A semi-structured interview was designed based on a transition literature review and the authors' knowledge and experience providing care for adolescent with HIV disease. A number of similar opinions and ideas emerged from the interviews. Seven of the adolescents stated that being introduced and beginning a professional relationship with an adult provider prior to the transition helped facilitate the process. Two situations were identified as the primary sources of anxieties and fear. The anxiety provoking situations surrounded disclosure of personal histories and HIV status. The anxiety was heightened when combined with fears associated with the adult clinic setting. Several participants mentioned a concern surrounding meeting and disclosing personal

information to a new provider, particularly if multiple specialty providers were needed. Other common sources of anxiety were the adult clinic setting and adult patients. The adolescents described feelings of discomfort in areas of the adult clinic. One young man explained how being in an adult HIV setting would “force him to confront the inevitable growing older with HIV, knowing well that the older he got, the longer he would have HIV and the higher the chance of developing illness” (p. 308). Several participants were surprised by the “all-adult waiting room covered with HIV specific posters and information” when they were used to “cartoon covered walls, games, play therapists and other children” (p. 309). Other participants verbalized surprise and discomfort when “sitting in a waiting room with a predominantly gay male population” (p. 309). Based on these concerns, recommendations for future transition programs included a visit to the adult clinic prior to the transfer and creation of a specific young person environment with youth focused magazines, music and computer access in the waiting room.

The adult clinic participating in this transition program has established a specialist adolescent clinic staffed by a dedicated group of professionals that offer an improved continuum of care from the pediatric to the adult clinic. This team works with the adolescents to develop skills for managing their health more independently. Preliminary data cited from personal communications suggest that the specialist adolescent clinic is improving regular clinic attendance and follow-up.

Fielden, et al. (2006) reported results of a study that examined issues affecting a select group of older children (9-16 years old) with perinatally-acquired HIV in British Columbia. The participants included 10 children, 6 familial caregivers, 5 foster parents and 11 service providers. Focus groups and in-depth semi-structured interviews were

used to generate the personal views of this group of stake-holders. The three themes that emerged were social stigma, mental health and sexual health. Social stigma was identified as a negative and destructive influence. The concept of stigma emerged from vignettes that described fear, secrecy and isolation surrounding trust and disclosure. One older participant explained her apprehensions about disclosure by stating, “I don’t want to be the center of attention and everybody is like, Oh, lookit! [*sic*] There’s the girl with HIV...and I’d rather people see me as Lucy, than people see, Oh, Lucy with HIV” (p. 1051).

Similar feelings were associated with discussions surrounding sexual health. Several of the older children revealed they had already had sexual experiences. Information related to whether or not they had disclosed their status was not included in this report. Concern was expressed that there was fear of maintaining a relationship when their HIV status was disclosed to a boyfriend or girlfriend. One of the health care providers offered a different perspective by emphasizing the need for positive feelings surrounding sexuality. She stated, “I think [it’s important to] to give them a positive approach to their sexuality...it can get tainted so easily” (p. 1051)

The possibility of mental health problems originating with opportunistic infections, fetal alcohol syndrome and poor socio-economic status was also suggested in the work by Fielden et al. (2006). Discussions were permeated with references to bereavement, loss of parents, feeling normal, security, self-esteem and the need for a positive attitude. Parents and care-providers expressed the need for the children to feel normal despite their HIV.

Fielden et al. (2006) described this population as being “in hiding” due to the experience and fears of HIV-associated stigma. They emphasize the need to identify strategies to build self-esteem and support healthy sexual development. They confirm the need for policy development and services that address partner disclosure and family planning. The authors acknowledged the lack of generalizability of the findings but suggest the finding may be useful to inform future research.

Weiner et al. (2007) conducted an interventional study that compared readiness to transition and anxiety associated with transition in a sample of HIV-infected adolescents enrolled in a National Institutes of Health (NIH) Clinical Research Program. At the time of the study, the announcement had been made that the clinic would be closing within the year due to a funding reallocation. Interviews were conducted with 51 families (39 parents or caregivers and 12 older adolescents between 18 and 25 years of age). Transition readiness and state anxiety were measured in a nonexperimental pre-post test design. Transition readiness was measured using a questionnaire designed by the investigators based on obstacles to successful transition that were previously suggested in the literature (Betz, 1998; Houser & Dorn, 1999). State anxiety was measured using Spielberger’s State/Trait Anxiety Inventory for Adults. The intervention was designed to individually address any barriers that had been identified during the interviews. The barriers identified were related to needing a physician in their home community, lacking confidence in the home community physician, needing health insurance, lacking funds to cover out-of-pocket expenses, needing a social worker in their home community, needing a pharmacy in their home community, and a knowledge deficit related to HIV disease or medications. Social workers attempted to address issues related to funding,



transportation, and pharmacy access. The medical providers took responsibility to contact the future adult provider and address any HIV-specific knowledge deficits.

As hypothesized, poor readiness scores were associated with increased state anxiety levels and a lack of confidence in the medical providers in their home community. Approximately one third of participants had poor or moderate scores of transition readiness at T1, while none scored in these categories at T2. By the time transition [or transfer of care] occurred, all participants scored in the good to excellent range of readiness. Thirty percent of participants scored above the clinical cutoff for state anxiety at T1 and twenty percent scored above the cutoff at T2. Concepts and feelings frequently mentioned in the interviews included loss, upset, frightened about the future, feeling abandoned, concerned about receiving a lower level of care, lack of HIV knowledge elsewhere and lack of monitoring of HIV patients at home. The authors concluded by suggesting that social workers are uniquely qualified to address the psychosocial needs, emotional barriers, resistance to transition, resource acquisition, and promotion of life-skills development in this population of adolescents.

Vijayan, Benin, Wagner, Romano, and Andiman (2008) conducted a qualitative study to identify and describe issues surrounding the transition of adolescents attending the Yale-New Haven Hospital pediatric HIV clinic. The sample included 18 adolescents with HIV, 15 of their principal guardians, and 9 pediatric health care providers from the Yale Pediatric AIDS Care Program. Each participant was interviewed by a single investigator not affiliated with the clinic. Open-ended questions with probes to elicit feelings and ideas related to the transition of care were used. Additional information regarding history of sexual activity and drug use was collected using a confidential

written questionnaire. Each participant also completed a health literacy test used to predict a level of potential self-efficacy and autonomy with regard to healthcare.

Vijayan, et al. (2008) identified two major themes during the analysis and were categorized as challenges caring for adolescents with HIV and barriers to transitioning adolescents to adult-oriented health care systems. Sub-categories emerged from each major theme and are presented in Table 2.

Table 2

*Challenges and Barriers to HCT in Adolescents with HIV disease*

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- Challenges to Caring for Adolescents with HIV
  - Difficulties with adhering to medication regimens \*
  - Difficulties managing adolescent sexuality \*
  - Negotiating disorganized social environments
- Potential barriers to transitioning adolescents to adult-oriented health care systems
  - Families' negative perceptions of and experiences with HIV\*
  - Perceived lack of autonomy
  - Difficulty letting-go

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*Note.* \*= The authors attributed these specific difficulties to perceived stigma of HIV disease and disclosure of the adolescent's HIV status.

The challenges of caring for adolescents with HIV disease emerged from each group of participants. Specific issues related to medication adherence were described by the adolescents themselves and included confusion about the need to take medication when feeling well, feeling a constant reminder of the diagnosis when taking medication and the fear of accidental disclosure of their status when taking medication around their

peers. The challenges associated with adolescent sexuality were identified by both the adolescents and the providers. The feelings of the adolescents were primarily linked to disclosure of their HIV status. Four of the 18 adolescents reported having had sexual intercourse and none had disclosed their status to their last partner. Twelve of the adolescents confirmed an ongoing peer pressure to have sex. The pediatric providers expressed concerns of their lack of experience with sexual health matters, gynecologic care and the legal complexities of partner notification. The disorganized social environments of the adolescents were primarily related to witnessing drug abuse, incarceration and frequent death of a parent with AIDS as well as exposure to foster care and adoption services at an early age.

The notion of stigma also emerged as a component of the potential barriers to transition to adult care. The adolescents and their guardians described multiple negative experiences surrounding the diagnosis of HIV. The adolescents described experiencing stigma and discrimination within their social networks, including extended family, other clinic and school setting. They reported fear associated with trusting individuals outside their immediate social circle. Unfortunately, this distrust and fear was also mentioned when discussing potential adult providers. Providers expressed concerns about the adolescents' lack of autonomy. These adolescents were never encouraged to be independent because they were never expected to live to reach adulthood. "They were never taught the life skills necessary to survive in an adult world" (Vijayan, et al., 2008, p. 11).

Adolescents, guardians and providers described a difficulty of letting-go of the relationships that had developed, in many instances, over the entire lifetime of the adolescent. There was a fear that the adult clinic setting and the adult providers would not

provide a comfortable, non-pressured experience similar to that in a pediatric setting. The pediatric providers conveyed the fear that the adult HIV clinic may be less welcoming and that the waiting room could be frightening for the adolescent.

Another of the HIV-specific transition reports describes a transition program for perinatally and behaviorally HIV infected adolescents that began in 2006. An abstract was presented in a poster exhibition at the International AIDS Society meeting in August, 2008 describing the transition program at Yale-New Haven Hospital, an urban, academic tertiary-care hospital with both pediatric and adult HIV clinics (Wagner, K., Murphy, A., Holmes, J., & Romano, S., 2008). The program includes a pediatric Nurse Practitioner who assesses the adolescent's readiness to transition, a single adult provider that accepts the adolescent into adult care, an introduction of the adolescent to the adult provider prior to the first appointment, a social worker who is shared by the pediatric and adult clinic to continue to manage the adolescent's complex psychosocial needs, and a multidisciplinary team including clinic nurses and home nurses who provide outreach and support for missed appointments and medication non-adherence.

The Panel on Antiretroviral Guidelines for Adults and Adolescents from the Department of Health and Human Services (DHHS) updated the Guidelines for the Use of Antiretroviral Agents in HIV-1-Infected Adults and Adolescents in November, 2008 (Panel on Antiretroviral Guidelines, 2008). These guidelines are considered to be the standard of care for the management of HIV disease and AIDS. This revision contained the first discussion of transitioning adolescents with HIV to the adult care setting. Differences between a teen-centered, multidisciplinary, primary care adolescent clinic and a larger adult clinic that uses a subspecialty model are contrasted. DHHS

recommendations to facilitate a successful transition are listed in Table 3. No operational definition of successful transition was included.

Table 3

*Department of Health and Human Services  
Recommendations to Facilitate Successful Transition*

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- 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 utilization of a primary care provider and 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 versus 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

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*Note.* Panel on Antiretroviral Guidelines for Adults and Adolescents, 2008 (p. 75).

### *Current State of the Science*

As recently as 2008, Cecily Betz, Ph.D., a nurse researcher who has worked for over 35 years with children and their families who have special health care needs and disabilities reinforced the urgency of the problem and growing needs of this population when she stated:

The critical mass of need evidenced by the growing numbers of adolescents with special health care needs (ASHCN) requiring transition services from a system of care still unprepared to meet them can no longer be ignored or tolerated. Youth and families have long experienced the frustration of this service inadequacy, are now being joined by increasing numbers of health care professionals, advocacy organizations, and health care institutions to effect the system changes needed (p. 13).

Betz (2008) described the continued challenges in conducting research in the area of HCT. Cited were inconsistencies in the data published from national surveys conducted with CWSHCN and AWSHCN. These inconsistencies included sample characteristics that varied based on different definitions of chronic illness and disability and data collected on multiple variables with inconsistent definitions.

Perhaps the most challenging issue involves the inability to track these individuals after they were transferred into the adult health care system. As a general rule, data collected by one agency cannot be linked or accessed by another agency and there is no universal database pertaining to this population. Notable exceptions to this rule are found in countries with national registries of individuals' health data associated with a

nationalized health insurance program such as the United Kingdom, France, Denmark, the Netherlands, and Canada (Betz, 2008).

Only one study was identified that reported a definition and measure of a “successful” transition. A Canadian study reported on the successful transition from pediatric to adult health care of a cohort of young adults with congenital heart defects (Reid, Irvine, McCridle, Sananes, Ritvo, Siu, et al., 2004). A cohort of patients with complex congenital heart defects was identified from the database of the cardiology program at the Hospital for Sick Children in Toronto, Canada. The sample consisted of all patients (n=360) aged 19 to 21 years of age with complex congenital heart defects. The Canadian Adult Congenital Health (CACH) Network defined successful transition as at least one follow-up appointment at a CACH center before the age of 22. In the total cohort of 360 young adults, 47% (CI: 42-52) met this criterion for successful transition.

In a recent report, Lotstein et al. (2009) presented results from the 2005-2006 National Survey of Children with Special Health Care Needs. The Maternal and Child Health Bureau made receipt of transition services a core performance outcome for community-based systems of care for youth with special health care needs. Parents or guardians of 18,198 youth with special health care needs (aged 12-17) were asked if specific topics had been discussed with their child’s health care provider. These topics included four outcome measures that all must be met to meet the overall transition outcome. The topics included discussions about future adult providers, future adult health care needs, changes in health insurance, and encouraging their child to take responsibility for his or her care. Overall, 41% of youth with special health care needs met the overall transition outcome. Individual indicators provided a more detailed view of the survey

results. Forty-two percent of respondents reported discussing transfer of care to an adult provider, 62% discussed their child's future health care needs, 34% discussed prospective changes in health insurance and 78% reported that their pediatric provider usually or always encouraged their child to take responsibility for his or her own health. In this sample, the sub-populations of the children that included non-Hispanic black, Hispanic, lower income, non-English speaking and without a medical home were less likely to meet the transition outcomes. Notably, these outcomes were measured prior to the transfer of care to the adult setting and do not reflect the "success" of the transition.

Viner (2008) acknowledges the paucity of transition program evaluation but stresses:

We should not wait for rigorous evaluation evidence before instituting programs that ensure that adolescents are adequately trained in disease self-management and that a plan is in place to ensure their disease control or quality of life does not suffer in the move from pediatric to adult services.

### *Summary*

As noted in Chapter One, there are no reports that describe current transition processes and practices used in adolescent HIV clinics in the United States. This lack of empirical data combined with the increasing numbers of HIV-infected youth makes it imperative to examine the HCT process in this population. Further understanding how HCT affects both perinatally infected and behaviorally infected adolescents may ultimately allow providers to improve care for this vulnerable population. It is important to first describe the current practices of HCT and to attempt to identify facilitators and



barriers to the process. This formative research is essential to provide a foundation for future studies that will attempt to identify and validate evidence-based practice models.

## Chapter Three: Methods

### *Introduction*

The purpose of this chapter is to describe the research methodology and analytical processes that were used in this study. Sections addressing the study design, bias and preconceptions, population and sampling strategy; data collection and management; data analysis and ATLAS.ti procedures are included.

### *Design of the Study*

There are no reports in the literature that attempt to describe the process of transitioning HIV-infected adolescents from child-centered care to adult-centered care. Qualitative data has often been advocated as the best strategy for “discovery, exploring a new area, and developing hypotheses” (Miles & Huberman, 1994, p. 10). Speziale and Carpenter (2007) contend that qualitative research is appropriate to discover, describe, interpret and understand human experiences. A qualitative descriptive study design was used to begin to explore this phenomenon. Qualitative research is often able to capture some of the issues that cannot be captured by aggregate statistics and can provide ideas and hypotheses for future study (Robson, 2002).

This project was a secondary analysis of data previously collected during a pilot study conducted in 2007 by this researcher. A preliminary analysis of the data was completed and the findings reported. This secondary analysis was completed using ATLAS.ti, 5.5.9, a qualitative data management software program (Muhr, 2004). This

secondary analysis, with the assistance of the tools available in ATLAS.ti, facilitated a more thorough analysis of the data through a variety of computer assisted lenses.

### *Bias and Preconceptions*

Potential conflicts exist when the researcher has the concurrent role of participant and thus an insider to the research process. Robson (2002) labels this position as the “researcher-as-instrument” (p. 217) and describes the roles of investigator, collaborator, facilitator, and participant. He describes the significance of the researcher’s perceptions and how they can be affected by perspectives from the various roles. It is difficult to prevent bias in these perceptions and this potential for bias must be acknowledged.

This researcher is an adult nurse practitioner who has provided primary care to adults with HIV disease in this community for the past 10 years. During the last several years, the number of adolescents with HIV disease transferring from a pediatric child-centered setting to an adult health care setting has increased. During a standard admission to the adult clinic, this researcher had no introductions or interactions with the adolescent’s clinic prior to the admission appointment. This researcher began to characterize some of these adolescents as unmotivated and poorly educated about their disease and self-management. Assumptions were made that the adolescents could not manage to get to appointments on time, if at all, and did not appear to be engaged in learning or practicing preventive health care appropriate for young adults. This researcher made the assumption that these behaviors may have been partially related to the unstructured pediatric environment and the providers that coddled and pampered these adolescents and continued to treat them as children.

During a portion of this time period, this researcher was working in a unique practice setting where she was invited to act as an informal liaison between the University Adult Immunology Clinic and the University Pediatric HIV/AIDS clinic. Those two different experiences resulted in recognition of previous biases and preconceptions held by this researcher. Interacting with the adolescents in the pediatric/adolescent setting resulted in the realization of the extensive effort spent to educate and prepare these patients to manage their disease and to function independently. Some of these patients were very successful and others were not. This researcher attempted to bracket these biases, preconceptions, and experiences on “both sides of the street” before initiating this study.

#### *Study Population*

Currently an estimated 19,979 adolescents between the ages of 13 and 24 are currently living with HIV or AIDS (CDC, 2008). The majority of HIV infected adolescents receive their medical care in a pediatric or child-centered medical setting (Adolescent Trials Network, n.d.). The population of interest is HIV-infected adolescents who are transitioning or will be transitioning from a child-centered health care environment to an adult-centered care environment. Since the beginning of the HIV epidemic, HIV-infected children were cared for by university-based clinicians as well as designated HIV specialty providers at the National Institutes of Health (Adolescent Trials Network, n.d.). The Department of Health and Human Services (DHHS) Panel on Antiretroviral Guidelines recently updated the recommendations for the treatment of HIV-1-infected adults and adolescents (Panel, 2008). The guidelines continue to stress that better outcomes are achieved in HIV-infected outpatients cared for by a clinician

with HIV expertise. The majority of HIV-infected adolescents, both perinatally and behaviorally infected, continue to be medically managed by HIV-specialists at university-based clinics.

### *Sampling Strategy*

Patton (2002) explains “the logic and power of purposeful sampling lie in selecting information-rich cases for study in depth”, (p. 230). These information-rich cases can reveal important details about issues related to the purpose of this inquiry. This detailed information, frequently referred to as thick and rich, can provide insights and in-depth understanding of the issues being investigated. The purposeful sample identified for this study was a selected group of representatives from clinics affiliated with the Adolescent Trials Network of HIV/AIDS Interventions (ATN). Representatives (key informants) from these clinics were selected because of their knowledge, experience and expertise in developing systems of care for adolescents with HIV. The ATN is a national, collaborative clinical trials network established by the Pediatric, Adolescent, and Maternal AIDS Branch of the National Institute of Child Health and Human Development in 2001. This group of clinics is affiliated with some of the most prestigious academic medical universities in the United States and represents the largest cohort of HIV-infected adolescents in the United States. The ATN conducts both independent and collaborative research, with co-funding from the National Institute on Drug Abuse, the National Institute of Mental Health, and the National Institute on Alcohol Abuse and Alcoholism, through a cooperative agreement mechanism. The University of South Florida College of Medicine, Department of Pediatrics, Division of Infectious Disease is an Adolescent Trials Network clinical site.

All eligible ATN clinics were invited to participate. Due to language and transcription problems in Puerto Rico and the severe disruption of services at the Tulane clinic in New Orleans resulting from Hurricane Katrina, these two sites were not included in the sample.

The Principal Investigator at each ATN site (Appendix A) was contacted and asked to identify one to three representatives from their site who they considered the most knowledgeable staff member(s) involved with their clinic's transition practice as well as those having the most experience with their clinic's practice related to transition.

#### *Data Collection and Data Management*

*Tools and Procedures.* Patton (2002) lists various types of questions that can be used in interviews. He provides examples of questions that focus on experiences, activities, or behaviors; opinions and values; feelings; knowledge; background and demographic information. A 37-item semi-structured interview tool (Appendix B) was designed by a multidisciplinary team experienced in the comprehensive care of adolescents with HIV disease. The interview tool was designed in 2006 in preparation for a grant application. This team was designated PSC 060 by the ATN during preliminary funding efforts. The PCS 060 team members are academic clinicians and researchers at university-affiliated clinics in the United States that include the University of South Florida, Johns Hopkins University and the University of Pennsylvania. Contact information for each of the PCS 060 protocol team is found in Appendix C. The interview tool was designed to collect information about the characteristics of the clinics, the patient populations served by the clinic and the practice models currently being used in the transition of their patients to the adult care setting. They were invited to share their

personal and collective views of the concept of transition and to describe anything that might be considered a barrier or facilitator to the process. While interested in whether the ATN sites have written transition policies, it was also important to gather information not available in written documents that might include the use of additional practices or procedures or practices and procedures that differ from those that appear in written documents.

All interviews were conducted by this researcher. The designated representative/s from each of the ATN clinics was contacted by email to schedule a 60 minute block of time for the telephone interview. The interview tool was distributed electronically prior to the telephone interviews. Verbal consent for both participation and recording of the interview was obtained.

*Institutional Approval.* Based on the Code of Federal Regulations, Part 46: Protection of Human Subjects, this study was granted an exempt status by the University of South Florida Institutional Review Board (IRB). This exemption was granted based on Subpart B (4) which states that “Research involving the collection or study of existing data, documents, records, pathological specimens, or diagnostic specimens, if these sources are publicly available or if the information is recorded by the investigator in such a manner that subjects cannot be identified, directly or through identifiers linked to the subjects”. The IRB also waived the need for informed consent based on this study as an internal quality improvement initiative that would not collect any personal identifying information on human subjects. IRB approval was obtained from the University of South Florida IRB on February 10, 2007 for the original study (Appendix D). The IRB Exempt Certificate number is 105455F. The application was revised and resubmitted in July,

2008. This revision reflects the extension of the project completion date to July 1, 2009. The revision was resubmitted and approved on August 6, 2008 (Appendix E).

*Collaborative Agreements.* Relevant leadership groups within the ATN and respective site leadership agreed to this research collaboration. A Memorandum of Agreement (Appendix F) was initiated between the Adolescent Trials Network for HIV/AIDS Interventions and Patricia Gilliam, MEd, MSN, ARNP, University of South Florida, College of Nursing doctoral student, Co-Principal Investigator; Diane Straub, MD, MPH, Associate Professor of Pediatrics and Chief of the Division of Adolescent Medicine, Co-Principal Investigator and the PSC 060 Protocol Team.

*Consultative support.* Nicholas Woolf, PhD provided consultation related to ATLAS.ti during the design and analysis of this project. Additional support was provided by members of PCS 060 protocol team.

*Data Management and Storage.* The interviews were digitally recorded and copies of each recorded interview were stored on an external flash drive. Written policies and procedures as well as other documents specifically related to transition were requested and when received were electronically scanned into PDF documents for analysis. These PDF documents were also stored on an external flash drive.

The first four interviews were transcribed verbatim by the primary researcher. The remaining 10 interviews were professionally transcribed by Hiredhand or Production Transcripts. Dr. Jon Ellen and Dr. Lori Leonard, members of the PSC 060 protocol team, assisted in the funding of these transcriptions. The transcribed interviews were returned to the primary researcher electronically in WORD format. When each document was returned, its contents were reviewed and compared to field notes taken during that



interview. Several of the transcripts contained words and phrases that were marked by the transcriber as inaudible. These sections were reviewed and compared to the audio recordings to confirm their completeness and accuracy. Electronic copies of all transcripts were transferred to the external flash drive to serve as a backup data source. A set of the electronic interview transcripts was retained by Diane M. Straub, M.D., who served as one of the secondary coders.

### *Data Analysis*

The purpose of data analysis in qualitative research is to impose some order on the large volume of data that are collected. Analysis provides clarification of the essential interpretations of the raw data (Miles & Huberman, 1994; Speziale & Carpenter, 2007). The transcribed interviews were copied and abridged to include notes taken during and immediately following each interview. These notes included ideas that this researcher wanted to clarify or follow-up as well as any intuitions by the researcher relating to the participants tone and feelings toward the interview question or the project in general. Attention was given to inconsistencies, subtleties of tone or hesitancy to discuss certain topics. Accurate interpretation of qualitative data is considered context dependent (Patton, 2002). An effort was made to assess factors such as the participants' support of this project which was conducted by a researcher who was not an adolescent provider and was not directly affiliated with an ATN clinic

Thoughtful consideration to the data requires several "reads" according to Mason (1996). Literal reading of the data involves the "form, content, structure, style, layout... words and language used, the sequence of interaction, the form and structure of the dialogue, and the literal content" (Mason, 1996, p. 109). A second interpretive read

involves expanding beyond the literal content to allow inferences in an attempt to understand the meaning for each of the persons interviewed. Each of the transcripts was read through a minimum of three times prior to beginning dissection and sorting of the data.

An a priori coding framework was prepared prior to the preliminary analysis. This framework was generated using the research questions and interview schedule. It was reviewed by the researcher and two of the doctoral committee members and modified until a consensus was reached. These a priori codes are listed in Table 4.

Table 4

*A Priori Coding Framework*

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<i>Views of Transition</i>	<i>Theoretical Constructs/ Framework</i>
Age-appropriate	Self-efficacy
Developmental	Readiness
Team approach	Stigma
Holistic	Stages of Change
Transition to adult life vs. adult care	Health Beliefs
<i>Discipline Specific Notes</i>	<i>Facilitators</i>
MD	Guidelines/processes
ARNP	Charting Tools
RN	Patient Education Tools
Mental health counselor	Access to mental health services
Case manager	Access to social worker
Social worker	Established relationship with adult provider
Health educator	Location of adult clinic
<i>Decisions Points</i>	<i>Barriers</i>
Age	Financial/funding constraints
Medical complexity	Low availability of adult HIV care providers
Gender	Transportation issues

Table 4 (continued)

<i>Decisions Points</i>	<i>Barriers</i>
Sexual orientation	Lack of social support or family support
Cognitive/developmental delays	Resistance to transition: patient
Psychosocial	Resistance to transition: provider
Mental health	
Substance abuse	

*ATLAS.ti*

*Becoming Familiar with ATLAS.ti.* The researcher attended a 2-day training session in September, 2007 presented by Nicholas Woolf, PhD, a consultant and trainer in both qualitative analysis and ATLAS.ti software. Immediately prior to beginning the analysis using the ATLAS.ti data management software, the researcher attended a 2-day refresher workshop also offered by Dr. Woolf. The workshop materials as well as the web-based ATLAS.ti Technical Manual were accessed during the initial start-up of the analysis. Ongoing consultation regarding HU design, query, and output issues was provided by local experienced researchers familiar with ATLAS and Dr. Woolf.

*Document Management.* Electronic versions of each transcript were imported into a dedicated project folder within ATLAS.ti in the requisite rich text format (RTF). The location of the folder and its unique path served as the permanent location of these files for all future access by the functional component of ATLAS.ti known as the "hermeneutic unit" (HU). After importing into this project file, the individual RTF files were never re-opened to prevent file corruption. The project HU was created and stored within this folder. Daily work in the HU was electronically archived with a file name describing the analysis performed that day.

*Coding Methodology and Framework.* The ATLAS.ti data analysis program provides tools to manage, extract, compare, and explore vast amounts of data. The data can be partitioned into various text passages and then reassembled to focus on specific themes or to answer specific research questions. There are two principal levels available for the analytical work performed in ATLAS.ti. There is the Textual Level that includes activities of segmentation of data file, coding text and writing memos. The second Conceptual Level focuses on combining concepts and model-building activities. “Families”, “supercodes” and “networks” are the ATLAS.ti tools that are used to filter data, combine concepts, identify patterns, and build models (Muhr, 2004).

The first step in this analysis consisted of a Textual Level activity that segmented sections of the interview transcripts into uncoded text passages. These text passages were selected as representative of the priori themes and specific responses to the research questions in the study. These quotations were marked but not coded during this iteration. The selected text passages were marked to provide a document that was later coded by one of the researcher’s doctoral committee members proficient in ATLAS.ti. This additional coding provided a check on the reproducibility of the coding framework. This activity provided investigator triangulation using two different researchers (Patton, 2002).

During this iteration, an ATLAS.ti “memo” was used to catalog a list of codes that would be considered for use during the analysis. A code that is generated but not attached to a text passage is known as a “free” code within the ATLAS.ti program. This list of “free” codes was populated with frequently used or provocative words identified during this read of the data set. The original list of “free” codes totaled 122 and can be seen in Table 5. This list of “free” codes was compared to the a priori codes previously

used in the manual coding of this data set. Any of the original codes that were not contained in this list of “free” codes were added. These “free” codes were then reviewed for relatedness and redundancy.

Table 5

*Original List of “Free” Codes (n=number of coded text passages)*

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demographics (n=93)	ER (n=0)	models of care (n=0)
!description /models of care (n=86)	extra question (n=0)	Motivational Interv (n=1)
!QUOTATION (n=51)	facilita* (n=10)	MSW (n=1)
!role (n=39)	Failed transition (n=21)	open door policy (n=4)
!social support (n=22)	find out (n=0)	option to transition (n=5)
!view/opinions (n=26)	follow* (n=0)	peer (n=4)
\$criteria for transition (n=29)	funding (n=4)	perinatal/behavioral (n=24)
\$differences in transition (n=43)	gay (n=15)	pregnancy (n=23)
adherence/nonadherence (n=6)	gender (n=2)	prev for positives (n=1)
admi* (n=0)	guidelines (n=0)	PRIVACY:= priva* (n=28)
adult clinic (n=48)	GUIDELINES:=guideline* (n=205)	procedure* (n=0)
age of clinic population (n=1)	hand" off (n=0)	proceed* (n=0)
anger (n=0)	Health Educator/outreach (n=1)	process vs. event (n=5)
anonym* (n=18)	hinder* (n=0)	process* (n=8)
ARNP (n=22)	HIPAA (n=2)	Program Manager, BS (n=1)
ARNP-Mary CHOP (n=8)	hold on (n=1)	protocol* (n=0)
ARNP Hannah & Donna (n=1)	holding on (n=0)	refer* (n=18)
ARNP/LCSW (n=1)	homeless (n=3)	relationship, long (n=5)
assist* (n=10)	HOSPITAL:=hospital* (n=28)	Research Coord.-BSN (n=1)
barrier* (n=15)	in the way (n=22)	return p transition (n=23)
cognitive (n=16)	insurance (n=25)	scale of 1 to 5 (n=14)
confidential* (n=1)		sexual orientation (n=0)
counseling (n=51)		shame (n=0)
		Social Worker (n=2)

Table 5 (continued)

criteria for transition (n=15)	interest in the study (n=10)	SW (LCSW) (n=3)
developmental (n=51)	keep* (n=0)length of	SW (MSW/MPH) (n=1)
difference in adult and pediatric	transition (n=8)	stigma* (n=5)
models (n=5)	let go (n=0)	success* (n=89)
disclos* (n=1)	letting go (n=0)	SW-LCSW (n=5)
disenfranch* (n=0)	life skills (n=19)	track* (n=16)
document* (n=3)	location (n=5)	transfer* (n=1)
drug use (n=10)	marginal* (n=1)	transgender* (n=9)
ED (n=0)	MD (n=3)	unit (n=0)
emergenc* (n=0)	MD interview/ NP	youth, not adol (n=0)
EMOTION:=abandon* (n=18)	transition point person	
	(n=1)	
	medically complex (n=19)	
	Mental Health Counselor	
	(n=4)	
	mental health problems	
	(n=7)	

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*Note.* n=number of text passages captured using “autocoding” feature.

Several frequently occurring concepts were identified while reviewing the original list of free codes. The concepts were discussed within the interviews using a variety of synonymous words and phrases. An ATLAS.ti programming tool known as “supercoding” was used to identify all text passages that contained synonymous words or phrases for these concepts. “Supercodes” are formulas, similar to macros in other software applications that when activated will query all the HU documents (transcribed interviews) and retrieve text passages that contain any of the individual components of the “supercode” (Muhr, 2004). The primary researcher identified four frequently

occurring concepts and constructed “super codes” that were used to code for any variation in the presentation of the concept. These “supercodes” are listed in Table 6. The supercodes PRIVACY, HOSPITAL, and EMOTION were considered emerging themes that did not directly relate to any of the research questions.

Table 6

*Super Codes*

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GUIDELINES:=guideline\*|process\*|protocol\*|document\*|proceed\*|track\*|follow\*|keep\*

PRIVACY:=priva\*|HIPAA|confidential\*|anonym\*|disclos\*|find out

HOSPITAL:=hospital\*|unit|emergenc\*|admi\*|ED|ER

EMOTION:=emotion\*|abandon\*|disenfranchi\*|marginal\*|letting go|let go|holding on|hold on| fear|stigma\*|anger|shame

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*Note.* \* is an ATLAS.ti programming symbol for a wild card or alternate endings to the root word that precedes the \*. The pipe symbol, |, is an ATLAS.ti programming symbol for the Boolean operator “or”.

The “autocoding” feature in ATLAS.ti was used during the first pass of coding the data set of transcribed interviews. “Autocoding” systematically processes through the documents and assigns the code to any passage that contains a specific word or a derivation of the root of the word followed by the symbol \* (Muhr, 2004). The volume of text contained in each automatically selected passage was defined by the researcher to include the entire paragraph that contained the word or its derivative. The documents were originally autocoded using each of the four “super codes” followed by “autocoding” using each of the individual codes.

The frequency of text passages associated with any “supercode” or individual code ranged from 0 to 205. Twenty-two of the original codes did not attach to any text passages during the first iteration of “autocoding”. These codes were deleted from the list of active codes. Text passages associated with a code that identified less than ten passages were reviewed. In several instances the passage had also been autocoded with another more relevant code. In those cases the more relevant code was retained and the less frequently assigned code was “unlinked”. Note that this “unlinking” did not lose the passage, it simply left the passage “linked” to the more frequently applied and relevant code. Several of the codes that identified less than ten text passages considered relevant and/or unique ideas and were retained with no modifications. After this consolidation of the code list, a more parsimonious list of 64 codes remained. The codes were then assigned to categories that represented an a priori theme, a research question or an emerging theme. The final list of codes and categories can be seen in Table 7.



Table 7

*Final Categories and Codes*

<i>Role &amp; Credentials</i>	<i>Characteristics of Transition</i>	<i>Social Factors</i>
ARNP	Criteria for transition	Social issues
MD	Differences in transition	Social Support
MPH	Documentation	Support Groups
MSW	Length of transition	Social Worker
LCSW	Transition as an option	Social Medicine
BS Social Work	Models of Care	Social Cognitive Theory
BS Nursing	Referral Sites	
BS Public Health	Rank of difficulty	
Health Educator	Program Description	
Mental Health Counselor	Return after transition	
Peer	GUIDELINES	
Case Manag*		
Nurs*		
Role		
<i>Facilitators</i>	<i>Barriers</i>	<i>Miscellaneous</i>
Assist*	barrier*	Demographics
Developmental	adherence/nonadherence	Gay
Facilita*	Adult clinic	Homeless
Life skills***	Cognitive delay	Interest in the study
Success*	Drug use	Motivational Interview
	Failed Transition	Peer
	In the way	Perinatal/Behavioral
	Insurance	Prevention for Positives
	Medically complex	Process*
	Mental health problems	Transgender*
	Long standing relationships	View of transition
	Stigma	Quotation
	Track*	HOSPITAL***
	EMOTIONS	
	PRIVACY	

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*Note:* \* is an ATLAS.ti programming symbol for a wild card or alternate endings to the root word that precedes the \*. Supercodes are presented in all capital letters.  
 \*\*\* = emerging theme.

Each of the interviews was re-read and the most applicable code was manually assigned if that passage had not previously been coded. This occurred if the passage did not contain the exact word or a derivative that would code while operating in the “autocode” mode. It was during this pass of the data that any text passage that was considered particularly rich was identified by the code, QUOTATION. Fifty seven quotations were coded and exported to a WORD document for later review and consideration for inclusion into the discussion section.

### *Rigor, Credibility, and Confirmability*

Lincoln and Guba (1985) suggested that quality in qualitative inquiry can be assured by credibility, transferability, dependability and confirmability. These concepts serve to replace the conventional positivist quality indicators of internal validity, external validity, reliability and objectivity. Patton (2002) similarly discussed credibility and rigor as the benchmarks for quality in qualitative research.

Rigorous methods of both data collection and analysis were employed throughout this research study. Rigorous investigation was supported by the credibility of the researcher, PCS 060 protocol team members, and doctoral committee members who are all experienced researchers in their respective academic communities. Rigor in the data analysis 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 clinic. Triangulation with analysts incorporated an independent analysis by one members of the researcher’s doctoral committee.

Member-checking of the data provided credibility, confirmability and transferability to the conclusions drawn from this study. Member checking provided the

participants or stake-holders an opportunity to correct errors in assumptions and provides an additional opportunity to volunteer additional information. A sub-set of the key informants were asked to verify whether the results and conclusions reached by the researcher reflected their own beliefs and experiences. These key informants included all ATN site representatives that attended presentation of these findings at meetings for Ryan White Title D funded sites in July, 2007 and ATN funded sites in October, 2007. Discussions during the formal question and answer sections of each of the presentations as well as informal conversations during these meetings suggested agreement with the findings and conclusion.

#### *Summary*

Chapter 3 described the study design, bias and perceptions, population and sampling strategy; data collection and management and data analysis including ATLAS.ti strategies and operations. Methods used to insure rigor, credibility, and confirmability were also described.

## Chapter Four: Findings

### *Introduction*

The purpose of this study was to identify and describe the characteristics, structured processes and practice models currently being used in the transition of HIV-infected adolescents from child-centered medical care to adult-centered medical care. This researcher believed that the transition and transfer of adolescents with HIV disease to an adult care setting could be improved if the current processes and practice models used in the Adolescent Trials Network (ATN) clinics were identified, compared and presented in a forum for discussion and future intervention development. This chapter presents findings from a secondary data analysis of 14 in-depth interviews with key informants from each ATN clinic and a document analysis of written policies, charting, or educational documents related to transition activities that were submitted for use in this analysis. The data was originally collected by this researcher for a pilot project in 2007. A preliminary data analysis was performed by the original PSC 060 research team to provide support for a grant application that continues in process. This secondary analysis provides a more thorough analysis using ATLAS.ti, a qualitative data management software program (Muhr, 2004).

The findings presented in this chapter are discussed in sections that address the relationship of codes to study demographic data, the relationship of codes to research questions, and salient themes that emerged during the analysis.

### *Relationship of Codes to Study Demographic Data*

Demographic characteristics that were collected in the interviews as well as any other text passage that contained a numerical value were manually coded in the category of 'demographics'. This code was assigned to 97 text passages. These text passages were transferred to a WORD document using an ATLAS.ti output feature. Related responses were reviewed and frequency data reported.

Fourteen Adolescent Trials Network (ATN) clinics were included in this study. These ATN sites were located in Chicago (2), Boston, Philadelphia, New York (2), Washington D.C., Baltimore, Memphis, Tampa, Ft. Lauderdale, Miami, Los Angeles and San Francisco. One to three staff members from each clinic were selected to participate in a single interview per clinic. Nineteen key informants were interviewed between March and December, 2007. Three key informants from the University of Miami clinic were interviewed. The group consisted of a case manager, social worker and nurse practitioner. Both St. Jude's Hospital and Children's Hospital of Philadelphia designated a social worker and a nurse practitioner to participate in the interview from their site. The clinic at Washington D.C. Children's Hospital designated a social worker and a registered nurse to participate in the interview. The clinic at the University of Maryland in Baltimore was represented by a health educator who functioned as a youth outreach worker and case manager. Site representatives included social workers (n=7), nurse practitioners (n=7), physicians (n=3), a registered nurse (n=1), and a health educator (n=1). These site representatives were previously identified as being the staff involved in their clinics' transition practice as well as those having the most knowledge and experience with the development of their clinics' transition practice. All but one of the

ATN sites was represented by staff members who met this criterion. That site was represented by a physician who mentioned other staff members in the clinic that were instrumental in planning and implementation of their transition efforts. Two requests were made to speak to those individuals and to obtain copies of their written materials. There was no response to these requests.

At the time of this inquiry, the patients in this age group who were currently in care at the fourteen clinics totaled approximately 1,775. The total number of adolescent patients (12 to 25 years of age) cared for at each site ranged from 31 to 266. Five clinics managed patients from infancy to age 25 and eight clinics exclusively managed adolescents from 12 or 13 years to age 25. Two of the clinics 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 4 to 16 per year. The interview tool requested information about the annual number of adolescents who had been transitioned and the annual number of those that had successfully transitioned during the previous 12, 24, 36 and 48 months. Answers to these questions could not be accurately or completely provided. The notion that there was no standard definition of a successful transition became apparent early in the course of the interviews. Only one of the key informants inquired about the definition of a successful transition to guide her data collection. Her interesting response was:

That was my question. Because it says successfully started adult care, I took that as an appointment. So in that, which is a very lenient term of success, then in 12 months we had six; in 24 we had nine; 36 was 11; and 48 was 13. But again, that's using just went to their first appointment in adult care. That's not saying a

lot about the success rate.

Another respondent's initial comment in the interview addressed her awareness of her inability to provide an accurate accounting of her clinic's transition statistics.

Some of the information you asked for, in terms of numbers of clients, etcetera. They're a little bit loose. They're not spot-on, because sometimes it's a little bit hard to track, but we did the best that we could....And I guess sometimes defining success versus failure we feel like any time they make it to adult, even if it's been two years, we'll give them a little bit of credit. There are some areas that are a little bit gray.

Respondents did, however, provide an estimated number of transitioned patients and in some cases an estimate of successful transitions based on feed-back from the adolescents themselves or through informal follow-up by a clinic staff member, usually acting in the role of a case manager.

Another interview question addressed whether or not the clinics had a system to track patients after they were transitioned to the adult clinic. This question provided additional insight into the inability to provide accurate numbers related to transition. 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 frequently consisted of feed-back from the adolescents themselves or through follow-up by a clinic staff member, usually acting in the role of a case manager. One of the respondents provided this insight:

That's the piece that we need to do some work on. That is the piece we hope will happen when [name] can dedicate some time to this project. We don't have any really good tools to track them after they have transitioned. We have a plan. What is probably very common across the country is that these kids have addresses and phone numbers that seem to change sometimes weekly so they are difficult to access after they stop coming here.

One of the interview questions elicited opinions on the preferred age range for an adolescent to transition to adult care. The question was posed in a multiple choice format offering choices of 18 to 20 years, 20 to 22 years, 22 to 24 years, older than 24 years or varies with the individual? The key informants from seven clinics opined that transition was best attempted between 22 and 24 years. There was another group representing six clinics who suggested the preferred age for adolescent transition would vary with the individual. One clinic representative stated that she believed the preferred age for transition to be 20 to 22 years of age.

The site representatives were asked to rate the difficulty of transitioning adolescents on a scale of 1 to 5, with 5 being the most difficult. It was interesting that at times the responses on the scale of 1 to 5 seem to contradict some of the imbedded quotations related to the difficulty of the process. A key informant rated the difficulty of the process as "maybe a two. I don't think it's that difficult at all. No, it's not very difficult. I'd say a two". He went on to say:

Well, I do primary care too. And I would say probably for my primary care patients without chronic illness, it's probably a two. For my primary care patients with HIV or other serious medical and mental health conditions--because I think



the ones that have mental health problems become the hardest all the time--it's probably between a three and a four.

Implementation of a structured transition process may decrease the perceived difficulty of transition as one respondent explained how her clinic's process had evolved over time. She said, "I think if you had asked me this question four years ago I would have told you about a 7, but now I would probably say a 2-3".

### *Relationship of Codes to Research Questions*

*Research question one.* How do ATN health care team members view transition?

This research question was synthesized from the following three questions in the interview tool.

- Are there differences among members of the health care team in terms of how you go about transition planning? If yes, could you describe these to me from your perspective and provide examples?
- Are there different opinions about how best to transition adolescents to adult care among the team members? If yes, can you tell me more about some of these differences?
- Can you tell me more about how providers at your site view transitioning adolescents to adult care?

The ATLAS.ti "autocoding" function was applied using the codes *differences in transition* and *view/opinions about transition* that attached to 45 and 26 text passages respectively. To determine if any of these passages were coded to more than one of these

codes, the ATLAS.ti function known as “cooccurrence” operator was used. There were no text passages co-occurring between these two codes. These 71 text passages were then transferred to a WORD document for review.

All of the key informants reported that staff members had similar views of transition. Phrases such as “we’re all on the same page”, “function as a team”, “collaborative, multidisciplinary approach” were mentioned frequently. Several of the informants reported a weekly interdisciplinary team meeting where patient issues, including transition, were discussed. The following is an example of these shared views:

But, you know, we meet as a collective team each week and talk about not just these cases but all the cases, so we generally are all on the same page in terms of how we want to do these transitions.... I think everyone is pretty much on the same page. I mean, we think it is a challenge at times, but I don’t think there are real fundamental differences in opinions.

In other cases a key informant would answer one of the questions with a response that suggested some difference of opinion within the team. Several examples of these discordant opinions were between the medical providers and the social workers. An example:

I think we are pretty consistent because we are all at the same site.... Differences are how much hand holding. What the doctor expects, what I [social worker] expect. That is what is inconsistent. Our view of how much self-sufficiency should someone be at [sic]. There is no one size model. Not everyone is functioning at an adult level. I think there is a unified view that we are not

transitioning appropriately, there is something missing, we have to learn how to do this differently or do it better....Case managers think they are holding their hands too much. They feel they are being asked to hold their hands when they shouldn't because it's not a realistic view of what the young person is going to experience in adult services.

So I think the differences may just come down to an individual preference, again, I mention the case managers may have a certain opinion about where clients may be more effectively served, and we may have another but I think, all in all, we're pretty much on the same page, as far as where and how best to get a client linked with an adult program.

There was a consensus of opinion that transition to adult care was an important issue that was increasing in urgency as the perinatally infected adolescents were approaching the age of 24. Six of the fourteen ATN clinics had written guidelines or written procedures that detailed their transition model. The key informants from these six clinics provided a much more comprehensive and detailed view of transition. This group also described a similar philosophy that incorporated ideas such as beginning the transition process early, individualizing the process, a gradual process, a process using adolescent development theory, and a holistic approach that incorporated patients' psychosocial and medical needs. A Pediatric Nurse Practitioner who was responsible for beginning to develop the clinic's process more than six years ago described her view of transition:

We view it as it needs to be something that goes on from the beginning. I mean,

even as a child--we take care of, you know, three-year-olds now--even at five and six talking to them about taking their meds and just developmentally-appropriate information and developmentally-appropriate responsibility so that when they reach the teenage years they already have some of this, or when they reach adulthood. You know, it's kind of a gradual learning. So it should begin early, it should be ongoing education and, like I said, developmentally-appropriate information, developmentally-appropriate responsibility. And then it should be individualized. That is very important. It needs to be something that goes on from the beginning.

There was also a spectrum of emotions described when discussing views about transition. Expressions of joy and satisfaction surrounding transition are contrasted to expressions of sadness and personal loss for both the adolescent and the providers. These feelings can be felt in the following passage:

The bulk of us think of it as it's almost like a graduation. Like, congratulations, you're an adult now. And you're going to do great. We've hopefully prepared them for managing a chronic illness for the rest of their life, and navigating the health care system.... I would say there's one or two who have, like I said, difficulty letting go. So to them, it's a loss. They feel a loss at losing those patients. So some of the times that gets--the patient picks up on that. So they feel like it's a negative thing... that they have to leave us. Our attitude towards it makes a big difference.

These feelings reflect the strength of the bonds between patient and providers. The emotions of sadness and loss are also considered in the discussion of barriers to transition.

*Research question two.* What do ATN health care team members perceive as facilitators to a successful transition to adult care?

This research question was synthesized from the following two questions in the interview tool.

- Can you think of a specific example of a successful transition? If so, why was it successful?
- Are there things at your site that facilitate the transition process? If yes, what are they? The codes used to identify text related to these concepts and their coding frequencies were *success\** (n=89), *assist\** (n=7) and *facilita\** (n=12). There were a total of 108 text passages identified using the “autocode” function. To determine if any of these passages were coded to more than one of these codes, the ATLAS.ti feature known as “cooccurrence” operator was used. There was only one text passage that co-occurred, resulting in a total of 107 passages that were coded to identify factors associated with a successful transition. These text passages were then transferred to a WORD document for review.

During the initial review of the transcripts, life skill development was frequently discussed as a facilitator and predictor of transition success. A specific code, *life skills*, was assigned during the first iteration of open coding and 19 text passages were attached to this code for later analysis.

Key informants agreed that successful transitions were facilitated in a patient who had strong social support, emotional maturity along with the ability and motivation to function independently. Maturity and independence were also mentioned frequently during the discussions of life skill development. The following text passages describe not only the specific skills but also methods for their instruction.

We have a support group that meets but those are for the kids that come to the group and we do teach life skills, we do have an advocacy group, how to negotiate systems....like the welfare office, how to get your insurance, those kind of things which are really difficult to negotiate as an adolescent or young adult....But for those kids that are transitioning that don't come to group, we will work with them individually. Locally there is a lot of education for consumers. There's a program in Philadelphia called Project Teach through an AIDS service organization. Project Teach is a class, I think it's 8 weeks, and they have a curriculum and part of that curriculum is how to navigate the medical system as an HIV+ person. That class is really helpful and we refer kids to that class. We have had kids go through that class which is invaluable training for our kids.

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 prepare these kids to move to adult care. It's a process and there is a lot of learning that they have to do.

Another scenario describing a successful transition experience emphasized the importance of starting early, dealing with emotional issues and trust:

The process was started early. The patient's reaction to approaching transition (fears, anxieties) was worked through. Barriers were addressed and worked through. Based on our years of working with the patient, we have built a relationship of trust so that they believe we are working for their best interests.

Another passage highlights the importance of collaboration with patient to make the first visit to the adult clinic a comfortable, well-planned visit. The importance of the adolescent's support system, readiness to transition, as well as communication between the adolescent and adult providers are also discussed as facilitators in this passage. This scenario also describes several of the staff interventions that were used during the transition process.

And this person that was her support system at that time--the three of us just went and visited the site. And I think that that whole collaborative kind of approach to transitioning... and, of course, I spoke with the agency on the other end, and they were expecting her so, when we got there, it was a positive experience. It was a

welcoming experience. And it was more than just, “Here, here’s a referral. Here’s some place that you can go. And I think that that might’ve helped to make it successful. But I also think that, again, that trusting relationship and the growth, the individual growth, that the person experienced, I think along with us working with her, helped to get her to a place where she was ready.

The following account of a transition experience is particularly poignant to this researcher because this young lady is now one of my patients. This account again reinforces the importance of including the adolescent in the planning process, listening to his or her concerns and individualizing the experience for each patient. References were made in several of the interviews to the reassurance given to the adolescent that the pediatric team will continue as a resource until transition is completed.

She was one of the first that would have been transitioned from this program. Ultimately we identified with her what would be helpful to her. She wanted to have somebody go with her to visit, so we did that. I think why it was successful was because we listened to her and didn’t just say, “You’re an adult, you can go on and do this, you’re going to be fine.” We listened to her fears and her concerns and said, “Just because this is a good thing that you’re moving on, look at what’s happened for you. Did you think you’d be doing this?” And just because we weren’t going to be her doctor, that we were here as a resource until she was comfortable in her new setting.

*Research question three.* What do ATN health care team members perceive as barriers to a successful transition to adult care?



This research question was synthesized from the following three questions in the interview tool.

- Can you think of a specific example of a failed transition? If so, why was it a failure?
- Are there things at your site that get in the way of the transition process?  
If yes, what are they?
- Have any failures occurred which made your site reluctant to transition your patients?  
If so, can you tell me about that failure?

Thirteen codes were used to identify text related to these concepts that are listed in 8. To determine if any of these passages were coded to more than one of these codes, the ATLAS.ti feature known as “cooccurrence” operator was used. There were 28 text passages identified as co-occurring that resulted in a total of 177 passages associated with barriers to a successful transition. These text passages were then transferred to a WORD document for review.

Table 8

List of Codes for Barriers to a Successful Transition (n=number of coded text passages)

Barrier* (n=15)	Insurance (n=27)
Adherence/nonadherence (n=6)	Medically complex (n=17)
HIV/AIDS adult clinic (n=51)	Mental health problems (n=7)
Cognitive Delay (n=16)	Long-standing relationship (n=5)
Drug use (n=11)	Stigma (n=5)
Failed transition (n=21)	Tracking (n=16)
In the way (n=22)	

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*Note.* \* is an ATLAS.ti programming symbol for a wild card or alternate endings to the root word that proceeds the \*. (n=X) represents the number of text passages assigned to each code.

The following passage describes the difficulty changing and terminating a long-standing relationship.

Like yesterday, we had such a rich discussion about one of our patients of how I held him back because I've had him since he was fourteen, and I keep treating him; it's very hard to change. It's the provider...my emphasis is really not on [sic] young people are going to grow up. It's the responsibility of providers to really change their behavior in relationship to their patients. And there's a big difference between a pediatric and adolescent and an adult model.

Site representatives reported the adolescents' perceptions and fears of the adult clinics as important barriers to HCT. These clinics are known in many communities as the 'AIDS' clinic. Adolescents cited the lack of confidentiality with a fear of being

recognized as 'positive'. The following passages describe multiple barriers to transition that are associated with many adult clinics. These passages were coded to the supercodes of PRIVACY and EMOTION. The supercode PRIVACY combined the individual codes of priva\*, HIPAA, confidential\*, anonym\*, disclosure, and find out. The supercode EMOTION combined the individual codes of emotion\*, abandon\*, disenfranch\*, marginal\*, letting go, let go, holding on, hold on, fear, stigma, anger, and shame. The supercodes of PRIVACY and EMOTION identified 48 and 18 text passages respectively. Several of the most descriptive passages follow:

Fear:

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're afraid of that.

Disclosure:

Some of them won't go to the program for people that's [*sic*] identified as being an HIV-positive clinic, even though it's not called that, everybody knows what it is. They just refuse.

Lack of privacy:

She got really turned off, because it's a very different system, a different clinic. It's overcrowded, it's not pretty, there's no privacy. It's the complete opposite of our clinic. You know, our clinic is in a pediatric facility and it's very friendly--or relatively friendly. We have front office staff that respect confidentiality. So all of those things put together...

Stigma:

Unfortunately, that is true with the adult clinic here on campus. They just stand out as a person with HIV. You wouldn't be sitting in that lobby or you wouldn't go down that hallway, corridor D, that says "Special Immunology," if you didn't have HIV.

Negotiating the Adult World:

We can do everything right and then we'll send a patient to the adult clinic and it's a different system. A client could maybe--their Medicaid card has expired, or they were ten minutes late and the front office person is not helpful, and then they get frustrated, and all of a sudden the patient just says, "Forget it," and they leave.

We could do everything right and still have a transition failure based on something that had absolutely nothing to do with our transition process.

Differences in Adolescent and Adult Care Models:

Adult services are just so different, you're lucky to have a 10 minute appointment. I just don't think they have the resources to provide the same level of care. We serve about 100 clients and some of them have 1000's coming through.

When we talk to them about how to assert themselves with doctor....Maybe you can write down some of your questions because the doctor is going to probably come in and going to probably have ten or fifteen minutes with you. So he's going to have an agenda. He's going to come in, he's going to rush, and that, if you're really not prepared for that, he might come across as somewhat intimidating.

There is evidence to support that transition of these adolescents from adolescent care into adult care can be very problematic. The problems are intensified when multiple barriers and obstacles are occurring simultaneously. Several scenarios of a failed transition are examples of these complex issues. One example follows:

She is also on our Community Advisory Board (CAB), in care with us since she was 2, in Peds clinic, transitioned to our clinic. In the process, she's had 2 children both negative, and she's also adopted 2 family members. She's just an amazing woman. Not truly literate just keeping her family together. Strong skills *[sic]* life skills are great. Anyone that can raise 4 children *[sic]* she's 25. Thinking of where she she lives, thinking about her children's care, all her kids are seen at our hospital. We found a clinic a block from us that specializes in women's care, has a good reputation, started the conversation early. Whatever, it never happened. Her meds ran out and she still hadn't seen a physician, Dr. [name] had to refill her meds. Failure to communicate on our part and the adult clinic *[sic]*. We use an information database in HIV care services funded through local health dept. In concept it's great, people sign one consent, and it is good for all Ryan White clinics. The whole idea is that people can go from clinic to clinic. We didn't have any type of paper system, do we contact them, what do we expect her to do? What do we give her, what will she need to be successful. What will she really need to get through the registration processes? Unfortunately we had not given her what she needed. She was not very vocal about it, and she got very frustrated with the process. Like many women she deferred her own care and focused on her kids. She never followed through Four months later, at a CAB she

still hadn't been seen [by a provider]. I don't have a doctor still and they haven't called me back. I needed this form from such and some case manager and I never got it. I really would have appreciated someone going with me to my first appt.

*Research question four.* What are the similarities and differences among the clinics that have a structured transition program and those that do not?

A comprehensive review of the data to discuss this research question could not be accomplished from a simple ATLAS.ti query. The first step included a manual review of each transcript and manually assigning codes to relevant text passages that addressed this research question. The two codes used were *criteria for transition* and *differences in transition*. These codes were assigned to 41 and 45 text passages respectively. The next step was a manual review of the transcripts from clinics with and without a structured transition program to identify patterns of similarities and differences. Any new pattern that was recognized during this manual review was recorded using the ATLAS.ti "memo" function and later reviewed.

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

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

Three clinics reported using documentation and charting tools that were specific to transition. These documents included a checklist of knowledge and skills for management of HIV and a transition specific plan of care. The topics addressed in the knowledge/skills checklist and plan of care are listed in Table 9. Two clinics described the use of a Transition Workbook developed by the Adolescent HIV/AIDS Workgroup from the National AIDS Education and Training Center (AETC, 2006). This workbook uses a developmental approach to teach and reinforce various life-skills and health information.

Table 9

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

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

The key informants from the clinics with the most comprehensive transition plans clearly articulated the need to use a developmental approach in planning transition. Examples of this developmental approach with the intent to teach and reinforce life skill are highlighted in the following passages:

We view it as it needs to be something that goes on from the beginning...You know, it's kind of a gradual learning. So it should begin early, it should be ongoing education and, like I said, developmentally-appropriate information, developmentally-appropriate responsibility. And then it should be individualized. That is very important.

The other conflict that we found is that if you do not understand adolescence as a developmental process itself then your expectations of each individual are beyond their capability. So what we have found out from the original chart review is that they actually are adolescents and did not have the life skills to follow-up after they were discharged. I mean it looked like we had transitioned them, but the fact is they did not have the skills to successfully stay in care.

We have a support group that meets but those are for the kids that come to the group and we do teach life skills, we do have an advocacy group, how to negotiate systems...like the welfare office, how to get your insurance, those kinds of things which are really difficult to negotiate as an adolescent or young adult.



The most striking difference between the clinics with and without a structured transition process is the fundamental approach to transition as a process rather than an event. This difference in approach explains that those clinics with a process of assessment, planning, intervention, and education as a preparation for transfer to an adult care setting. The profound difference in these two approaches is evident in the following passages. When queried about the length of their clinics transition process, the following replies were provided by the key informants from clinics without a transition process in place: “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 24<sup>th</sup> birthday”, or “six to seven months”. The responses from the clinic representatives who had a transition process in place revealed a very different perspective: “With our old process it could be a year or more but with our new plan it can vary from 6 months to 2 years”, “the process starts the day they come into our clinic”, and “we start at age 16 and discuss at every visit”.

Numerous scenarios described transition as a process. They illustrate that lessons are learned over time and that the process of transition is an iterative one that needs frequent evaluation and revision. An example:

So I think all of our providers think it’s [transition planning] incredibly important, and we really have worked hard to create this protocol, fine-tune it. We’re constantly revising it, so I would say that for all of the providers, it’s one of our biggest priorities.

*Research question five.* What strategies have ATN systems of care developed to assist patients in making a successful transition to adult medical care?

This research question was synthesized from the following four questions in the

interview tool.

- Are there specific criteria that your team uses when thinking about transitioning a patient to adult care?
- Are there any tests performed that figure in the decision about whether to transition an adolescent to adult care?
- Is there any documentation that is part of the transition process at your site?
- Are there things at your site that facilitate the transition process? If yes, would you describe?

The codes used to identify text related to strategies used in ATN systems of care and are criteria for transition (n= 41), facilitators (n=12), assist\* (n=7), success\* (n=89), life skills (n=19) and developmental (n=14). To determine if any of these passages were coded to more than one of these codes, the ATLAS.ti function known as “cooccurrence” operator was used. There were 8 text passages identified as co-occurring which resulted in a total of 174 passages coded to factors associated with barriers to a successful transition. These text passages were then transferred to a WORD document for review.

Representatives from several sites described practice models that serve to gradually orient the adolescent to his or her future adult provider and adult clinic environment. Several of the sites arrange tours of the potential adult clinics. The adolescents are accompanied on these visits, as well as first appointments, by either case managers or peer educators as well as a member of his or her family or support group. Several of the site representatives commented on the benefits of case management for the adolescent entering adult care. They described benefits of continuing contact between the

adolescent and his or her adolescent case manager during the first year following transfer to the adult clinic.

Two sites employ an adult nurse practitioner to manage the care of the transitioning patients during the last year or two prior to transfer to the adult clinic. This adult provider would then become the adolescent's provider following the transfer to the adult clinic. One site uses a psychiatrist that sees patients at both the adolescent and adult sites. One nurse practitioner that practices at both the adolescent and adult clinics describes her responsibilities in the following text passage:

And everyone agrees, at least intellectually, that transitioning patients to me when they're twenty-four [is a good idea]....that they have a year to get used to me while still in the same clinic environment. And part of my job in that year is to teach them adult behaviors around making appointments and keeping appointments and coming on time and how to talk to a pharmacy about your prescriptions, and stuff like that.

Representatives from one clinic described a celebration that is enjoyed by patients, their families as well as the health care team.

The other thing that we do is we have a graduation ceremony so, like, in May they wear a little cap and gown, and we get them a plant, and we have a big ceremony for the people who are graduating, which is really nice for people because it gives them a sense of accomplishment and closure.

### *Salient Themes*

Two themes emerged from the data that did not directly relate with any of the research questions. One of the emergent themes involved differences in the transition experience for various subpopulations of adolescents with HIV disease. This inquiry was framed around the following interview question: Have you noticed any differences in how your team transitions patients based on variable X? The variables of interest included age, developmental delays, cognitive limitations, medical complexity, and membership in a sexual or gender minority group, or pregnant. Respondents from 13 of the 14 sites reported that more attention and time devoted to skill development would be provided to those adolescents with developmental or cognitive delays. Informants representing 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 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.

However, it was noted by informants from seven sites that pregnant adolescents seemed to experience an easier transition to adult care. This information is of interest because some of the explanations may be instructive in planning transition interventions for other adolescent groups. Pregnant adolescents were frequently reported to be referred to other providers during their pregnancy. They were often referred to adult OB/GYN providers and could opt to stay in the adult clinic or return to the adolescent clinic after the birth. Several site representatives expressed the belief that women appeared to have

an easier transition to adult care if they had experience with a different provider during pregnancy. The following passage describes such an experience:

The obstetrician, who had taken care of her during her pregnancy, also works as a primary care provider in the adult clinic. And she wanted to go to him; she already knew him. And she is in care on antiretroviral therapy with an undetectable viral load and she's twenty-five.

It was also noted that females with children received Medicaid benefits and other entitlements that would not only increase the number of available adult providers but might also assist in other expenses necessary to stay in care, such as money for transportation, co-pays, and stable housing.

Another set of issues that was frequently mentioned surrounded hospitalizations and emergency visits to hospitals for adolescents and young adults with HIV/AIDS ranging in age from 15 to 25 years. The fundamental issues relate to age restrictions at specific health care locations and scope of practice for pediatric, adolescent and adult providers. The medical settings most often mentioned as problematic were children's hospitals and emergency departments. Problems occur when there are hospital policies related to age restrictions for admission to specific units, scope of professional practice and reimbursement issues. From a patient perspective, if admitted to a children's hospital, he or she begins to become uncomfortable in the child-centered environment. Other problematic situations were reported that involved either a recently transitioned adolescent or an adolescent who was transitioned in the past but is now lost to follow-up. In both of these situations, it is common for the young person to provide the name of their previous pediatric or adolescent provider as their contact. Another reported concern was

an inconsistency of policies related to adolescents with congenital illnesses when compared to adolescents with HIV disease.

The following passages describe several of these dilemmas:

Children's Hospital Emergency Room: Because they start realizing that they're the oldest person...that when they go to the emergency room, they're the oldest person there who is not a parent. And they also start getting rejected at various specialty clinics.

Responsibilities during a hospital admission: I am a pediatric nurse practitioner, Dr. [name's] a pediatrician, so it's not only difficult in terms of what we are licensed to do in our clinic, but it also becomes an issue when you have to hospitalize a patient and you can no longer put them on the pediatric floor. Then you have to turn their care over to the adult providers, which becomes very difficult to manage.

Aging out of pediatric services: ...as they get too old for certain Children's Hospital services, and the first one of those where it happens is mental health. Our Psychiatry Department at Children's Hospital will not accept referrals of anyone over the age of 18 because of some kind of reimbursement issues.

Child-centered Culture: It's a major problem because largely they are uninsured. And it is also a problem because a lot of them are like gay or transgender youth that, for whatever reason, and I'm not making a judgment about this, they don't fit the culture of sort of a pediatric in-patient hospital facility.

Inconsistency: 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.

Post-transition responsibilities:...and many of them don't call us to say, hey, that guy you transitioned to us last year [*sic*] he stopped coming. We don't realize it. And when they pop up in someone's emergency room, often times, we are the name that they give.

Who can provide optimal care for a 24 year old with HIV? We can't admit them. They get admitted to adult...[after the age of] twenty-one. So the medically complicated, I think, are the most complicated because you feel such a [dilemma]...are you abandoning your patient? It's an ethical conflict. And sometimes you just have to get past it and just do it.

### *Chapter Summary*

This chapter presented the findings that were obtained in this qualitative analysis. The actual findings were presented through discussions of the relationship of codes to study demographic data, relationship of codes to research questions, and salient themes that emerged during the analysis. It was instructive to present demographic information that described the population of patients, the composition of care team members and frequency data related to patients in transition from each clinic. The significance and implications will be discussed in Chapter Five.

## Chapter Five: Discussion

### *Introduction*

The purpose of this final chapter is to provide a summary of the study and a discussion of the research findings presented in the previous chapter. A discussion of the strengths and limitations of the study, plans for dissemination, implications for nursing practice and recommendations for future studies are also presented.

### *Summary of the Study*

The purpose of this secondary data analysis was to describe the characteristics, processes and practice models used by the Adolescent Trials Network (ATN) systems of care to assist adolescents with HIV disease to transition from child-centered care to adult-centered care. This secondary analysis, with the assistance of the tools available in ATLAS.ti, offers an analysis of the data through a variety of computer assisted lenses.

The population of interest was adolescents with HIV disease who are or soon will be transitioning from child-centered medical care to adult-centered care. This study used health care providers affiliated with the Adolescent Trials Network of HIV/AIDS Interventions (ATN) as key informants who were most familiar with the phenomenon of transition in this population. One to three representatives from each site considered to be the most knowledgeable staff member(s) involved with their clinic's transition were interviewed. Nineteen representatives from 14 ATN sites participated in the study. These designated key informants were invited to share their personal and collective views of the phenomenon of transition and to describe anything that was considered a barrier or



facilitator to the process. The data set consisted of 14 audio-taped interviews as well as clinic documents that were submitted for review. An a priori coding framework was prepared prior to the initial preliminary analysis based on the study research questions and the interview questions. This initial coding framework was refined using the constant comparative method and subsequent coding discrepancies in the remaining analysis were resolved by consensus. Transcripts and clinic documents were analyzed using content analysis within an ATLAS.ti data management system.

This research provided valuable information related to the phenomenon of transition together with anecdotal information about the adolescents with HIV disease that are currently experiencing or have recently experienced this transition to adult care. Current policies and practices of the ATN clinic health care teams were discussed as well as factors that were perceived as barriers and facilitators to the transition process. The study is unique in that no known investigations have previously described transition practices across a geographically diverse group of clinics in the United States. The significance of this study relates to the fact that this is the first report to describe transition practices from the ATN network clinics whose care teams manage the largest cohort of adolescents with HIV disease in the United States. Implications of these findings and suggestions for future study were explored.

#### *Discussion of the Findings*

*Relationship of codes to study demographic data.* At the time of this inquiry, patients between the ages of 12 and 25 years enrolled in care at the 14 ATN clinics totaled approximately 1,775. The numbers of adolescents within this age group ranged from 31 to 266 across the fourteen sites. The annual number of adolescents transitioned

during the last 12- 48 months ranged from 4 to16 per site. While inquiring about the number of adolescents who had transitioned per year and the number of those transitions that were considered successful, an important finding emerged. The numbers of adolescents who had been successfully transitioned to adult care could not consistently be determined because there was no standard definition of a successful transition and because there was no mechanism in place to track patients from one site to another.

Ultimately the measure of success for any transition program would require specific outcomes by which “success” could be measured. The measures might include behavioral outcomes such as showing up for the initial appointment, attending a specific number of appointments in one year or adherence to antiretroviral therapy. Measures might also include clinical outcomes such as an undetectable HIV viral load.

Blum et al. (1993) acknowledged the need for and lack of controlled studies of transition models and the lack of criteria to evaluate success. They propose that the success of adolescents with chronic diseases transitioning into adulthood must include a variety of measures such as disease-specific measures, functional status and sense of well-being. Furthermore, even with a standard definition and defined outcomes, there are obstacles to measurement that include the lack of formal tracking mechanisms to follow the adolescents after they leave the adolescent care setting. Other considerations are the restrictions created by the Health Insurance Portability and Accountability Act of 1996 (HIPAA).

*Research question one: How do ATN health care team members view transition?*

All of the key informants agreed that staff members shared similar views of transition. When describing these similar views, words such as teamwork, collaborative and

multidisciplinary were frequently used. These cooperative approaches addressed aspects of transition models that have been described by various agencies and professional organizations (MCHB, 1989; Blum et al., 1993, Blum, 2005; Rosen et al., 2003).

Collaboration among a multidisciplinary team would offer a holistic approach to the adolescent's chronic physical, developmental, behavioral, or emotional needs.

The key informants from the six clinics that incorporated a structured transition process provided a much more comprehensive and detailed view of transition. Their views together with propositions previously noted in the literature can be considered the foundations for development of a structured transition program. Blum et al. (1993) in the original position paper from the Society of Adolescent Medicine encouraged a gradual approach to purposeful, planned movement toward independence. Rosen et al. (2003) posited that a successful transition experience would promote an adolescent's sense of autonomy, personal responsibility and self-reliance. One outcome criterion in the Healthy People 2010 program for children with special health care needs addresses the ability of the child or adolescent to take charge of his or her own health care (CDC, 2000). Descriptors such as family-centered, continuous, comprehensive, coordinated, compassionate, culturally competent, and developmentally appropriate are now consistently seen throughout the HCT literature. Proposed foundations for a structured transition program are listed in Table 10.

Table 10

*Foundations for a Structured Transition Program*

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- Application of adolescent developmental theory
  - Consideration of developmental age together with chronological age
  - Early initiation of transition planning (ages 14 to 16) or when admitted to adolescent care clinic
  - Gradual transition process
  - Individualization of the transition plan
  - Use of a holistic approach to medical and psychosocial needs
  - Planned learning activities during transition to enhance the adolescent's sense of autonomy, personal responsibility and independence.
  - Care provided by culturally competent staff
- 

Key informants from the 11 of the 14 ATN clinics described a spectrum of emotions when discussing views about transition. Expressions of joy and satisfaction surrounding transition are contrasted to expressions of sadness and personal loss for both the adolescent and the providers. These feelings reflect the strength of the bonds between patient and providers. These emotions of sadness and loss are considered in the discussion of barriers to transition.

*Research question two: What do ATN health care team members perceive as facilitators to a successful transition to adult care?* Characteristics identified as possible facilitators to a successful transition were extracted from anecdotal reports of successful transitions. These characteristics can be distinctly categorized as intrinsic or extrinsic to the adolescent. These 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 their preferred adult referral sites. As these questions

were answered, a picture of the ideal adult clinic began to emerge. Characteristics of the ideal adult clinic that were commonly reported as desirable and perceived to facilitate successful transition are listed in Table 11.

Table 11

*Characteristics of Adult Clinics Associated with Successful Transition*

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- A single contact person assists the adolescent in transition
  - The new provider is introduced to the adolescent at the start of the transition process
  - Comprehensive services are provided including primary care, pharmacy, and dental services
  - Psychosocial services such as case management, mental health, and support groups, are provided.
  - Flexibility is provided as the adolescent adjusts to the adult clinic environment
  - The staff is culturally competent and lesbian, gay, bisexual and transgender (LGBT) friendly
  - Follow-up is facilitated by the case manager from the pediatric clinic
  - Adult providers deliver age and developmentally appropriate care for the adolescent
  - Communication between providers from the adolescent and adult sites is shared and timely
- 

The characteristics of preferred clinic referral sites mirror the suggestions for transition programs previously identified in the literature. A single professional acting as a coordinator and advocate who would take responsibility for the transition process was

included as a necessary component of a transition program. This designated professional would work in partnership with the patient and the family to facilitate and streamline the transition experience. This idea of a designated professional responsible for coordinating HCT was also included in the consensus statement from the American Academy of Pediatrics, the American Academy of Family Physicians and the American College of Physicians-American Society of Internal Medicine (2002). These organizations identified the first “critical step” in HCT is ensuring that all ASHCN have an identified health care professional who “assumes responsibility for current health care, care coordination, and future health care planning” (p. 1385).

*Research question three: What do ATN health care team members perceive as barriers to a successful transition to adult care?* Representatives from 10 of the 14 ATN sites reported that adolescents frequently share perceptions of the adult clinics that created barriers to HCT. These clinics were known in many communities as the ‘AIDS’ clinic and adolescents cited the lack of confidentiality with a fear of being recognized as ‘positive’. Negative emotions such as fear, shame and anger were often mentioned as characterizing adolescents who were unsuccessful in transition. Shame was discussed in relation to the stigma of HIV disease that can result in marginalization and social isolation. These barriers have been considered somewhat unique to HIV disease and have been previously predicted in the literature (AIDS Education and Training National Resource Center, 2006; Brown, Laurie, & Pao, 2000; HIV/AIDS Bureau, 1999). Reports from interviews with adolescents with HIV disease corroborate these perceptions (Miles and Clapton, 2004; Fielden, et al. 2006; Weiner et al., 2007; Vazquez, 2006; Vijayan, et al., 2008).

Representatives from nine of the 14 sites representatives included drug abuse and mental health issues when asked to identify barriers to transition. Examples of failed transitions similarly contained frequent reference to ‘crystal meth’, ‘crack cocaine’, heroin as well as untreated depression and bipolar disorder. Difficulties associated with adolescents participating in treatment for drug abuse and mental illness were also described.

Similar difficulties have been reported in the literature both for the general population of adolescents with chronic illnesses as well as the more specific population of adolescents with HIV disease (Blum, 1995; Reiss et al., 2005; Brown et al., 2000). Nasr (1992) and Geenen et al. (2003) reported that pediatricians expressed discomfort when discussing sex, drugs and alcohol with adolescent patients. This body of knowledge would suggest that staff specializing in prevention as well as treatment of substance use and mental health issues would be a beneficial component of transition programs.

The spectrum of emotions experienced by adolescent providers and patient at the ATN clinics included expressions of sadness and personal loss when terminating their long-standing therapeutic relationships. These emotions often resulted in delay of transition and difficulty terminating the relationship. Key informants reported that adolescents who had been transferred to adult care would often return and ask for assistance. There was variation in the clinics’ responses to adolescent requests. Difficulties associated with terminating long-standing provider-patient relationships are commonly reported in the literature (Houser & Dorn, 1999; Schidlow & Fiel, 1990; Sinnema, Bonarilus, Laag, & Stoop, 1988). The problems frequently referred to in the

literature as “letting go” was described from both the pediatric provider and the patient-family perspective.

Lastly, there were the references to various funding issues that have interfered with a successful transition. They are summarized in Table 12.

Table 12

*Access and Funding Barriers to Successful Transition*

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- Lapses in health insurance at ages 18 and 21\*
- Lack of access to affordable transportation
- Lack of affordable and safe housing\*
- Inability to fund out-of-pocket medical expenses
- Lack of adult HIV specialist providers\*
- No confidence in the home community physicians\*
- Shortage of HIV social workers and case managers\*
- Need for a pharmacy in home community\*

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*Note.* \* = Barriers also included in Weiner et al. (2007) study.

*Research question four: What are the similarities and differences among the clinics that have a structured transition program and those that do not?* Six of the 14 clinics had structured transition programs. Four of these clinics submitted written documents (policies, procedures, guidelines, patient information, and templates for chart documentation) for review and use in this study. Items addressed in these documents included the age when transition planning and patient education are initiated; ages when certain behaviors are expected and accomplished; and staff assignments for transition



objectives, responsibilities and activities. Checklists were used to assess certain skills and behaviors thought to be essential to independent functioning with a chronic disease. Deliberate attention was given to knowledge and management of HIV, wellness behaviors, responsible sexual activity, and health insurance and community resources. Only one key informant used the term “prevention for positives” that is the name of the CDC initiative aimed to reduce the risk of HIV transmission from individuals infected with the virus (CDC, 2003). The key informants from the clinics with the most comprehensive transition plans consistently articulated the need to use a developmental approach to plan an individualized transition experience.

The staff members involved in transition often included a care manager, social worker, health care provider, and a youth advocate or peer partner. Five of these clinics with written policies and procedures credited nurse practitioners, social workers or a combination of the two as either the formal or informal transition team leaders. These clinics that acknowledged a transition team leader appear to be moving toward the recommendation that a single health care professional assume responsibility for current health care, care coordination, and future health care planning during the transition to adult care (Blum, et al., 2002; Rosen et al., 2003).

A significant difference identified between the clinics with and without a structured transition process was a fundamental difference in approach to transition as a process rather than an event. The clinics that used a structured transition program viewed transition as a process that occurs over time. The clinics that were not using a structured program often spoke about transition as an event or the actual transfer of care.

After identifying this difference, a literature search provided a better understanding of the use of these terms in practice. Transition is an anticipated, coordinated process where

transfer is an event: the movement to a new health care setting, provider, or both (Callahan, et al., 2001). “First, the transition should be a process, not an event, and should involve the entire family as a support system. It would also begin early, even as early as diagnosis, ensuring that by young adulthood, youth are fully prepared to assume more responsibility for their lives.” (Blum, White, & Galla, 2005, p1). Numerous scenarios illustrated this difference in approach that was distinguished those clinics that used a structured approach to transition and those that did not. Representatives from both types of clinics recognize a continued need to improve practice related to transition. It is instructive to note that this recognition comes from anecdotal issues surrounding individual patients’ experiences and not actual measures of transition outcomes.

*Research question five: What strategies have ATN systems of care developed to assist patients in making a successful transition to adult medical care?* The six ATN clinics that have developed a structured transition program included a mechanism that provided introductions or gradual exposure of the adolescent to their prospective adult provider. These six sites also include a tour of the potential adult clinics during the transition process. The adolescents were accompanied on these visits, as well as first appointments, by either case managers or peer educators as well as a member of his or her family or support group. These program components were described as key elements in a program that would assist in a smoother transition to adulthood (Blum, et al., 2005). Representatives from four sites commented on the benefits of continuing contact between the adolescent and his or her adolescent case manager during the first year following transfer to the adult clinic.

Two sites employed an adult nurse practitioner to manage the care of the transitioning patients during the last year or two prior to transfer to the adult clinic. This adult provider would continue as the adolescent's provider following the transfer to the adult clinic. One site employs a psychiatrist that manages patients at both the adolescent and adult sites. Miles and Clapton (2004) reported that six of the seven adolescents with HIV disease who were previously transferred to an adult clinic later reported a perceived benefit from being introduced and working with the adult provider prior to transfer. The adult clinic that participated in this transition program in the United Kingdom had established a specialist adolescent transition clinic that offered care with an adult provider during the period during and after transition. Wagner et al. (2008) described a transition program that assigned each patient to a pediatric Nurse Practitioner who assessed the adolescent's readiness to transition, an introduction of the adolescent to the adult provider prior to the first appointment, a single adult provider that accepted the adolescent into adult care, a social worker who was shared by the pediatric and adult clinic and a multidisciplinary team including clinic nurses and home nurses who provided outreach and support for missed appointments and medication non-adherence. Evaluation of this program is ongoing.

*Salient themes.* Two salient themes were identified during the analysis that were not directly related to any of the research questions. A series of questions were used to determine if there were differences in the approach or experience of transition based on age, developmental delays, cognitive limitations, medical complexity, and membership in a sexual or gender minority group, or pregnancy. ATN clinic policy allows patients to remain in care until their 25<sup>th</sup> birthday. Efforts to initiate transition and transfer did not

occur unless requested by the adolescent at an earlier age. There was no discussion surrounding the choice of this particular age for transfer to adult care. The literature suggests that developmental age be considered along with chronological age when planning transition (Blum, et al., 2002; Rosen et al., 2003). Representatives from 13 of the 14 sites acknowledged special consideration during transition for those adolescents with cognitive or developmental delays yet only one site reported using any psychometric tools to assess the adolescents' cognitive function or readiness to transition. Another entire domain within the transition literature focuses on readiness to transition and the development of psychometric instruments to measure and evaluate this construct. Research efforts in the domain of transition for adolescents with HIV disease would be enhanced if readiness to transition were included as a variable of interest. No differences in any aspect of transition were noted for gay, lesbian, transgendered or other minority groups of adolescents other than attempting to identify adult referral sites that were culturally competent and "friendly" to these groups of adolescents.

Another interesting perception described by key informants from seven of the sites related to pregnant adolescent females experiencing a smoother and more successful transition to adult care. The rationale cited for this perceived difference was the exposure during pregnancy to different a medical provider in a different setting prior to the actual transfer of care to an adult HIV provider. This observation may have also been related to the additional support that is provided to all pregnant adolescents through programs such as WIC and Medicaid which provided additional exposure to different individuals and different agencies. This additional support might also provide intangibles that assist with expenses necessary to stay in care, such as money for transportation, co-pays, and stable

housing. The transition experiences of these adolescent females offer several models that may be instructive for future investigation.

The second salient theme that was identified addressed various issues surrounding age-related professional competencies, hospital policies and reimbursement concerns. The fundamental issues relate to age restrictions at specific health care locations and scope of practice for pediatric, adolescent and adult providers. Problems can occur when hospital policies regulate age restrictions for admission to specific units, scope of professional practice and reimbursement issues. Key informants described scenarios involving personal experiences with these problems. Particularly problematic were the emergency medical situations following discharge from the adolescent clinic. Many times an adolescent has not established care with an adult provider and when admitted through the emergency department will provide the name of the previous adolescent provider. That pediatric or adolescent provider is unable to manage a patient admitted to an adult unit and patient care is compromised. Alternatively, adults cared for by pediatricians exceed legal scope of practice and raise liability concerns. These issues cannot be resolved through transition research but certainly warrant discussions of institutional policy and professional practice standards.

#### *Strengths and Limitations of the Study*

The strengths of this study include a high voluntary participation rate from this purposeful sample of clinics as well as representatives from several professional disciplines. The clinics were geographically diverse and provided comprehensive care to adolescents from all subpopulations living with HIV. The ATN clinics' Principal Investigator, location, academic affiliation are listed in Appendix A. As previously

noted, these clinics are those that successfully competed for the primary NIH funding in this area and are likely representative of the most experienced academic programs in the United States.

Potential limitations identified include researcher bias, a social desirability bias in the key informants and a lack of generalizability. This researcher recognizes her own unique construction of reality as a nurse practitioner who provides medical care to HIV-infected adults and who frequently encounters these adolescent during their transfer and admission to adult care. A social desirability bias may also exist due to the lack of anonymity of participants. The participants may have embellished their clinics transition program and alternatively found it difficult to be completely forthcoming when discussing less than ideal practices. Alternatively, staff members may have declined to participate or were not selected to participate by the clinic's Principal Investigator if he or she had different experiences or opinions about their clinics transition programs. There is a lack of generalizability to clinical sites outside the ATN clinic network. The data and findings from this research represent the policies and practices of clinics of the Adolescent Trials Network for HIV/AIDS Interventions. In many cases, the adolescent population cared for in these clinics are those who are indigent or have government provided health insurance such as Medicare or Medicaid. Adolescents whose parents have commercial health insurance and older adolescents who are employed in jobs that provide health insurance may prefer a private practices setting for their HIV care. This subset of adolescents with HIV would be expected to have a different set of characteristics that has the potential to affect the success of transition.

### *Dissemination*

The first analysis and preliminary results were presented and discussed at two meetings attended by representatives of the Adolescent Trials Network for HIV/AIDS Interventions. These results were presented by invitation at a Ryan White Title D program conference in July, 2007 and an Adolescent Trials Network biannual conference in October, 2007. Poster presentations were offered at the 20<sup>th</sup> Annual Conference of the Association of Nurses in AIDS Care in November 2007 and at the Annual Meeting of the Society for Adolescent Medicine in April 2008.

This more extensive data analysis and findings will be disseminated locally to the staff at the ATN site at the University of South Florida as well as the Ryan White funded adult clinics in Hillsborough and Pinellas counties. An abbreviated report of these findings has been prepared for submission to *AIDS Care*, a peer-reviewed HIV specialty journal.

### *Implications for Nursing Practice*

The findings of this study support the role of nurses in the transition of adolescents with HIV in pediatric, adolescent, and adult practice as well as in both in-patient and out-patient settings. Nurses are educated to consider the holistic individual together with his or her family and environment. Nurses consistently use developmental theory to provide the most appropriate level of care. Nurses often have more contact with the patient than any other member of the health care team and are in a pivotal position to assess, plan and provide interventions to assist the adolescent in acquiring the education and skills necessary for a successful transition.

There was consensus in the literature regarding the scarcity of adult providers interested and skilled in the care required by chronically ill young adults (Houser &

Dorn, 1999; McDonough, Foster, Hall, & Chamberlain, 2000; Reiss et al., 2005; Scal, Evans, Blozis, Okinow & Blum, 1999; Scal, 2002; Schidlow & Fiel, 1990; Sinnema, Bonarilus, Laag, & Stoop, 1988). Nurse practitioners (NPs) are one of the largest groups of providers of primary care for children, adolescent and adult patients with HIV disease in the United States. A nurse practitioner certified in family or adult practice possesses the skills and credentials to provide care to adolescents with HIV during these young adult years. A nurse practitioner would be the ideal provider to act as the identified health care professional who assumes responsibility for current health care, care coordination, and future health care planning for these adolescents both in the adolescent setting and the adult setting. Nurses are known for their ability to successfully function in multiple roles within complex healthcare environments. Strengths in communication, patient education, health promotion, and patient advocacy combine to make nurses ideal project directors for transition programs. Nurse researchers are active in adolescent HIV prevention, treatment and transition research and continue to contribute to this growing body of knowledge.

#### *Recommendations for Future Studies*

Respected leaders in the field of qualitative research methodology acknowledge that qualitative research is most appropriate when discovering and exploring a new area (Corbin & Strauss, 2008; Miles & Huberman, 1994; Patton, 2002). Additional qualitative investigations of the adolescents with HIV disease both during transition and following transition (transfer) are critical to a better understanding of the current state of transition practice and to obtain a more comprehensive idea of elements to include in transition programs.



It would seem apparent that adult providers of HIV care need to be represented in this formative research to determine their perspective on the status of adolescents that have transitioned as well as their expectations in terms of knowledge and skills that are needed for HIV self-care. This essential knowledge and skills could be compared to those being emphasized during adolescent transition experiences. Identification of the requisite set of knowledge and skills would logically lead to the development of a psychometric tool for assessment.

Stakeholders in the success of transition that include the adolescent providers, adult providers but most importantly the patients should collectively discuss and decide what are acceptable and measurable outcome criteria for a successful transition.

From the perspective of this researcher, who has a special interest in health communication and patient-provider relationships, it would be interesting to assess if the strength of the relationship and qualities of the relationship between patient and provider can affect transition experiences as suggested in the literature related to HIV medication adherence.

### *Summary*

The purpose of this study was to identify and describe the characteristics, structured processes and practice models currently being used in the transition of HIV-infected adolescents from child-centered medical care to adult-centered medical care within the ATN systems of care, a unique network of pediatric HIV clinics that manage the care of the largest cohort of children and adolescents with HIV in the United States. Examples of practice models that were used in several of clinics that had a structured transition program were described. Ideas for future research were suggested. From these

and other data, clinical care-based delivery systems can be designed, implemented, evaluated, and an evidence base can be established that addresses the transition needs of this unique population.

In summary, research in the domain of transition from child-centered care to adult-centered care began in the 1980's. Efforts have been made during these twenty years to improve the transition for children with special health care needs but successful models for transition programs remain elusive. Betz (2008) declared "the critical mass of need evidenced by the growing numbers of adolescents with special health care needs requiring transition services from a system of care still unprepared to meet them can no longer be ignored or tolerated" (p. 13).

Professionals who care for children, adolescents and adults with HIV disease and AIDS are now addressing this issue as adolescents with HIV disease are beginning to transfer to adult care. Cervia (2006) commented that "few diseases better illustrate the potential complexities of transitioning than does HIV/AIDS" (p. e1). Based on the transition literature and the findings from this study, this researcher would like to propose a definition of health care transition that may serve as a template upon which a model program can be designed. Health care transition is a process of learning, developing and maturing that promotes the change of an adolescent with special health care needs into an adult that is capable of self-care and successful interaction with adult systems of care. The process begins early and occurs over a period of time. Transition is individualized and planned to be developmentally and culturally appropriate. This learning process facilitates the development of a young adult who possesses the knowledge, skills, motivation and self-efficacy to begin to function independently as an adult.

This researcher recently received an email from one of the Principal Investigators in the ATN network. With his permission to quote, he asked, “Could you update me as to the status of your “Transitions” protocol? Our issue is becoming ever more acute and I’d appreciate ANY evidence based help I can get (L.J. D’Angelo, personal communication, February, 2, 2009).

There is much work yet to be done.

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## Appendices

## Appendix A

### Adolescent Trial Network Clinical Sites and Principal Investigators

University of South Florida  
Tampa, FL  
Dr. Patricia Emmanuel

Children's Hospital  
Philadelphia, PA  
Dr. Bret Rudy

University of Miami  
Miami, FL  
Dr. Lawrence Friedman

Montefiore Medical Center  
Bronx, NY  
Dr. Donna Futterman

Children's Diag. & Treatment Center  
Ft. Lauderdale, FL  
Dr. Ana Puga

Mount Sinai Medical Center  
New York, NY  
Dr. Linda Levin

Children's Hospital  
Boston, MA  
Dr. Cathryn Samples

Univ. of Maryland  
Baltimore, MD  
Dr. Ligia Peralta

St. Jude's Research Hospital  
Memphis TN  
Dr. Patricia Flynn

Children's National Med. Ctr.  
Washington, D.C.  
Dr. Lawrence D'Angelo

Children's Memorial Hospital and  
Howard Brown Health Center  
Chicago, IL  
Dr. Rob Garofalo

Univ. of California  
San Francisco  
Dr. Barbara Moscicki

Cook County Hospital  
Chicago, IL  
Dr. Jaime Martinez

Children's Hospital Los Angeles  
Los Angeles  
Dr. Marvin Beltzer

## Appendix B

### Transitional Care Coordinator Interview Schedule

1. Does your ATN site care for children of all ages with HIV or adolescents only?  
1=All ages, up to \_\_\_\_\_ yrs.  
2=Adolescents only, up to \_\_\_\_\_ yrs.  
How many total adolescent patients do you care for in your clinic? \_\_\_\_\_
  
2. Does your ATN site have a specific age range that is considered adolescence?  
1= NO      2= Yes      If yes, what is the age range? \_\_\_\_\_
  
3. Is transition from adolescent care to adult care an option at your care site?  
1=No      2=Yes      If NO, why is it not an option?
  
4. Is a specific member of the health care team at your site the point person or the main one responsible for initiating the transition process?  
1=No   2=Yes  
If yes, what is the official role of that person? Case manager, RN, ARNP, MD, other?
  
5. Do you have written guidelines regarding transition from adolescent to adult care as of January 2007?  
1=No   2=Yes  
If yes, Could you please send it to us, if you haven't already done so.  
If NO, Could you tell me why your site does not have a policy?  
Since there is no policy, could you describe how your site approaches transitions?
  
6. Are there differences among members of the health care team in terms of how you go about transition planning?  
1= NO   2= Yes  
If yes, could you describe these to me from your perspective and provide some examples?
  
7. Can you tell me more about how providers at your site view transitioning adolescents to adult care?



Appendix B (continued)

8. Are there different opinions about how best to transition adolescents to adult care among the team members? 1=No 2=Yes  
If yes, Can you tell me more about some of these differences?
9. Are there specific criteria that your team uses when thinking about transitioning a patient to adult care?  
1=No 2=Yes If yes, what are these?
10. Are there any tests performed that figure in the decision about whether to transition an adolescent to adult care?  
1=NO 2=Yes If yes, what are they?
11. Is there any documentation that is part of the transition process at your site?  
1=No 2=Yes  
What are these documents? And did you send us copies?
12. How long does transition usually take at your site?
13. Can you think of a specific example of a successful transition? If so, why was it successful?
14. Can you think of a specific example of a failed transition? If so, why was it a failure?
15. Are there things at your site that facilitate the transition process?  
1=No 2=Yes What are these?
16. Are there things at your site that get in the way of the transition process? 1=No 2=Yes  
What are these?
17. On a scale from 1 to 5, with 1 being the easiest and 5 being the most difficult, could you tell me what your experience has been in terms of being able to transition adolescent patients to adult care?
18. How many adolescent patients has your site attempted to transition in the last  
12 months? \_\_\_\_\_ 24 months? \_\_\_\_\_ 36 months \_\_\_\_\_ 48 months \_\_\_\_\_
19. How many adolescents have successfully started adult care in the last  
12 months? \_\_\_\_\_ 24 months? \_\_\_\_\_ 36 months \_\_\_\_\_ 48 months \_\_\_\_\_

Appendix B (continued)

20. Does your site have a way to track transitioned patients?  
1=No 2=yes If yes, could you describe how you do this?
21. How many of your patients that you know of have been lost to follow-up or regular care during the transition to adult care? \_\_\_\_\_ number \_\_\_\_\_ in what time period?
22. Can you tell me more about the referral sites: Where do you refer most of your patients?  
Specific  
name \_\_\_\_\_
23. What type of care site is this?  
1=University Affiliated Site 2=Public Care Site 3=Community-Based Program  
4=Private Provider 5=Other \_\_\_\_\_
24. Do different patients get referred to different sites?  
1=No 2=Yes If yes, What affects how you refer a patient to a specific site?
25. Do you believe that the adult site that you refer your patients to cares for your patients as well as, better as or worse than your site?  
1=Same 2=Better 3=Worse  
What is it about their care that makes you evaluate it as worse/better than the care that you provide?
26. How many adolescents have returned to your site after attempting to transition to adult care in the last 12 months \_\_\_\_\_ 24 months \_\_\_\_\_?
27. When an adolescent returns to your site after attempting to transition to an adult care site, what does your site do? Does your site provide care or refer again?  
1=refer again 2=provide care 3=other  
Can you tell me more about this?
28. Have any failures occurred which made your site reluctant to transition your patients?  
1=No 2=Yes Can you tell me about that failure?

Appendix B (continued)

*Thinking about the transitioning at your site:*

29. Is it better for an adolescent to transition between?  
1=18-20yrs, 2=20-22yrs, 3=22-24yrs, 4=>24yrs, or 5=varies with the individual.  
If the answer is 5, what are some of the individual variations that would influence the decision to transition?
30. Have you noticed any differences in how your team transitions patients based on their age?  
1=No 2=Yes If yes, how does age affect the way you transition patients?
31. Have you noticed any differences in how your team transitions a patient who has developmental delays or cognitive limitations (meaning an adolescent who cannot make age appropriate health decisions)?  
1=No 2=Yes If yes, how does this affect the way you transition patients?
32. Have you noticed any differences in how your team transitions a patient who is a member of a sexual minority or is gay?  
1=No 2=Yes If yes, how does this affect the way you transition patients?
33. Have you noticed any differences in how your team transitions a patient who is a member of a gender minority or is transgendered?  
1=No 2=Yes If yes, how does this affect the way you transition patients?
34. Have you noticed any differences in how your team transitions a patient who is medically complicated?  
1=No 2=Yes If yes, how does this affect the way you transition patients?
35. Have you noticed any differences in how your team transitions a patient who has cognitive changes related to HIV?  
1=No 2=Yes If yes, how does this affect the way you transition patients?
36. Have you noticed any differences in how your team transitions a patient who becomes pregnant?  
1=No 2=Yes If yes, how does this affect the way you transition patients?
37. Have you noticed any differences in how your team transitions a patient who has a long-standing therapeutic relationship with the team?  
1=No 2=Yes If yes, how does this affect the way you transition patients?

Do you have any further questions, comments, concerns, or stories you would like to share?

Appendix B (Continued)

Thank you so much for your participation. This information will be collated, analyzed, and will be available to the ATN as a whole and to each ATN site in aggregate form. If you have any further questions or concerns, please feel free to contact me at (727) 934-1728

or by email at [pgilliam@health.usf.edu](mailto:pgilliam@health.usf.edu).

Thank you!

**Mailing address:**

Patricia Gilliam, MEd, MSN, ARNP, BC

1131 Mistwood Drive

Tarpon Springs, FL 34688

01.29.2007

## Appendix C

### PSC 060 Protocol Team Contact Information

Patricia P. Gilliam, MEd, MSN, ARNP, BC  
Doctoral Candidate  
College of Nursing  
University of South Florida  
[pgilliam@health.usf.edu](mailto:pgilliam@health.usf.edu)

Diane M. Straub, M.D. M.P.H.  
Associate Professor of Pediatrics  
Chief, Division of Adolescent Medicine  
University of South Florida  
[dstraub@health.usf.edu](mailto:dstraub@health.usf.edu)

Jonathan M. Ellen, M.D.  
Professor of Pediatrics  
Deputy Chief of Adolescent Medicine  
Johns Hopkins University  
College of Medicine  
[jellen@jhmi.edu](mailto:jellen@jhmi.edu)

Lori Leonard, ScD  
Associate Professor  
Bloomberg School of Public Health  
Johns Hopkins University  
[Lleonard@jhsph.edu](mailto:Lleonard@jhsph.edu)

Sara B. Kinsman, M.D. Ph.D.  
Assistant Professor of Clinical Pediatrics  
Division of Adolescent Medicine  
Children's Hospital of Philadelphia  
[kinsman@email.chop.edu](mailto:kinsman@email.chop.edu)

## Appendix D

### Original IRB Exempt Certification



February 10, 2007

Diane Straub, MD  
College of Medicine  
MDC 15

RE: **Exempt Certification** for IRB#: 105455F  
Title: *Transitional Care for Adolescents With HIV*

Dear Dr. Straub:

On February 7, 2007, the Institutional Review Board (IRB) determined that your research meets **USF requirements and Federal Exemption criteria two(2)**. It is your responsibility to ensure that this research is conducted in a manner reported in your application and consistent with the ethical principles outlined in the Belmont Report and with USF IRB policies and procedures.

Please note that changes to this protocol may disqualify it from exempt status. It is your responsibility to notify the IRB prior to implementing any changes.

The Division of Research Integrity and Compliance will hold your exemption application for a period of five years from the date of this letter or for three years after a Final Progress Report is received. If you wish to continue this protocol beyond those periods, you will need to submit an Exemption Certification Request form at least 30 days before this exempt certification ends. If a Final Progress Report has not been received, the IRB will send you a reminder notice prior to end of the five year period; therefore, it is important that you keep your contact information current with the IRB Office. Should you complete this study prior to the end of the five-year period, you must submit a Final IRB Progress Report for review.


**Please reference the above IRB protocol number in all correspondence** to the IRB c/o the Division of Research Integrity and Compliance. In addition, we have enclosed an Institutional Review Board (IRB) Quick Reference Guide providing guidelines and resources to assist you in meeting your responsibilities when conducting human subjects research. **Please read this guide carefully.**

OFFICE OF RESEARCH • DIVISION OF RESEARCH INTEGRITY & COMPLIANCE  
INSTITUTIONAL REVIEW BOARDS, FWA No. 00001669  
University of South Florida • 12901 Bruce B. Downs Blvd., MDC035 • Tampa, FL 33612-4799  
(813) 974-5638 • FAX (813) 974-5618

Appendix D (continued)

We appreciate your dedication to the ethical conduct of human subject research at the University of South Florida and your continued commitment to human research protections. If you have any questions regarding this matter, please call 813-974-9343.

Sincerely,



Paul G. Stiles, J.D., Ph.D., Chairperson  
USF Institutional Review Board

Enclosures: IRB Quick Reference Guide

Cc: Christy A Stephens, USF IRB Professional Staff  
Patricia Gilliam, M.Ed.

SB-EXEMPT-0602

Appendix E

Revised IRB Exempt Certificate # 105455F



DIVISION OF RESEARCH INTEGRITY AND COMPLIANCE  
Institutional Review Boards, FWA No. 00001669  
12901 Bruce B. Downs Blvd., MDC035 • Tampa, FL 33612-4799  
(813) 974-5638 • FAX (813) 974-5618

August 6, 2008

Diane Staub, MD, MPH  
College of Medicine  
2A Columbia Dr., Suite 500

RE: **Exempt Certification Modification Request**  
IRB#: 105455 F  
Title: *Transitional Care for Adolescents With HIV*

Dear Dr. Straub:

On February 7, 2007, it was determined that your project referenced above meets the federal criteria, which exempts it from further IRB oversight.

You have requested the following changes to your research:

1. **Change in contact address;**
2. **Change in procedures: Initial application considered as preliminary work towards PI's doctoral research. Project now approved for a dissertation project;**
3. **Change in projected length of study: New end date of 7/1/2009.**

On August 5, 2008, the IRB Chairperson reviewed your request and determined this change does not impact the study's eligibility for exemption. The study continues to meet Exempt Criteria. Any grants supporting this project must be submitted to the Institutional Review Board for review.

Please note that future changes to this protocol may disqualify it from its current exempt status. It is your responsibility to notify the IRB prior to implementing any changes.

Please reference the above IRB protocol number in all correspondence to the IRB c/o the Division of Research Integrity and Compliance. It is your responsibility to ensure that this research is conducted in a manner consistent with the ethical principles outlined in the Belmont Report and with USF IRB policies and procedures.



Appendix E (continued)

We appreciate your dedication to the ethical conduct of human subject research at the University of South Florida and your continued commitment to human research protections. If you have any questions regarding this matter, please call 813-974-9343.

Sincerely,

Paul G. Stiles, J.D., Ph.D., Chairperson

USF Institutional Review Board

Cc: Anna Davis/cd, USF IRB Professional Staff

SB-EXEMPT-MOD-0801

## Appendix F

### Memorandum of Agreement

PCS 060 MOA  
Vs. 1.0  
Page 1 of 3

#### MEMORANDUM OF AGREEMENT

February 9, 2007

#### **A PLANNED COLLABORATION BETWEEN THE ADOLESCENT MEDICINE TRIALS NETWORK FOR HIV/AIDS INTERVENTIONS (ATN) AND THE FOLLOWING COLLABORATORS:**

- DR. DIANE STRAUB, ATN SITE 01, CO-PRINCIPAL INVESTIGATOR,
- MS. PATRICIA GILLIAM, ARNP, DOCTORAL STUDENT, UNIVERSITY OF SOUTH FLORIDA, AND
- PCS 060 PROTOCOL TEAM

#### **PCS 060: TRANSITIONAL CARE FOR ADOLESCENTS WITH HIV**

##### Index of Contents

- I. Background of the Collaboration
- II. Summary of PCS 060
- III. Regulatory Issues
- IV. Site Registration and Training
- V. Subject Registration and Data Management
- VI. Clinical and Local Costs
- VII. Serious Adverse Event (SAE) Reporting
- VIII. Central Specimen Repository
- IX. Data Analyses and Publications

#### **I. Background of the Collaboration**

Transition of infected adolescents to adult care has been identified as a clinical priority by the ATP. As such, PCS 060 was developed in response. However, given the funding constraints and research priorities, this protocol was not brought forward for development in ATN II. The protocol team decided to pursue alternate sources of funding. Independently, Ms. Gilliam, an ARNP practicing HIV care and pursuing a PhD at USF, developed a dissertation topic related to the transition of HIV-infected adolescents into adult clinical care.

This collaboration proposes for Ms. Gilliam, under the direct guidance of Dr. Straub, and with the oversight of the PCS 060 protocol team, to conduct phase one of PCS 060 at each AMTU. Subsequently, the protocol team will use this pilot data to seek additional funding to implement the remainder of the protocol.

#### **II. Summary of PCS 060 Phase I**

Phase I of PCS 060 is designed to examine existing clinical practices related to transition of HIV-infected adolescents within the ATN. Sites will be queried as to whether a transition program currently exists at their site. If so, they will be asked to submit all related documentation, including policies/procedures, forms, checklists, information

brochures, etc. Site PIs will be asked to select an individual at each site to participate in a 45 minute structured telephone interview about transition practices at their site. The data will be collated, analyzed, and summarized; this information will be used to apply for future independent support to carry out subsequent phases of the protocol.

Roles of collaborators:

- Ms. Gilliam will collect the printed materials and conduct all phone interviews. She will also take the lead on the data analysis, with assistance from Dr. Straub and the protocol team.
- Dr. Straub will serve as Ms. Gilliam's field supervisor and will oversee all aspects of phase I of this protocol.
- The protocol team will serve as a consultative body, assist with data analysis, and will guide planning for subsequent phases of the protocol.
- The ATN will provide limited resources for the purposes of conducting phase I of PCS 060
  - ATU principal investigators will provide 45 minutes of their time in a single telephone interview with Ms. Gilliam.
  - ATU site staff will provide a one-time compilation of any site protocols and/or procedures on transition of clinical care to Ms. Gilliam and/or the protocol team.
  - No DOC resources are to be used in this study

**III. Regulatory Issues: Institutional Review Board (IRB) Review and Informed Consent**

Though research is being conducted as part of PCS 060 phase I, 45 CFR part 46 regarding the conduct of research with human subjects does not apply since "no information about living individuals is obtained". Given this and the programmatic and non-sensitive nature of this phase of the research, Dr. Straub and Ms. Gilliam have applied for an exemption certification from the University of South Florida Institutional Review Board, for which Dr. Craig Wilson, PI of the ATN, provided a letter of support. It is the assumption of the ATN that the study will be conducted in compliance with the decision of the University of South Florida Institutional Review Board.

**IV. Site Registration and Training**

Site registration and training will not be required for this protocol. Site PIs were notified of this potential collaboration via e-mail in December of 2006. No concerns were voiced related to the plan to conduct this protocol as proposed. In fact, all responses were positive and endorsed the plan.

**V. Subject Registration and Data Management**

**a. Subject Registration**

All "subjects" for this protocol are ATN staff; no subject registration will be required for this protocol (phase 1).

**b. Data Management**

Data management will be the responsibility of Ms. Gilliam and Dr. Straub, under the guidance of the PCS 060 protocol team. All materials collected by the sites will be maintained by Ms. Gilliam.

**VI. Costs**

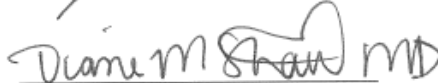
Costs for Phase 1 of PCS 060 will be minimal, with the costs of the telephone interviews being the most significant cost. These costs will be supported by the USF Division of Adolescent Medicine, as per permission of Dr. Straub.

**VIII. Data Analyses and Publications**


Data analysis will be the responsibility of Ms. Gilliam and Dr. Straub, under the guidance of the PCS 060 protocol team. Publications will also be determined by the protocol team, with Ms. Gilliam taking the primary lead (and first author role) for this pilot data. Other use of this data, either for securing funding to conduct subsequent phases of the protocol, for additional analyses, or other purposes, will be determined by the protocol team. All publications will recognize the ATN for its contributions as is found acceptable by the ATN Executive Committee and will cite the ATN on the authorship line.

  
Chair, Executive Committee, ATN

Date 2/14/07

  
Diane M. Straub, MD, MPH

Date 2/9/07

  
Patricia Gilliam, ARNP

Date 2/9/07

  
Dr. Jonathan Ellen, Protocol Chair

Date 2/11/07

### About the Author

Patricia Pyland Gilliam has a B.S. degree in Chemistry Education, an M.Ed. degree in Exercise Physiology and an M.S.N. in Nursing. She has a Ph.D. from the University of South Florida in Nursing Science. She is currently employed by St. Joseph's Hospital's Tampa Care Clinic where she practices as a nurse practitioner in Adult HIV/AIDS care. She holds certifications as an Adult Nurse Practitioner with the American Nurses Credentialing Center and as an HIV Specialist with the American Academy of HIV Medicine.