TRANSITION EXPERIENCES OF THE CHRONICALLY ILL ADOLESCENT

by

Kelly N. White

A Dissertation Submitted to the Faculty of
The Christine E. Lynn College of Nursing
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Doctor of Philosophy

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This dissertation was prepared under the direction of the candidate’s dissertation advisor, Kathryn B. Keller, Ph.D., R.N., College of Nursing, and has been approved by the members of her supervisory committee. It was submitted to the faculty of the Christine E. Lynn College of Nursing and was accepted in partial fulfillment of the requirements for the degree of Doctor of Philosophy.

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ABSTRACT

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The continued development of the American health care system and evolving technology have led to an increased life expectancy within the general population. In fact, these advancements have also resulted in growing numbers of young people with chronic illnesses living into adulthood. Approximately one third of children ages 10-17 have a chronic disease, and the vast majority of these children will survive beyond their 20th birthday (Blum, 1995; Lotstein, McPherson, Strickland, & Newacheck, 2005; White, 2002). The main objective of this study was to explore the healthcare transition (HCT) practices of health care providers and the HCT experiences of chronically ill young adults living with sickle cell disease, cystic fibrosis, and/or diabetes. Meleis, Sawyer, Im, Hifinger Messias, & Schumacher’s (2000) theory on transition and Boykin and Schoenhofer’s (2001) theory of Nursing as Caring provided the theoretical lenses through which study findings were viewed.
This was a descriptive exploratory mixed methods design that consisted of survey data and used conventional content analysis to analyze the qualitative data. The quantitative portion of this study incorporated a 41-question survey that was completed by 33 health care providers working with chronically ill young adults in the southeast Florida region. Additionally, semi-structured interviews were conducted with eight young adults (18-24 years of age) living with a sickle cell disease, cystic fibrosis, and/or diabetes. Five themes emerged from an analysis of the data describing the healthcare transition (HCT) experience: Transition Confusion, Familial Reliance, Lost in Transition, Fiscal Stressors, and Transition Uneasiness. The findings of this study demonstrate that there are, at minimum, three general parts of the HCT process that remain deficient: educational preparation, consistent communication between all parties involved in the HCT process, and guidance for the independent negotiation of the present healthcare system.

Recommendations for healthcare providers that work with chronically ill young adults include establishing a HCT framework that incorporates consistent communication among team members and patients/families, individualized educational formats, and guidance for navigational skills to negotiate the healthcare system.
DEDICATION

To my Nana, you remain “the wind beneath my wings.”

To my husband, “Let’s take each other’s hand as we jump into the final frontier.”

There are no words to describe the impact you have had on my heart or in my life.

Thank you for your unconditional love.
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CHAPTER 1. INTRODUCTION

Health care systems and technology are evolving continually. The continued advancement of the American health care system and advancing technology has led to an increased life expectancy within the general population. In fact, these advancements also have resulted in growing numbers of young people with chronic illnesses living into adulthood. Approximately one third of children ages 10-17 have a chronic disease, and the vast majority of these children will survive beyond their 20th birthday (Blum, 1995; Lotstein, McPherson, Strickland, & Newacheck, 2005; White, 2002).

In general, when healthy children reach the age of 18-21 years, they independently transition from a pediatric-oriented health care system to an adult-oriented system. However, when a child has complex health care needs, he/she requires additional preparation and the involvement of several support systems (i.e., health care team, parents, grandparents, school system, churches). Therefore, the development of a universal health care transitional program, which incorporates preparation and a strong support team, is essential as more adolescents with chronic illnesses are joining the adult population.

In 1989, C. Everett Koop, the United States Surgeon General, brought the need to improve health care transition (HCT) to the forefront by recommending that all adolescents with special health care needs have a HCT plan in place by age 12 (American Academy of Pediatrics, American Academy of Family Physicians, American College of Physicians, & Transitions Clinical Report Authoring Group, 2011). While methods of
transition have been explored throughout the past several decades, internationally and by various disciplines, a standardized framework for the health care transition of the chronically ill adolescent remains undefined within the literature. In fact, the current American health care system does not offer a standardized approach to HCT. Instead, there currently exist many HCT frameworks that vary among medical practices and/or disease processes.

Scope of Problem

The application of HCT services and the understanding of the influence that these services provide represent important gaps within the literature. Scal and Ireland (2005) have identified that the “Approaches to understanding the determinants of unmet health care needs and health care service utilization may provide a useful framework for understanding HCT services” (p. 1607). In fact, many young adults hesitate to transition to adult health care providers. Instead, they often struggle to remain with their pediatric primary care providers after the age of 18, or even leave medical supervision altogether due to lack of support or finances.

Health Care Transition

While there are many definitions regarding the transition process, there are few clear descriptions specific to the term health care transition. For the purpose of this study, the health care transition (HCT) process is defined as “The purposeful planned movement of adolescents and young adults with chronic physical and medical conditions from child-centered to adult-oriented health-care systems” (Blum et al., 1993, p. 570). Ensuring an effective HCT requires teamwork between the pediatric and adult health care teams and does not stop when the transfer occurs. Instead the support, ongoing education,
and financial guidance should continue throughout the adolescent’s progression to a stable, independent young adult.

Currently, there remains a “Lack of well-defined criteria for determination of transition readiness” (Peters, Laffel, & the American Diabetes Association Transitions Working Group, 2011). Many HCTs occur simply based on biological age, not developmental stage (Duguépéroux et al., 2008; Fernandes et al., 2011). Reiss and Gibson (2002) noted that young adults may be ready for the impending transition at various ages, depending on the maturity level of the patient. Therefore, the actual transition process should be evaluated based on an individual basis by assessing the developmental readiness and characteristics of the patient and supporting family members involved.

**The Need for Research**

Information about HCT is abundant throughout the literature for specific chronic illnesses that occur in childhood. As technology advances and more children with chronic illnesses live into adulthood, the literature periodically grows in different areas specific to these individual disease processes. While methods of transition have been explored throughout the years, internationally and by various disciplines, a standardized framework for health care transition for chronically ill adolescents has not been well defined within the literature. Perhaps this large gap in the literature exists due to the fact it is only recently that 90% of young children living with chronic illnesses such as sickle cell disease or cystic fibrosis began having life expectancies longer than late childhood (Kennedy & Sawyer, 2008; Shaw & DeLaet, 2010). There are numerous sources of written guidelines for transitional care of the adolescent and young adult that vary in
approach within the American health care system. However, there remains a lack of a uniform HCT approach to assist this diverse population (American Academy of Pediatrics, American Academy of Family Physicians, American College of Physicians, & American Society of Internal Medicine, 2002).

Sickle cell disease, cystic fibrosis, and diabetes mellitus are among the most prevalent childhood chronic diseases. In fact, more than one third of all children living with a chronic disease have been diagnosed with one of these three childhood illnesses (Callahan, Winitzer, & Keenan, 2001). This study will use these three diagnoses as a focus to explore current practices within the HCT process of young adults.

The major challenges in caring for adolescents transitioning into adult care include, but are not limited to, communication difficulties, educational challenges, and financial/policy encounters. The approach to overcoming these challenges requires the work of an interdisciplinary health care team. A complete health care team can be comprised of a primary care provider, nurse, educator, nutritionist, doctor of pharmacy, and social worker. Together, this group offers direct access to education, guidance, and support for these young chronically ill individuals within the health care system. In order for this process to be successful, the pediatric interdisciplinary team, the adult interdisciplinary team, and the adolescent/family should work in unison during the HCT process.

Identifying generalized parallels and barriers that these adolescents repeatedly experience is a crucial step in the primary development of a general HCT framework. An all-purpose HCT model would provide a common approach for health care providers of different specialties and patients/families living with various chronic illnesses. This study
will assess the current transition practices of health care providers and the experiences of young adults who recently underwent a HCT or who currently are transitioning from pediatric to adult-oriented health care.

**Theoretical Perspectives**

Meleis’ transition theory provided the theoretical framework for this study (Meleis, Sawyer, Im, Hifinger Messias, & Schumacher, 2000). Transitions occur cognitively, behaviorally, and interpersonally at various times throughout the life span as actual and potential changes occur in the health status of the patient (Schumacher, Jones, & Meleis, 1999). While each of these parts of transition is identified individually within the literature, none of the subcategories are mutually exclusive. Instead, transitions occur in patterns that vary from patient to patient (Meleis et al., 2000). These experiences often are shaped by several essential properties of the transition experience (Meleis et al., 2000). Furthermore, transitions are personal experiences that can create diverse and multifarious challenges for the patient, family and the HCT team often compounding the outcome of the transition (Meleis et al., 2000). Figure 1 highlights this transition theory.
Chick and Meleis (1986) identified four subcategories of transitions’ experiences: developmental, situational, health-illness, and organizational. In 1994, Schumacher and Meleis identified organization transitions as an additional typology to be considered during this process. Developmental transitions denote the stages that occur in the lifecycle (e.g., the transition to parenthood). A situational transition refers to the transition from one role to another role (e.g., transition from a bedside nurse to an administrative role). Next, health-illness transitions focus on the impact of illness on patients and families (e.g., the transition of the patient and family after the patient experiences cerebral vascular accident with left sided hemiparesis). Lastly, organizational
transitions exemplify transitions in the environment that affect the lives of the persons who work within the setting and their patients (e.g., implementation of electronic medical records within a medical practice) (Schumacher & Meleis, 1994).

**Patterns of Transitions**

Transitions occur in patterns: single, multiple, sequential, simultaneous, related, or unrelated. Schumacher and Meleis (1994) found that multiple transitions often occur concurrently. For example, developmental transitions and health-illness transitions often overlap throughout childhood when a young child is diagnosed with a chronic illness. Accordingly, an adolescent living with a chronic illness can experience all four of the subcategories (single, multiple, sequential, simultaneous –related/unrelated) at the same time when preparing for the transition from the pediatric health care world to the adult-centered health care world. Concurrently, the family members and the HCT team may potentially experience this shift within all four categories.

**Properties of Transition**

Meleis et al. (2000) identified some important properties of transition: awareness, engagement, change and difference, transition time span, and critical points/events. Awareness is an essential characteristic of transition, as the person/s involved in the transitional process must have some awareness of the changes that are evolving. However, Meleis et al. (2000) stated, “the lack of manifestation of such awareness does not preclude the onset of the transition experience” (p. 17). Engagement is directly influenced by awareness. Examples of engagement include active preparation and information seeking. Patients may not actively engage in these activities as they are unaware of the pending physical, emotional, social, or environmental changes. On the
other hand, as awareness is heightened, the level of engagement may be influenced directly. Next, change and difference are essential properties of transition. Change refers to the modification in identities, roles, relationships, abilities, and patterns of behavior (Schumacher & Meleis, 1994). Meleis et al. (2000) believe that difference could be illustrated by the patient being perceived as different, feeling different, viewing the world in different ways, and conflicting expectations. Next, time span directly refers to the time span of each transition experience. Meleis et al. (2000) stated that the possibility of “flux and variability over time” (p. 19) can occur; thus placing time span limitations on the transitional process could be counterproductive. Finally, critical points/events (i.e., birth, death, diagnosis of illness) can directly impact the transitional process of the individual/s participating in the transitional process. Meleis et al. (2000) identified each of these individual properties as interconnected and essential in the transition experience.

**Transition Conditions**

Transition conditions are the events that directly impact how a person moves through a transition (Schumacher & Meleis, 1994). These conditions are *personal conditions, community conditions*, and *societal conditions*. These conditions can promote or impede the progress of the patient throughout the transitional process (Meleis et al., 2000).

Personal conditions are subcategorized into four different titles: meanings, cultural beliefs and attitudes, socioeconomic status, and preparation and knowledge. Meanings attributed to events triggering the transition or the actual transition process may affect a healthy transition progression. Cultural beliefs and attitudes such as stigmatization attached to a transition can directly impact a transition. Socioeconomic
status can inhibit this process directly. Lastly, the preparation and knowledge level of the person/s participating in the transition directly affects the overall transition experience.

Community conditions refer to the resources that are available to facilitate or inhibit transitions. Trusted health care providers, role models, or insufficient resources to support a mental health diagnosis are examples of resources that can impact the transition of a patient directly.

Societal conditions refer to the stigmatizations or society’s conventional meanings associated within a transitional experience. Various cultural interpretations of this process can assist or deter from the experience of the individual/s participating in the transitional event (Meleis et al., 2000).

**Patterns of Response**

Patterns of response are characterized by a combination of process and outcome indicators (Meleis et al., 2000). Some healthy transitional patterns identified in this middle range theory include *feeling connected, interacting, location/being situated*, and *developing confidence and coping*. Outcome indicators recognized by Meleis et al. (2000) are *mastery* and *fluid integrative identities*. Accordingly, it is important to note that these process indicators can indicate that a patient is moving either in the direction towards a healthy transition or towards vulnerability and risk.

**Process Indicators**

The need to feel connected to personal contacts, health care professionals, and various relations throughout the community has been demonstrated as a prominent theme throughout the literature indicating a healthy transition (Messias, 1997; Schumacher et al., 1999). Patients experiencing a transition interact with peers, family, and health care
providers throughout the process. These interactions help expose, clarify, and acknowledge the implications of the transition and the behaviors developed in response to the transition (Meleis et al., 2000). Location and being situated refers to the direction one is moving, from one place to another, and “‘situating’ themselves in terms of time, space and relationships” justifying “how or why they came, where they are and where they have been, and who and what they are” (p. 25). Developing confidence and coping is a progressive experience that occurs on the transitional timeline as the patient gains better understanding of the diagnosis and the impact a disease will have on his/her life (Meleis et al., 2000).

**Outcome Indicators**

Meleis et al. (2000) identified two major outcome indicators of transition: *mastery* of new skills needed to manage transition and the development of a *fluid yet integrative identity*. The level of mastery will indicate the level at which a healthy transition has been attained. Fluid integrative identity reflects a “new sense of identity” (p. 26) that occurs as a direct result of the transition. The completion of the transition will vary, as will the time to measure the outcome indicators, as each transition is unique and complex.

**The Health Care Team’s Role in Health Care Transition: A Caring Perspective**

While Meleis et al.’s (2000) middle range theory offers a solid framework for the HCT process, the encompassing effect of a caring lens should be regarded as a foundational component in the development of a standardized model for HCT. Boykin and Schoenhofer’s (2001) general theory of nursing as caring serves as a broad conceptual frame that can be easily woven throughout the context of a standardized model for HCT. Theoretically, depending on the area of focus, a caring lens can offer
numerous views or approaches to any situation. Though the theory is nursing focused, all
HCT health care team members and patients, regardless of their educational background,
would benefit by incorporating a caring lens during the HCT process. As each patient’s
experience will be unique, both the patient and the caregiving team members will be
affected by the outcomes of the caregiver/patient interactions occurring during the HCT
process. Boykin and Shoenhofer (2001) supported this thought in the following
statement: “In relationships lived through caring, changes in the one who cares and the
one cared for are evident” (p. 2). Additionally, Mayeroff (1971) stated that caring is an
important factor in helping an individual grow. Just as the HCT team members help the
young adult grow towards a more independent lifestyle, the young adult that is
experiencing the HCT process allows the HCT member to grow as a caregiver.

Further demonstrating a caring approach, each health care team member should
participate as an unequivocal link for communication between all members of the
interdisciplinary team and the patients and/or families. Adolescents living with chronic
illnesses require frequent monitoring and clinic visits throughout the year to maintain or
reach optimum health. Various health care team members are on the forefront of
communication when the patient arrives to and departs from a health care visit. For
example, the nurse’s role includes obtaining information about the patient’s emotional
and physical health upon arrival and throughout all visits with the primary care provider.
This job requirement opens the door to relationship development and trust, an essential
characteristic needed for a healthy transition (Mayeroff, 1971).

Moreover, “The nurse joins in the life process of the person being nursed and
brings his or her life process to the relationship as well” (Boykin & Shoenhofer, 2001, p.
18). Health care team members can “shift from being an onlooker to being a participant in the health experience of the patient…” (Newman, 2010, p. 71) and come to understand the needs and calls of the adolescent with a chronic illness in a unique way. Watson (2008) further interconnected this thought when stating, “Nurses have the honored position of entering another’s private physical-environmental surroundings as well as having access to one’s sacred body-physical-personal private space” (p. 146). For these reasons, a nurse in the pediatric setting and a nurse in the adult setting should be identified clearly as the primary communicators within the disciplinary team and with the patient as the transition of care occurs.

Next, each health care team member’s varied role in patient education is essential. “Chronically ill individuals need knowledge about their illness and its management so that they can make decisions and take actions relative to the illness” (Miller, 1983, p. 260). Watson (2008) suggested that a caring nurse has a coaching role as the teaching-learning initiative begins with the patient, where as many team members are taught to instruct the patient through the conformist way of conveying information. In addition, a health care team member’s role in the educational arena requires personal knowing of the patient in order to educate the patient successfully at the applicable developmental level and at the appropriate time. Boykin and Schoenhofer (2001) described this phenomenon as a caring dance where no one person is more important than the other in the nursing situation. Thus, the health care team members and the patient are equal partners and require support from one another in order for the transition process to be successful. Newman (2010) described this same concept as transpersonal learning, where “teaching becomes a direct engagement of intuitive awareness” (p. 75). Providing the young adult
with a guiding hand, rather than interact in a dictatorial role, will promote independence, empower the patient to make decisions, and improve self-reliance in the everyday management of his/her illness.

**Purpose of the Study**

At the same time that technology is advancing and the population of young adults living with chronic illnesses is increasing, the approach of health care providers to HCT is remaining inconsistent and unconnected. Although the literature reflects various approaches to HCT, there remains a need for a universal approach to transitioning young adults living with chronic illnesses from the pediatric to adult-oriented health care system. Therefore, the purpose of this study was to explore the HCT practices of health care providers and the HCT experiences of chronically ill young adults living with sickle cell disease, cystic fibrosis, and/or diabetes within the southeast Florida region. The two specific aims were to examine current HCT practices of health care workers working with the chronically ill adolescents and to explore the experiences of chronically ill young adults who are currently transitioning/recently transitioned from a pediatric to adult-oriented health care provider. These specific objectives were explored through the following questions:

1. How are health care teams preparing chronically ill adolescents living with sickle cell disease, cystic fibrosis, and/or Type I diabetes to transition to adult-oriented health care?

2. While residing in southeast Florida, what was the health care transition experience of the chronically ill young adult living with sickle cell disease, cystic fibrosis, and/or Type I diabetes?
Definitions

Chronic Illness. A disease or condition that has one or more of the following characteristics: is permanent; leaves residual disability; is caused by nonreversible pathological alteration; requires special training of the patient for rehabilitation; or may be expected to require a long period of supervision, observation, or care (Goodman, Posner, Huang, Parekh, & Koh, 2013).

Cystic Fibrosis. A chronic lung illness that causes airway obstruction through tenacious mucous production. Ultimately, it can progress respiratory failure (Baker & Coe, 1993).

Developmental age. Human ages across the lifespan that are marked by changes in physical, intellectual, psychological, and social growth.

Diabetes Mellitus. Condition characterized by hyperglycemia resulting from the body’s inability to use blood glucose for energy. In Type 1 diabetes, the pancreas no longer makes insulin and therefore blood glucose cannot enter the cells to be used for energy. In Type 2 diabetes, either the pancreas does not make enough insulin or the body is unable to use the insulin correctly (American Diabetes Association, 2014).

Health Care Provider. Any professional who provides health care to patients; may include physician, advanced practice nurse, physician’s assistant, nurse, pharmacist, office staff, and social worker.

Health Care Transition (HCT). “The purposeful planned movement of adolescents and young adults with chronic physical and medical conditions from child-centered to adult-oriented health-care systems” (Blum et al., 1993, p. 570).
**Sickle Cell Disease.** A chronic hematologic condition that is “Characterized by the production of hemoglobin S, anemia, and acute and chronic tissue damage” (Newland, 2008, p. 177).

**Young Adult.** A person that is 18-25 years of age.

**Chapter Summary**

A significant gap in the transitional care of adolescents living with chronic illnesses in the United States reflects the need for a standardized HCT framework for young adults living with chronic diseases. Growing numbers of chronically ill adolescents now are living into adulthood, resulting in the need for a plan to transition into adult health care services. A successful and supportive transition process requires a participative process that includes inter-agency coordination. This research study examined the interprofessional approach currently used by HCT teams working with patients living with cystic fibrosis, type I diabetes, and/or sickle cell disease and explored the experiences of young adults living with at least one of these chronic illnesses. These results contribute information towards the development of a basic framework for a HCT model to assist health care providers as well as adolescents living with various chronic illnesses.
CHAPTER 2. REVIEW OF THE LITERATURE

The transition from pediatric to adult health care for adolescents with chronic illnesses is a complex process. Young adults are at high risk for becoming disconnected from the health care system. The transition of care can lead to lapses in medical care, deterioration in health, or in the adolescent leaving medical care altogether.

Some of the most common chronic diseases diagnosed in childhood that extend into adulthood are sickle cell disease, cystic fibrosis, and diabetes mellitus. The considerable advances in medicine and medical technology in recent years have enabled patients with these common chronic illnesses to have a better quality of life and to live longer. Yet, these medical improvements have left gaps within the HCT infrastructure that bridges the modern pediatric world to contemporary adult health care, as many adult health care providers may not have the knowledge to care for these chronically ill young adults living longer lives (Kennedy & Sawyer, 2008; Steinbeck, Brodie, & Towns, 2008).

The review of the literature is composed of three sections. The objective of the first section of this chapter was to describe three common chronic childhood diseases: sickle cell disease, cystic fibrosis, and diabetes, and the impact of recent medical advancements specific to the population of people living with each disease. The objective of the second section is to review the literature on the current HCT practices of health care providers working with adolescents living with the three common chronic illnesses described previously. Finally, the third section will provide a literature review on the
common challenges that occur during the HCT process from the chronically ill young adult’s point of view.

The Common Chronic Childhood Diseases: Sickle Cell Disease,

Cystic Fibrosis, Diabetes

In the United States, one in 500 African-Americans is born with sickle cell disease (SCD) each year (Doulton, 2010). In 1973, the average life expectancy of children living with this disease was 14 years, whereas, today, the anticipated lifespan of someone diagnosed with sickle cell disease is 50 years (Doulton, 2010). As this group of young people ages into adulthood, they are at high risk for developing additional health complications such as infections, cerebral vascular accidents, vaso-occlusive crises, and life-threatening anemia (Doulton, 2010; National Center for Youth with Disabilities, 1996; Rosen, 1995).

Cystic fibrosis (CF) is one of the most common life-shortening genetic diseases, affecting 30,000 adults and children in North America (Cystic Fibrosis Foundation, 2014). Today, children with cystic fibrosis have a 90% chance of reaching adulthood, whereas 40 years ago, these children were expected to live only to young adult ages (Hagood, Lenker, & Thrasher, 2005).

Diabetes’ diagnoses are increasing at unprecedented rates around the world. In the United States in 2010, about 215,000 people younger than 20 years (11.3% of this population) have diabetes, type 1 or type 2 (National Diabetes Information Clearinghouse, 2011). Young adults living with this disease are at a higher risk for kidney disease, hypertension, ocular impairments, dental issues, heart disease, and amputations
In fact, diabetes mellitus is currently the seventh leading cause of death in the United States (CDC, 2011). Each of these disease processes varies in presentation and prognosis. Similarly, these chronic illnesses often present unique hurdles to the patients and families living with the disease as well as presenting distinctive complications for the health care teams working with this population. However, most importantly, it must be noted that the literature also reveals that this entire group of young adults experience a variety of mutual challenges that occur at some point during their transitional process.

**Current HCT Practices of Healthcare Providers Working with Chronically Ill Adolescents**

Healthcare providers inconsistently utilize a variety of approaches while participating in the HCT process. Multiple similar educational and planning hurdles appear throughout the literature. Chick and Meleis (1986) recognized that “as knowledge accumulates concerning the likely course or trajectory of different types of transition, it will become increasingly possible to plan interventions according to the optimum moment and manner” (p. 251).

Reiss, Gibson, and Walker (2005) stated that the HCT process should “Start in childhood or at the time of diagnosis by ‘envisioning a future’” (p. 119). For this reason, education on the concept of the transition process should be introduced as early as 12 years old or when most developmentally appropriate, allowing time for the patient/family/care provider to adjust psychologically to the idea of changing health care venues (Reiss & Gibson, 2002; Visentin, Koch, & Kralik, 2006). Further support is offered by the American Diabetes Association’s (ADA) position statement that offers
recommendations that are congruent with the previously discussed studies (Peters et al., 2011).

As adolescents transition from the pediatric-oriented provider (P-OP) to the adult-oriented provider (A-OP), one theme that resonates throughout the literature is the lack of trust that the patient has for a new provider. Brez, Rowan, Malcolm, Izzi, Maranger, and Liddy’s (2009) qualitative study gathered information from 22 primary care physicians specializing in diabetes care from a variety of practice settings in Canada. Data were collected through three focus groups. Providers identified gaps in primary care providers’ knowledge and confidence related to diabetes treatment, competing time demands, and excessive workloads as barriers to HCT. Additionally, insufficient patient confidence or trust in the provider’s ability to manage the disease, poor motivation, and “non-compliance” emerged as potential barriers to care. Several studies suggested that educating A-OPs on childhood disease management and identifying the complexity of needs that these patients require would enhance the transition experience for all parties involved (Peter, Forke, Ginsberg, & Schwarz, 2009; Scal & Ireland, 2005; Steinbeck et al., 2008).

Communication between the pediatric and adult-oriented care settings is often inconsistent. In McLaughlin et al.’s (2008) study, survey responses from 448 members of HCT teams working in 170 of 195 of the cystic fibrosis programs within the United States found that less than one third of the programs reported that adult health care providers attended transition meetings of individual patients at pediatric team meetings. Furthermore, 46% of programs reported that the preparation of a medical summary about patients’ medical histories seldom occurs with the HCT from pediatric care to adult care.
In 2002, the American Academy of Pediatrics et al. recognized the inadequacy of the existing HCT programs. In a consensus statement regarding young adults living with special health care needs (SHCN), these groups outlined one step for improvement in this area, which included preparing/maintaining up-to-date medical summaries that are portable and accessible to enable stronger collaboration among health care professionals.

Developing programs that include informing health care workers on how to approach and educate these families about transitioning from the pediatric to the adult health care system is also essential. Telfair, Alexander, Loosier, Alleman-Velez, and Simmons’ (2004) landmark survey of 227 health care providers serving SCD patients experiencing HCT concluded that educational goals should be outlined to focus specifically on the patient, family members, multidisciplinary team, and local community to promote independence, autonomy, and psychological well-being. Additionally, Steinbeck et al.’s (2008) qualitative study gathered data regarding patient care for strategic planning and optimal management of patients during HCT. This group conducted face-to-face interviews with 200 health care providers living in South Wales. Participants worked in tertiary pediatric hospitals in 68 various clinical services in the area. One of the limitations of this study was that the researchers did not identify demographic backgrounds of the participants taking part in the study. The authors concluded that there is a lack of structure (i.e., there are very few defined transition policies/procedures in existence; there is a lack of a formalized link between pediatric and adult services) within the HCT process with communicating specific transition information needed for a successful outcome. Fernandes et al.’s (2011) survey of 479 clinicians providing pediatric transitional care at a large academic children’s hospital in
the northeastern part of the United States concluded that instituting a structured program that offers educational resources for transitioning skills, education, and assessment to the patient/family is a necessary step in building a strong HCT program.

Suris, Akre, and Rutishauser’s (2009) international survey of 209 A-OPs confirmed that only 41% of the providers had a transfer protocol that was followed within the practice. Additionally, these A-Ops often failed to discuss common concerns of HCT with their patients. Similarly, Peter et al.’s (2009) two stage study involved mailing surveys to randomly selected internal medicine providers belonging to the American Board of Medical Specialties. In Stage I, 67 internal medicine providers completed a survey and identified their concerns regarding accepting care of transitioning young adult patients. These participants identified patient maturity, patient psychosocial needs, family involvement, providers’ medical competency, transition coordination, and health system issues as primary concerns that were occurring within the HCT process. In Stage II, 65 internists surveyed rated the following primary concerns about working with patients living with childhood-onset chronic diseases, from highest to lowest in priority: lack of training in congenital and childhood-onset conditions, lack of family involvement or families’ high expectations, difficulty meeting patients’ psychosocial needs, needing a super-specialist, lack of adolescent training, facing disability/end-of-life issues during youth and early in a relationship, and financial pressures limiting visit time. Scal, Evans, Blozis, Okinow, and Blum’s (1999) survey of 122 transition health care services programs throughout the United States concluded that educating A-OPs on the complexity of needs for the incoming patients with SHCN will allow for a smoother transition and encourage more A-OPs to consider working with these young adults.
The previously discussed studies offer support for the consensus statement of the American Academy of Pediatrics et al. (2011), which identified that a written plan that includes “Services to be provided, who will provide them, and how they will be financed” (p. 1305) should be incorporated into the HCT process for each patient. One of the major issues that should be addressed within these services is health insurance. Many centers focused on pediatric care help to coordinate insurance issues, but adult care centers do not have this as a central focus (Tuchman, Schwartz, Sawicki, & Britto, 2010). “Therefore, proactive planning is essential, because eligibility for public funded insurance options end at 21 years of age” (Tuchman et al., 2010, p. 570).

Young, more independent adults living with a chronic illness are at a higher risk for lacking the knowledge on how to negotiate the medical care system independently and competently as they shift from pediatric-centered care to adult care, according to Telfair et al. (2004). Their survey of 227 health care providers serving SCD patients experiencing HCT further recognized that this specific type of guidance often either is missing within the health care setting or is not given priority when educating the patient. Also, Nishikawa, Daaleman, and Nageswaran’s (2011) retrospective study of a survey from the 2005-2006 National Survey of Children with Special Health Care Needs concluded that the biggest challenge often surrounds health insurance issues. Ongoing patient advocacy is needed before and after the HCT due to the insurance barriers many patients encounter (Latzman et al., 2011; Reiss et al., 2005). As a result of these challenges, numerous young adults opt out of care altogether following the HCT, but then resurface with complications in the hospital (Nakhla, Daneman, To, Paradis, & Guttman, 2009).
The literature reveals that there are no standard policies or guidelines that recommend when HCT should occur with this population. Allen and Gregory (2009) completed an in-depth literature review of the youth studies and sociology of chronic disease management in the United Kingdom. This study of the problems of transition indicated that policy makers and health professionals must become aware of five main concerns regarding transition:

1. The value and vulnerability of young people,
2. Psychosocial barriers to transfer,
3. The importance of clinic attendance,
4. Contrasting service cultures, and
5. The challenge of organizational continuity (p. 163).

What remains consistent throughout the literature is the need for a solid educational HCT framework for health care providers to utilize when working with patients living with chronic illnesses. Focusing on the educational preparation of the health care providers and the young adults transitioning to a different health care initiative offers a variety of opportunities for all parties involved. In addition, the evidence indicates that it is imperative to apprise HCT providers on the potential complications that may occur during the journey towards a successful transition. Education should include how to navigate support services, coordinate care, discuss vocational/career choices, develop individualized care plans, and consider high costs of medications and supplies; these are only a few of the system factors that are needed for a successful transition for this group (Brez et al., 2009).
In conclusion, the life expectancy of many patients living with chronic illnesses has risen significantly in the past few decades due to substantial advancement in medicine and technology, leaving the health care system without the support systems in place (Tuchman et al., 2010). As a result, many patients lack the rudimentary knowledge of how to transition competently between pediatric and adult-oriented systems (Telfair et al., 2004). In addition to financial difficulties that develop and/or health insurance coverage that often wanes or disappears all together for young adults living with special health care needs, there are many challenges. It is important to discover the barriers that remain within the current health care system, and that many healthcare providers are overlooking during the HCT process.

**HCT: Unmet Needs of Young Adults**

Young adults transitioning from the pediatric to the adult-oriented system can have many unmet needs, which can be due to a lack of education about the disease process and what to expect in the future (While & Mullen, 2004). These two issues are overlooked or are addressed fragmentally throughout the HCT process. For example, Modi et al.’s (2009) focus group study of 31 adolescents and 71 caregivers of children (6-18 years of age) receiving care at three comprehensive SCD clinics in Ohio concluded that pain management and potential side effects of medications are two important topics that often are identified as barriers in the HCT process. As two key components to maintaining a future quality of life, these issues should be addressed with every patient living with a chronic illness.

McPherson, Thaniel, and Minniti’s (2009) survey of 70 patients (14-20 years of age) receiving care at a pediatric SCD center in the United States concluded that learning
about the transitional process (including anticipatory guidance about possible outcomes as the patient moves toward the transitional stage) through written information is another effective strategy identified to assist patients. Interestingly, Scal and Ireland’s (2005) retrospective analysis of the 2000-2001 National Survey of Children with Special Health Care Needs surveying of over 4,000 adolescents (14-17 years of age) showed that 50.2% of parents had reported that they had discussed HCT with their child’s pediatrician. Yet, only one in six young adults reported having discussed changing needs and had created a plan to address these changes.

Despite knowing that there is a need to develop a comprehensive plan to address the patients’ physical and psychological needs, transition programs are not identifying all the components of HCT sufficiently. Newland’s (2008) descriptive correlational study of participants, aged 14-21 years and living with SCD, indicated that young adults transitioning to adult care experienced adjustment to sexual maturity, development of self-esteem, and achieving autonomy from the family. Psychological transition also occurs with these patients when transferring from a family-oriented pediatric setting to an autonomous adult setting. Further supporting these ideas, based on the retrospective data gathered from seven pediatric clinics that managed care for more than 1,000 patients, Duguépéroux et al.’s (2008) retrospective survey of 68 patients experiencing HCT and living with cystic fibrosis, in France, concluded that the transfer process should be lengthy and planned individually with the adolescent/family and should occur seamlessly when the patient is ready. Finally, Madge and Bryon’s (2002) cross-sectional study, comprised of a 5-point Likert scale questionnaire given to 21 teenage (14-17 years of age) patients living with cystic fibrosis and attending the Great Ormond Street Hospital
for Children, supported pre-study thoughts that pediatric health care settings are, by philosophy, “prescriptive” and “nurturing” and adult health care sites focus more on “collaboration” and empowerment (p. 284). In addition, 81% of the participants agreed that there is significant importance in spending time planning the movement towards adult care. Ninety percent of the young adults in this survey felt they should be involved fully in the decision making about when and where to move within the health care system. Also, 71% looked forward to being treated as an adult and 85% of those surveyed wanted to discuss the HCT with others living with cystic fibrosis. These findings indicated a gap that must be closed in order for the transitional care to occur successfully.

Transitioning from one health care provider to another can be challenging. Latzman et al.’s (2011) qualitative study surveyed 71 African American patients (14-26 year olds) living with SCD as well as their caregivers in the southern region of the United States. This study found that trust of the health care provider was a major concern for patients and families. Latzman et al. (2011) also found that pre-transition patients and caregivers identified one important aspect that should occur when preparing for HCT: meeting the adult team before transition. The adult SCD (post-transition) patients in this study confirmed that getting to know the adult team before transition and being convinced that the adult team gives good care also were of great importance. Consequently, the adult caregivers of patients with SCD, in the transitioning clinic, identified that education about SCD issues were among the most important aspects of an adult clinic. Additionally, Nishikawa et al.’s (2011) study used data obtained from the 2005-2006 National Survey of Children with Special Health Care Needs (SHCN) to compare the approaches to HCT used by children-only providers to providers providing
care to all age groups. A total of 100 caregivers of adolescents with SHCN (12-17 years of age) were analyzed. Interestingly, findings indicated that children were more likely to discuss issues related to the HCT process if the primary care provider offered care to patients across the lifespan rather than specializing in child-only or adult-only care. Thus, from a young adult’s perspective, “getting to know” the health care provider enhances a trusting relationship and could encourage a stronger commitment to participate in medical care as the HCT progresses.

Supporting this idea, Crosby et al.’s (2009) qualitative study using focus groups (n = 13) and individual semi-structured interviews of 32 adolescents (13-21 years old) living with SCD in the midwest United States examined barriers to clinic attendance and strategies to overcome these barriers for young adults living with SCD. The participants identified competing activities, health status, patient-provider relationships, adverse clinic experiences, and forgetting as barriers to clinic attendance. The study findings indicated that a positive relationship with the health care provider influences attendance to clinic appointments and open dialogue during these office visits “May allow clinicians to develop proactive and preventative approaches to the management of barriers to adherence” (p. 119) with patients living with SCD. In addition, focus group participants in this study discussed their dissatisfaction with communication among staff members participating in their health care. For instance, having to give the same information repeatedly to various HCT team members within the same clinic and not understanding the physician’s instructions were two specific barriers that were identified specifically by participants in this qualitative study.
The experience of the young adult transitioning from the pediatric to adult-oriented provider is impacted by the communication style of each of the HCT team members. Reiss et al.’s (2005) qualitative study was comprised of 143 young adults (13-35 years of age) living with SHCN/disabilities as well as their family members and their health care providers. This study pointed out a common theme: there remains a significant lack of communication between pediatric oriented providers (P-OPs) and adult-oriented providers (A-OPs). Participants also reported that communication between the providers was influenced directly by “residency training, continuing education, professional meetings, and the physical separation between pediatric and adult-oriented treatment spaces” (p. 118). Several qualitative studies confirmed that young adults want to meet with the A-OPs before the HCT occurs (Latzman et al., 2011; Reiss et al., 2005). Expanding further, Dovey-Pearce, Hurrell, May, Walker, and Doherty’s (2005) study of 19 young adults (16-25 years of age) living with diabetes in the United Kingdom identified continuity of staff as a major issue when seeking care in the clinic area. Patients “described the burden they felt in repeatedly sharing information with different health care professionals, particularly doctors, and the perceived lack of individual relevance of clinic appointments” (p. 413). Also, Smith, Lewis, Whitworth, Gold, and Thornburg’s (2011) recent research, with 33 adolescents (15-18 years of age) living with SCD at Duke Pediatric Transition Program in North Carolina confirmed that introducing members of the adult team to the adolescent early in the transition process has been proven to alleviate anxiety. Thus, an early introduction to the adult team will allow for a continuity of care, decrease anxiety, and ultimately improve communication when the transfer of care actually occurs. It must be noted that this study’s model exists within an
academic teaching center. These centers comprise only 6% of the hospital settings and differ in culture/services from those of community health care settings (Association of American Medical Colleges, 2013). Academic centers often have the structured support to sustain these programs, while the community liaisons do not have these systems in place. This study offers insight, but careful consideration must be taken regarding how to apply these outcomes to a community population of young adults.

Strategies that enhance continuity encourage communication between all parties involved and embolden trust between the young person preparing for transition and the health care providers on both the pediatric and adult teams. Opening these lines of communication before the transfer is complete helps the teenagers better prepare for the inevitable transfer. Cultivating a mutually trusting relationship with the A-OP, while developing an ongoing support system after the transition is completed, is equally important to ensure a successful HCT.

Chapter Summary

A review of the literature demonstrated that the HCT processes lack consistency. While there are limited HCT frameworks focused only on specific chronic illnesses, the literature demonstrated that none are indicating successful outcomes recurrently. The review of the literature demonstrated a stronger commitment to identifying HCT challenges on an international level, as many of the studies have taken place in Europe and within the United Kingdom’s health care system. Accordingly, the United States health care system remains behind with development and integration of a transitional care framework for adolescents moving into adulthood. Although there is research to discover gaps in the transitional process, no one has identified a singular successful transitional
framework for young adults living with special health care needs. Sickle cell disease, cystic fibrosis, and diabetes mellitus are chronic illnesses that have been seen regularly in pediatric practice for decades. Due to advancements in technology in recent years, these patients have the opportunity to live a longer life. For example, before the early 1980s, life expectancy for people with cystic fibrosis was, at best, early adulthood (Tuchman et al., 2010). However, these improvements have left many young adults living with a chronic illness seeking a stronger support system as they transition from the pediatric to the adult health care worlds. Further research is needed to move forward with HCT in order to provide a successful transitional care program that can address the needs of these young adults as they transition to the adult-oriented health care provider.
CHAPTER 3. METHODOLOGY

This chapter presents the methods used to examine current health care transition (HCT) practices of health care workers working with chronically ill adolescents and to explore the experiences of the chronically ill young adult who recently underwent HCT or currently is transitioning from a pediatric to adult-oriented health care provider. The following questions were explored:

1. How are health care teams preparing chronically ill adolescents living with sickle cell disease, cystic fibrosis, and/or Type I diabetes to transition to adult-oriented health care?

2. While residing in southeast Florida, what was the health care transition experience of the chronically ill young adult living with sickle cell disease, cystic fibrosis, and/or Type I diabetes?

**Study Design**

This mixed methods study design integrated quantitative and qualitative approaches to gain understanding of the characteristics of various health care transitional practices that provide care to chronically ill adolescents living with conditions such as sickle cell disease, cystic fibrosis, and/or diabetes mellitus. These chronic conditions were chosen as a focus because of the paucity of formalized transitional models.

Creswell (2003) stated that all single methods of research have biases and limitations. Mixed methods research incorporates both quantitative and qualitative approaches when collecting and examining data. This approach takes a pragmatic
perspective by looking “to many approaches to collecting and analyzing data rather than to subscribing to only one way (e.g., quantitative or qualitative)” (Creswell, 2003, p. 12) Furthermore, an exploratory design strategy gives the researcher the ability to further develop or “expand the findings of one method with another method” (Creswell, 2003, p. 16). This perspective allows for the data to be interconnected by using one set of data to cultivate, inform, and shape the other; then the researcher blends the data findings so that a single, comprehensive picture of the problem is developed (Creswell & Plano Clark, 2007). Subsequently, Munhall (2007) stated that a mixed-method design is stronger design than the single method approach because the “supplemental component enhances validity of the project…” (p. 554).

This descriptive exploratory mixed-method study was divided into two categories. The first category, “Healthcare Transition and the Healthcare Provider,” gathered relevant demographic and interventional characteristics of interprofessional team members of various pediatric practices throughout southeast Florida that transition adolescents living with a chronic illness from pediatric to adult-oriented health care providers through the use of an anonymous survey. In the second category, “Unmet Needs of Young Adults,” data collection methods included a semi-structured interview format using open-ended questions with young adults (18-25 years) living with one or more of these chronic illnesses. These narrative results were used to gain a better understanding of the experiences of young adults who recently underwent or who currently are involved in the health care transition process.
Healthcare Transition and the Healthcare Provider

Research Plan and Method

As the current health care system offers an incongruent approach to the HCT process, the need for inquiry regarding this issue is imminent. Therefore, a descriptive exploratory study about the approaches of HCT teams to the health care transition of adolescents living with chronic illnesses in southeast Florida was completed by distributing an anonymous survey. The purpose of the survey was to obtain information from a specific sample population so that suggestions could be made to a general population about viewpoints, characteristics, and experiences (Creswell, 2003). A significant advantage of the survey design is that it offers the researcher a “rapid turnaround in data collection” (Creswell, 2003, p. 154). This approach allowed for participants to answer a series of written questions regarding the current HCT process offered within their workplace; then the HCT surveys were gathered and responses to each question was summarized through statistical analysis.

Procedures

Institutional Review Board (IRB) approval from Florida Atlantic University (FAU) was secured (Appendix A) before the study began. Additionally, administrative and/or leadership approval by the organizations/medical practices involved in this research was obtained (Appendix B) prior to any data collection and submitted to the FAU Institutional Review Board. Once permission was obtained from each business, participants were recruited by mailing flyers (Appendix C) to local chapters of nonprofit foundations whose focus was on cystic fibrosis, diabetes, or sickle cell disease; local specialized medical practices; and general pediatric practices within the southeast Florida
The flyers contained an explanation of the study, the risks, and benefits as well as contact information (e-mail and phone) for the principal investigator and the co-investigator (a doctoral student who is a nurse practitioner providing health care to this specific population) to enable the potential participants to ask questions about the study. The flyers contained the necessary information for the participant to complete in the survey online or to contact the investigators for a hard copy of the questionnaire should they choose.

Additionally, the co-investigator visited health care specialty practices and distributed flyers describing the study and requesting study participation. The focus of this research was explained to the office staff in a verbal presentation and participants were solicited. A cover letter was provided outlining criteria for participation, phone numbers/email addresses, and consent processes so that all questions or concerns could be addressed prior to giving consent or completing the survey. The participants were provided the time to read the information about the study and to ask questions. Participants who chose to complete the questionnaire were asked to read the information about the study, including purpose of the study and risks/benefits associated with the study prior to being able to complete the survey. They were provided with the necessary contact information to enable them to ask questions prior to giving consent. Thus, completion of the survey indicated that participants acknowledged that they had read the information about the study, and the risks and benefits, and that they gave informed consent to participate in the study. Participants completing this paper and pencil version were advised that they could stop at any point prior to completion, the data would not be retained, and any documents from that participant would be destroyed.
Although a Survey Monkey© website was approved by the FAU IRB as a means of collecting survey data, none of the participants chose this option. As a result, all surveys collected were completed in hard copy format. The participants had two choices on how they could return the completed surveys: (1) a self-addressed stamped envelope (with no identifiers) was included with each survey to enable the participant to mail the completed survey anonymously back to the investigators, or (2) the co-investigator returned to participating offices to pick up completed surveys on a mutually agreed upon date and time.

Confidentiality

Confidentiality of consenting participants was maintained to assure privacy and in observance of institutional procedures. These surveys were completed anonymously; therefore, participants could answer questions honestly without fear of reprisal from their employers or co-workers. All data was encrypted using alphabetical and numerical coding to prevent individual responses from being identified. For purposes of presenting data, pseudonyms were assigned to each qualitative participant who was interviewed.

Instrumentation

A modified version of the Health Care Transition Interview I Survey for Health Care Providers in the Clinical Setting (HCTIIS) (Appendix D) was used to measure and describe the transition practices of current southeast Florida HCT teams working with young adults living with sickle cell disease, cystic fibrosis, and/or diabetes mellitus. This survey was developed by Reiss and Gibson (2002) at the Institute for Child Health Policy at the University of Florida in Gainesville. The HCTIIS survey initially was administered to Children’s Medical Services programs throughout the state of Florida in order to assess
the routine care given to chronically ill patients experiencing HCT. Results of the initial study had not been evaluated at the time of this research. However, the authors of the survey are considered content experts in the field of health care transition. Moreover, questions posed within the survey address key tactics, routines, and policies that are cited throughout the health care transition literature.

The HCTIIS contains 43 questions with 9 items related to respondent demographics, and 34 open-ended, closed-ended, short answer, or Likert scale items grouped within the domains of transition services. The survey obtained information on age requirements for discharge from a medical practice, practice preparation for transfer of patients from pediatric outpatient (P-OPs) to adult outpatient (A-OPs), and HCT practice routines of a medical program. Some of the questions in this survey were based on McLaughlin et al.’s (2008) survey of P-OPs and A-OPs working with young adults living with cystic fibrosis and experiencing HCT within cystic fibrosis clinics throughout the United States. Verbal and written consent to utilize and modify the HCTIIS survey was obtained.

The Young Adults’ Healthcare Transition Experience

Research Method

The narrative descriptions about health care transition were gathered using a semi-structured interview guide with young adult volunteers living with at least one of the following chronic illnesses: cystic fibrosis, diabetes mellitus, sickle cell disease. The interview method was used to provide the researcher with the ability to obtain historical information from the participants. This approach involves asking participants a small quantity of unstructured and customarily open-ended questions to intentionally elicit
opinions and beliefs from the participants when direct observation is not an option for data gathering (Creswell, 2003). Interviews provide the ability to capture a participant’s experiences in his/her own words, as they are usually conducted with an individual subject (Tappen, 2011).

Prior to beginning the study, the researchers engaged in reflexivity to identify any personal biases or beliefs (Polit & Beck, 2010). Reflexivity is defined as the researcher’s ability to self-reflect and acknowledge how his/her own experiences may impact data collection and analysis. In this study, the investigators brought both academic and clinical knowledge of young adults living with a chronic illness to the research experience. In the clinical setting, the co-investigator, as an advanced registered nurse practitioner, manages the health care needs of many adolescents and young adults living with chronic illnesses. Therefore, reflexivity was an important consideration while gathering and analyzing data for this study.

**Study Population**

A purposive sample was comprised of young adults (18-25 years of age) living with one or more of the following chronic illnesses: cystic fibrosis, diabetes mellitus, sickle cell disease, and who currently are experiencing or recently have experienced the transition from a pediatric to adult-orient healthcare provider. To participate, each subject met the following qualifications: was between the ages of 18-25 years old, had one (or more) of the following chronic illnesses: cystic fibrosis, diabetes mellitus, sickle cell disease, and was able to speak and read English.

Demographic data was obtained from the participants verbally and audio-taped prior to each interview. To ensure confidentiality, this information contained no
information identifying the interviewees or the names of their primary care providers. Demographic data included the following information regarding the young adult: age, ethnicity, current chronic illness/es, age at diagnosis of chronic illness/es, age when the health care transitional process began, and county of residence (e.g., Palm Beach County, Broward County, Miami Dade County) during transitional process. Alpha-numeric coding was used instead of names of participants on all transcribed reports to ensure the privacy of each individual. Additionally, pseudonyms were given to each participant in the presentation of the results of the data.

**Procedures**

For the qualitative component of this research, participants were recruited by flyers (Appendix E). These flyers were distributed at the Sickle Cell Association of Palm Beach County and the Treasure Coast, the Florida Atlantic University (FAU) Diabetes Education and Research Center, and regional medical offices. The flyers contained an explanation of the study, the risks and benefits as well as contact information (e-mail and phone) for the principal investigator, co-investigator, and the Florida Atlantic University Division of Research to enable the potential participants to ask questions about the study. Interested candidates were asked to advise the office manager of their willingness to participate in the study. The office managers of the organizations then telephoned this researcher with the potential participant’s contact information. Next, the possible participants were contacted by the researcher to answer questions, to advise each candidate that no incentives were being offered to participate in the study, and to inform the candidate that the interview would be audio-tape recorded and all recordings would be transcribed and destroyed following the completion of the data analysis. The audio-
recorded interview lasted approximately 30-60 minutes. If the potential participant agreed to these conditions, a meeting place for the interview, date, and time were arranged mutually between the investigator and the subject.

Although occurring in various locations, each of the interviews took place in similarly quiet and safe environments (e.g., participant’s home, business office, medical office). All interviews began by using the following interview procedure: Informed consents were reviewed, read, and signed with the purpose of the interview and issues related to confidentiality verbally explained (Appendix F). The consent form described the purpose of the study, the potential risks, and benefits associated with participating in the study, and the protection of confidentiality. The consent form also included permission to be audio-tape recorded. These interviews were audio taped and transcribed by an experienced transcriptionist from SpeakWrite©. Transcripts were locked and secured in the personal locked office of the investigator.

All young adult participants were informed that they could withdraw from the study at any time. Participants also were advised that there were no right or wrong answers and they could decline to answer any of the questions posed by the investigator. Additionally, participants were informed that the goal of the interview was to identify opinions and beliefs about the experiences of their recent health care transitions from the pediatric health care setting to the adult health care setting. These interviews were conducted in a private room; therefore participants could feel free to say what they thought without fear of reprisal.
Interviews

The primary method of data collection was interviews of young adults (18-25 years of age) living with one or more of the following chronic illnesses: cystic fibrosis, diabetes mellitus, sickle cell disease, and who currently are experiencing or recently have experienced the transition from a pediatric to adult-orient health care provider. The researcher used a semi-structured interview guide with six questions to guide the dialogue:

1. Tell me how it was for you to change from getting care from a pediatrician to another health care provider.
2. Tell me how the pediatrician and the staff at the office helped you get ready for this change.
3. Tell me how you felt during this change.
4. Tell me what things were done that helped you with this change.
5. Tell me about any barriers you faced when making this change.
6. Discuss how you are doing now.

The interview questions were developed using a caring lens while incorporating Meleis et al.’s (2000) transitional theory. The first goal was to determine what the experience of the young adult was like during the health care transition (HCT) of moving from a pediatric health care provider to an adult health care provider. Participants were asked to describe their experiences as they prepared for the HCT with the staff in the pediatricians’ offices and their feelings during this process. Questions regarding how the health care team prepared the participant for the transition elicited details of how the HCT process progressed (Meleis et al., 2000). The second goal was to identify the challenges these
young adults perceived as impeding a smooth HCT experience. Meleis et al. (2000) stated, “to understand the experiences of the patients during transitions, it is necessary to uncover the personal and environmental conditions that facilitate or hinder progress toward achieving a health transition” (p. 19). Lastly, exploring the present day status of the young adult living with a chronic illness who currently is transitioning or recently has transitioned from a pediatric to adult-oriented health care provider is essential in the understanding of HCT outcomes. Meleis et al. (2000) believe that the “levels of which these outcomes are experienced may reflect by proxy the quality of life for those who are experiencing transition” (p. 26).

**Data Analysis**

The researcher used a conventional content analysis approach to describe the young adults’ experiences (Hsiu-Fang & Shannon, 2005). The audio-taped interviews were transcribed by an experienced transcriptionist at SpeakWrite©. The researcher reviewed these transcripts word-by-word to ensure accuracy.

To organize the transcribed data from the interviews, the researcher coded the interviews while reading and rereading the transcripts by highlighting words, key phrases, and statements describing the health care transition experience of the young adult. These codes then were clustered into themes. Next, two other readers with expertise in qualitative coding, independently read and analyzed transcripts of the eight interviews following the same process of coding and confirmed the findings for theme development. The researcher maintained detailed records of the data coding process during this process. Data were reviewed by these three researchers in multiple group meetings to ensure consistency of the findings and to reflect on the data in order to
establish the relationships between codes and to confirm and disconfirm themes for dependability and confirmability (Creswell, 2007; Lincoln & Guba, 1985). Lastly, the reliability of the findings was enhanced by the group meetings, which analyzed and re-analyzed the data credibility (Lincoln & Guba, 1985). Once the descriptions of the experiences elicited no new information, saturation was reached.

**Trustworthiness**

The reliability of this study was centered on the trustworthiness of the data to maintain objectivity (Lincoln & Guba, 1985). Trustworthiness of the data was substantiated by adherence to four principles: credibility (truth value), dependability (consistency), confirmability (neutrality), and transferability (applicability). Credibility of the data was upheld through peer debriefing to evaluate the accuracy of the interpretations of the experience of the participants. Dependability was supported through the independent review of the analysis and then two other researchers examined the process and product of the study to evaluate accuracy and whether conclusions were supported by the data. Confirmability was established by maintaining a detailed audit trail that included raw data, summaries and notes, initial structuring and restructuring of categories, and personal field notes. Finally, through providing a thick description, one can begin to evaluate the extent to which the findings are transferrable to other settings, situations, and people experiencing the HCT process.

**Triangulation**

Triangulation of data is the “convergence of evidence” (Munhall, 2007, p. 355) or the use of various approaches that assist the researcher in providing different perspectives in a study. As the methodology used to address the research questions was a descriptive
exploratory mixed methods design, triangulation of this research provided a method of convergence of the quantitative and qualitative approaches.

Chapter Summary

This study sought to investigate the existing practices of HCT team members and explore the experiences of young adults who currently are going through or who recently went through HCT. The HCTIIS survey of healthcare providers and the individual participant interviews aided the investigator in identifying characteristics of the current HCT process. This evidence provided information needed for the preliminary development of a generalized HCT framework, which will assist with the transition of a varied population of young adults living with various chronic illnesses from pediatric to adult-oriented health care.
CHAPTER 4. PRESENTATION OF FINDINGS

The purpose of this chapter is to present the descriptive exploratory mixed methods findings of this study by examining two questions:

1. How are health care teams preparing chronically ill adolescents living with sickle cell disease, cystic fibrosis, and/or Type I diabetes to transition to adult-oriented healthcare?

2. While residing in southeast Florida, what was the health care transition experience of the chronically ill young adult living with sickle cell disease, cystic fibrosis, and/or Type I diabetes?

In order to discern how health care teams prepare adolescents with chronic illnesses to transition to adult-oriented health care, a survey was distributed to several health care practices throughout Palm Beach and Broward counties in southeast Florida. Additionally, to understand perceptions of the health care transition experiences of the adolescent, eight young adults (18-23 years) were interviewed and data were analyzed using processes consistent with a descriptive exploratory method.

**Healthcare Transition and the Healthcare Provider**

One hundred surveys were distributed to health care providers throughout southeast Florida and 33% (n=33) surveys were completed and returned to the investigators. The population for the quantitative portion of the study consisted of a convenience sample of health care transition team members throughout southeast Florida who held one of the following positions: center director, primary care provider, nurse
educator, nutritionist, doctor of pharmacy, office worker without a formal administrative role, social worker, or additional personnel who are identified as highly involved in the care of young adults living with a chronic illness. If a participant worked with patients living with more than a single chronic illness, he/she was asked to identify the chronic illness (cystic fibrosis, diabetes, or sickle cell disease) that represented the largest population within that particular health care setting. Then, the participant was directed to answer all remaining survey questions specifically based on the health care transition process used in that particular setting with that specific group. To be included in this study, participants had to be at least 18 years of age and working in the same position for a minimum of six months.

**HCT Survey: Demographic Descriptive Statistics**

A total of 33 health care providers were surveyed and 94% (n=31) practiced in Palm Beach County, 3% (n=1) was from Broward County, and 3% (n=1) did not specify his/her practice location. Of these health care providers, 82% (n=27) indicated they have a professional license, while 18% (n=6) did not have a license. Of the 27 participants with a professional license, 19% (n=5) were nurses, 30% (n=10) were physicians, 11% (n=3) were social workers, 7% (n=3) were certified medical assistant, 7% (n=2) were medical assistants, 7% (n=2) were nurse practitioners, 4% (n=1) was a pharmacist, and 4% (n=1) was a physician’s assistant.

The type of care provided in specific clinics or practices was varied with more than half (52%, n=17) only providing specialty care, 24% (n=8) only providing primary care, and 24% (n=8) providing both primary and specialty care. Of those clinics that offered specialty care, 52% (n=17) had a principle focus on diabetes, while 12% (n=4)
had a focus on cystic fibrosis, and 33% (n=11) on sickle cell disease. Three percent of respondents were general pediatricians who identified other specialty care areas within their clinic: asthma and allergy, attention deficit hyperactivity disorder (ADHD), autism, reactive airway disease, and thyroid disease.

**HCT Survey: Discharge Descriptive Statistics**

Eighty-two percent (n=27) of respondents indicated that their clinic/practice discharges patients because of age, 3% (n=1) indicated that they sometimes discharge patients because of age, and 15% (n=5) said they do not discharge patients because of age. Thirty-nine percent (n=13) stated that patients generally are discharged at age 18, 24% (n=8) at age 21, and 42% (n=14) said patients generally are discharged at age 18 or over. When asked if they discharge patients because they reach age 21, 54.5% (n=18) responded ‘Yes,’ 27.3% (n=18) said ‘Sometimes,’ and 15% (n=5) said ‘No.’ When asked if they continue to see older patients after they are no longer eligible for pediatric services at age 21, 12% (n=4) said ‘Yes,’ 48.5% (n=16) said ‘Sometimes,’ and 33% (n=11) said ‘No.’

**HCT Survey: Policy Descriptive Statistics**

Seventy-six percent (n=25) of the health care providers surveyed indicated they have a policy regarding ceiling age over which patients will not be seen, 12% (n=4) did not have policy on ceiling age, and 12% (n=4) did not respond to the question. A majority of the respondents, 82% (n=27), said they had no written transition policies or guidelines, 9% (n=3) indicated they had one, and 9% (n=3) did not respond.
HCT Survey: Preparation for Transition Descriptive Statistics

Thirty-six percent (n=12) of the respondents said their clinic/practice provides services/supports/engages in activities that prepare adolescent patients for a transition to adult-oriented providers, while 64% (n=21) said they did not provide these services. Of those who said they provide services to prepare adolescent patients for a transition to adult-oriented providers, only three said it was part of the formal program. Of those who said they do not provide these services, only three said they have criteria for assessing a young person’s readiness to transfer to adult-oriented health care services. A summary of the criteria that the clinics/practices use to assess a young person’s readiness to transfer to adult-oriented health care services is listed on Table 1. When asked about the age when young patients start talking about health care transition, the average age is 17.4 years (std. dev. = 1.6), with the minimum age being 12 years and a maximum age of 21 years. Of the 33 health care providers surveyed, only 33% (n=11) said they had a primary care coordinator for the transitional process, the majority (84%, n=21) said they didn’t have a primary care coordinator, and one did not respond.
Table 1

*Criteria to Assess Youth’s Readiness to Transfer to Adult-Oriented Health Care Services*

<table>
<thead>
<tr>
<th>Criteria</th>
<th>Frequency</th>
<th>Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Patient’s age</td>
<td>31</td>
<td>93.9</td>
</tr>
<tr>
<td>Patient’s knowledge of medication and other function</td>
<td>11</td>
<td>33.3</td>
</tr>
<tr>
<td>Patient’s ability to interact with health care providers independently</td>
<td>11</td>
<td>33.3</td>
</tr>
<tr>
<td>Patient’s ability to attend clinic visit independently</td>
<td>8</td>
<td>24.2</td>
</tr>
<tr>
<td>Patient’s ability to recognize emergent situations and seek care appropriately</td>
<td>6</td>
<td>18.2</td>
</tr>
<tr>
<td>Patient’s knowledge of their health insurance (coverage, how to contact insurer, etc.)</td>
<td>1</td>
<td>3</td>
</tr>
<tr>
<td>Patient’s developmental maturity</td>
<td>16</td>
<td>48.5</td>
</tr>
<tr>
<td>Family readiness</td>
<td>1</td>
<td>3</td>
</tr>
<tr>
<td>Refusal to see another doctor</td>
<td>1</td>
<td>3</td>
</tr>
<tr>
<td>Refusal to see another specialist</td>
<td>1</td>
<td>3</td>
</tr>
</tbody>
</table>

*Note.* Frequencies are not mutually exclusive.

**HCT Survey: Transition Activities Descriptive Statistics**

Among transition-related activities, only one activity is significantly different across the three groups. Meeting with the patients alone, for at least some of the medical visit, is significantly different among respondents grouped by the type of care their clinic/practice offers. The majority of the health providers who responded that they ‘usually’ meet with the patient worked in clinics/practices that only offer specialty services (24%, n=8), while a majority of those who responded ‘rarely’ worked in clinics/practices that only offer primary services (15%, n=5). A comparison summary of
the transition-related activities provided to patients 15 years and older and grouped by type of care offered is listed in Table 2.

Table 2

Comparison of Transition-related Services, Supports, and Activities

<table>
<thead>
<tr>
<th>Activity</th>
<th>Frequency</th>
<th>Primary Care Only (n=8) % (n)</th>
<th>Specialty Care Only (n=17) % (n)</th>
<th>Primary and Specialty Care (n=8) % (n)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Discuss with youth and or families eventually seeing doctors or health providers who treat adults.</td>
<td>Usually</td>
<td>50.0 (4)</td>
<td>58.8 (10)</td>
<td>75.0 (6)</td>
</tr>
<tr>
<td></td>
<td>Sometimes</td>
<td>25.0 (2)</td>
<td>23.5 (4)</td>
<td>12.5 (1)</td>
</tr>
<tr>
<td></td>
<td>Rarely</td>
<td>0.0 (0)</td>
<td>0.0 (0)</td>
<td>12.5 (1)</td>
</tr>
<tr>
<td></td>
<td>Don’t know</td>
<td>25.0 (2)</td>
<td>17.6 (3)</td>
<td>0.0 (0)</td>
</tr>
<tr>
<td>Talk with youth and/or families about health care needs when patient is an adult.</td>
<td>Usually</td>
<td>25.0 (2)</td>
<td>58.8 (10)</td>
<td>50.0 (4)</td>
</tr>
<tr>
<td></td>
<td>Sometimes</td>
<td>50.0 (4)</td>
<td>23.5 (4)</td>
<td>25.0 (2)</td>
</tr>
<tr>
<td></td>
<td>Rarely</td>
<td>0.0 (0)</td>
<td>0.0 (0)</td>
<td>12.5 (1)</td>
</tr>
<tr>
<td></td>
<td>Don’t know</td>
<td>25.0 (2)</td>
<td>17.6 (3)</td>
<td>12.5 (1)</td>
</tr>
<tr>
<td>Discuss possible changes in eligibility for health insurance coverage when the patient becomes an adult.</td>
<td>Usually</td>
<td>0.0 (0)</td>
<td>29.4 (5)</td>
<td>37.5 (3)</td>
</tr>
<tr>
<td></td>
<td>Sometimes</td>
<td>50.0 (4)</td>
<td>17.6 (3)</td>
<td>12.5 (1)</td>
</tr>
<tr>
<td></td>
<td>Rarely</td>
<td>25.0 (2)</td>
<td>11.8 (2)</td>
<td>25.0 (2)</td>
</tr>
<tr>
<td></td>
<td>Don’t know</td>
<td>25.0 (2)</td>
<td>41.2 (7)</td>
<td>25.0 (2)</td>
</tr>
<tr>
<td>Encourage patients to take responsibility for their health care needs.</td>
<td>Usually</td>
<td>75.0 (6)</td>
<td>64.7 (11)</td>
<td>62.5 (5)</td>
</tr>
<tr>
<td></td>
<td>Sometimes</td>
<td>0.0 (0)</td>
<td>17.6 (3)</td>
<td>25.0 (2)</td>
</tr>
<tr>
<td></td>
<td>Don’t know</td>
<td>25.0 (2)</td>
<td>17.6 (3)</td>
<td>12.5 (1)</td>
</tr>
<tr>
<td>Schedule a visit specifically focused on transition.</td>
<td>Usually</td>
<td>0.0 (0)</td>
<td>35.3 (6)</td>
<td>12.5 (1)</td>
</tr>
<tr>
<td></td>
<td>Sometimes</td>
<td>0.0 (0)</td>
<td>11.8 (2)</td>
<td>12.5 (1)</td>
</tr>
<tr>
<td></td>
<td>Rarely</td>
<td>75.0 (6)</td>
<td>17.6 (3)</td>
<td>37.5 (3)</td>
</tr>
<tr>
<td></td>
<td>Don’t know</td>
<td>25.0 (2)</td>
<td>35.3 (6)</td>
<td>37.5 (3)</td>
</tr>
<tr>
<td>Provide educational materials about health care transition to patients.</td>
<td>Usually</td>
<td>0.0 (0)</td>
<td>29.4 (5)</td>
<td>25.0 (2)</td>
</tr>
<tr>
<td></td>
<td>Sometimes</td>
<td>25.0 (2)</td>
<td>35.3 (6)</td>
<td>12.5 (1)</td>
</tr>
<tr>
<td></td>
<td>Rarely</td>
<td>50.0 (4)</td>
<td>5.9 (1)</td>
<td>25.0 (2)</td>
</tr>
<tr>
<td></td>
<td>Don’t know</td>
<td>25.0 (2)</td>
<td>29.4 (5)</td>
<td>37.5 (3)</td>
</tr>
</tbody>
</table>
Table 2 continued

<table>
<thead>
<tr>
<th>Activity</th>
<th>Frequency</th>
<th>Primary Care Only (n=8)</th>
<th>Specialty Care Only (n=17)</th>
<th>Primary and Specialty Care (n=8)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Assess patient’s understanding of the transition process.</td>
<td>Usually</td>
<td>12.5 (1)</td>
<td>29.4 (5)</td>
<td>12.5 (1)</td>
</tr>
<tr>
<td></td>
<td>Usually</td>
<td>12.5 (1)</td>
<td>23.5 (4)</td>
<td>37.5 (3)</td>
</tr>
<tr>
<td></td>
<td>Sometimes</td>
<td>25.0 (2)</td>
<td>35.3 (6)</td>
<td>12.5 (1)</td>
</tr>
<tr>
<td></td>
<td>Rarely</td>
<td>37.5 (3)</td>
<td>11.8 (2)</td>
<td>25.0 (2)</td>
</tr>
<tr>
<td></td>
<td>Don’t know</td>
<td>25.0 (2)</td>
<td>29.4 (5)</td>
<td>25.0 (2)</td>
</tr>
<tr>
<td>Ask about patient’s long-term health goals.</td>
<td>Usually</td>
<td>37.5 (3)</td>
<td>52.9 (9)</td>
<td>50.0 (4)</td>
</tr>
<tr>
<td></td>
<td>Sometimes</td>
<td>37.5 (3)</td>
<td>11.8 (2)</td>
<td>12.5 (1)</td>
</tr>
<tr>
<td></td>
<td>Rarely</td>
<td>0.0 (0)</td>
<td>0.0 (0)</td>
<td>12.5 (1)</td>
</tr>
<tr>
<td></td>
<td>Don’t know</td>
<td>25.0 (2)</td>
<td>29.4 (5)</td>
<td>25.0 (2)</td>
</tr>
<tr>
<td>Involve the family in transition planning.</td>
<td>Usually</td>
<td>0.0 (0)</td>
<td>29.4 (5)</td>
<td>12.5 (1)</td>
</tr>
<tr>
<td></td>
<td>Sometimes</td>
<td>0.0 (0)</td>
<td>23.5 (4)</td>
<td>37.5 (3)</td>
</tr>
<tr>
<td></td>
<td>Rarely</td>
<td>62.5 (5)</td>
<td>17.6 (3)</td>
<td>25.0 (2)</td>
</tr>
<tr>
<td></td>
<td>Don’t know</td>
<td>37.5 (3)</td>
<td>29.4 (5)</td>
<td>25.0 (2)</td>
</tr>
<tr>
<td>Provide a transition timeline to patient.</td>
<td>Usually</td>
<td>0.0 (0)</td>
<td>23.5 (4)</td>
<td>12.5 (1)</td>
</tr>
<tr>
<td></td>
<td>Sometimes</td>
<td>0.0 (0)</td>
<td>29.4 (5)</td>
<td>12.5 (1)</td>
</tr>
<tr>
<td></td>
<td>Rarely</td>
<td>75.0 (6)</td>
<td>11.8 (2)</td>
<td>37.5 (3)</td>
</tr>
<tr>
<td></td>
<td>Don’t know</td>
<td>25.0 (2)</td>
<td>35.3 (6)</td>
<td>37.5 (3)</td>
</tr>
<tr>
<td>Designate who is responsible for key elements of transition.</td>
<td>Usually</td>
<td>0.0 (0)</td>
<td>17.6 (3)</td>
<td>0.0 (0)</td>
</tr>
<tr>
<td></td>
<td>Sometimes</td>
<td>0.0 (0)</td>
<td>23.5 (4)</td>
<td>12.5 (1)</td>
</tr>
<tr>
<td></td>
<td>Rarely</td>
<td>62.5 (5)</td>
<td>17.6 (3)</td>
<td>50.0 (4)</td>
</tr>
<tr>
<td></td>
<td>Don’t know</td>
<td>37.5 (3)</td>
<td>41.2 (7)</td>
<td>37.5 (3)</td>
</tr>
<tr>
<td>Develop a written health care transition plan.</td>
<td>Usually</td>
<td>0.0 (0)</td>
<td>47.1 (8)</td>
<td>25.0 (2)</td>
</tr>
<tr>
<td></td>
<td>Sometimes</td>
<td>12.5 (1)</td>
<td>17.6 (3)</td>
<td>37.5 (3)</td>
</tr>
<tr>
<td></td>
<td>Rarely</td>
<td>62.5 (5)</td>
<td>5.9 (1)</td>
<td>12.5 (1)</td>
</tr>
<tr>
<td></td>
<td>Don’t know</td>
<td>25.0 (2)</td>
<td>29.4 (5)</td>
<td>25.0 (2)</td>
</tr>
<tr>
<td>Meet with the patient, alone, for at least some of the medical visit.</td>
<td>Usually</td>
<td>12.5 (1)</td>
<td>23.5 (4)</td>
<td>50.0 (4)</td>
</tr>
<tr>
<td></td>
<td>Sometimes</td>
<td>37.5 (3)</td>
<td>35.3 (6)</td>
<td>12.5 (1)</td>
</tr>
<tr>
<td></td>
<td>Rarely</td>
<td>25.0 (2)</td>
<td>5.9 (1)</td>
<td>12.5 (1)</td>
</tr>
<tr>
<td></td>
<td>Don’t know</td>
<td>25.0 (2)</td>
<td>35.3 (6)</td>
<td>25.0 (2)</td>
</tr>
</tbody>
</table>
Among transition-related protocol activities, only one activity is significantly different across the three groups. Assessing the patient’s readiness to transfer to adult care, for at least some of the medical visits, is significantly different among respondents grouped by the type of care their clinic/practice offers. The observed frequency of the health providers who responded that they ‘usually’ assess the patient’s readiness to transfer to adult-oriented care only offer specialty services (30%, n=10), while the majority of those who responded ‘rarely’ worked in clinics/practices that only offer primary services (15%, n=5). A comparison summary of the transition-related protocol activities for transferring pediatric patients to adult-oriented healthcare services, grouped by type of care offered, is listed in Table 3.
<table>
<thead>
<tr>
<th>Activity</th>
<th>Frequency</th>
<th>Primary Care Only (n=8)</th>
<th>Specialty Care Only (n=17)</th>
<th>Primary and Specialty Care (n=8)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td>% (n)</td>
<td>% (n)</td>
<td>% (n)</td>
</tr>
<tr>
<td>Assess the patient’s readiness to transfer to adult care.</td>
<td>Usually</td>
<td>12.5 (1)</td>
<td>58.8 (10)</td>
<td>25.0 (2)</td>
</tr>
<tr>
<td></td>
<td>Sometimes</td>
<td>12.5 (1)</td>
<td>5.9 (1)</td>
<td>37.5 (3)</td>
</tr>
<tr>
<td></td>
<td>Rarely</td>
<td>62.5 (5)</td>
<td>5.9 (1)</td>
<td>0.0 (0)</td>
</tr>
<tr>
<td></td>
<td>Don’t know</td>
<td>12.5 (1)</td>
<td>29.4 (5)</td>
<td>37.5 (3)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>58.8 (10)</td>
<td>25.0 (2)</td>
<td></td>
</tr>
<tr>
<td>Write a discharge summary and include it in the patient’s chart.</td>
<td>Usually</td>
<td>25.0 (2)</td>
<td>35.3 (6)</td>
<td>12.5 (1)</td>
</tr>
<tr>
<td></td>
<td>Sometimes</td>
<td>12.5 (1)</td>
<td>11.8 (2)</td>
<td>25.0 (2)</td>
</tr>
<tr>
<td></td>
<td>Rarely</td>
<td>50.0 (4)</td>
<td>29.4 (5)</td>
<td>50.0 (4)</td>
</tr>
<tr>
<td></td>
<td>Don’t know</td>
<td>12.5 (1)</td>
<td>23.5 (4)</td>
<td>12.5 (1)</td>
</tr>
<tr>
<td></td>
<td>25.0 (2)</td>
<td>58.8 (10)</td>
<td>25.0 (2)</td>
<td></td>
</tr>
<tr>
<td>Give the discharge summary to the patient.</td>
<td>Usually</td>
<td>25.0 (2)</td>
<td>47.1 (8)</td>
<td>62.5 (5)</td>
</tr>
<tr>
<td></td>
<td>Sometimes</td>
<td>25.0 (2)</td>
<td>11.8 (2)</td>
<td>0.0 (0)</td>
</tr>
<tr>
<td></td>
<td>Rarely</td>
<td>25.0 (2)</td>
<td>29.4 (5)</td>
<td>25.0 (2)</td>
</tr>
<tr>
<td></td>
<td>Don’t know</td>
<td>25.0 (2)</td>
<td>11.8 (2)</td>
<td>12.5 (1)</td>
</tr>
<tr>
<td></td>
<td>25.0 (2)</td>
<td>58.8 (10)</td>
<td>62.5 (5)</td>
<td></td>
</tr>
<tr>
<td>Refer the patient to a specific adult provider or practice.</td>
<td>Usually</td>
<td>50.0 (4)</td>
<td>64.7 (11)</td>
<td>62.5 (5)</td>
</tr>
<tr>
<td></td>
<td>Sometimes</td>
<td>25.0 (2)</td>
<td>17.6 (3)</td>
<td>25.0 (2)</td>
</tr>
<tr>
<td></td>
<td>Rarely</td>
<td>12.5 (1)</td>
<td>5.9 (1)</td>
<td>12.5 (1)</td>
</tr>
<tr>
<td></td>
<td>Don’t know</td>
<td>12.5 (1)</td>
<td>5.9 (1)</td>
<td>0.0 (0)</td>
</tr>
<tr>
<td></td>
<td>50.0 (4)</td>
<td>58.8 (10)</td>
<td>62.5 (5)</td>
<td></td>
</tr>
<tr>
<td>Send a discharge summary to the patient’s new adult provider.</td>
<td>Usually</td>
<td>25.0 (2)</td>
<td>41.2 (7)</td>
<td>0.0 (0)</td>
</tr>
<tr>
<td></td>
<td>Sometimes</td>
<td>12.5 (1)</td>
<td>5.9 (1)</td>
<td>25.0 (2)</td>
</tr>
<tr>
<td></td>
<td>Rarely</td>
<td>50.0 (4)</td>
<td>23.5 (4)</td>
<td>37.5 (3)</td>
</tr>
<tr>
<td></td>
<td>Don’t know</td>
<td>12.5 (1)</td>
<td>29.4 (5)</td>
<td>37.5 (3)</td>
</tr>
<tr>
<td></td>
<td>25.0 (2)</td>
<td>58.8 (10)</td>
<td>37.5 (3)</td>
<td></td>
</tr>
<tr>
<td>Talk with the new adult provider by phone or in person.</td>
<td>Usually</td>
<td>0.0 (0)</td>
<td>23.5 (4)</td>
<td>0.0 (0)</td>
</tr>
<tr>
<td></td>
<td>Sometimes</td>
<td>12.5 (1)</td>
<td>29.4 (5)</td>
<td>25.0 (2)</td>
</tr>
<tr>
<td></td>
<td>Rarely</td>
<td>75.0 (6)</td>
<td>17.6 (3)</td>
<td>50.0 (4)</td>
</tr>
<tr>
<td></td>
<td>Don’t know</td>
<td>12.5 (1)</td>
<td>29.4 (5)</td>
<td>25.0 (2)</td>
</tr>
<tr>
<td></td>
<td>0.0 (0)</td>
<td>58.8 (10)</td>
<td>0.0 (0)</td>
<td></td>
</tr>
<tr>
<td>See the patient along with the new adult providers (conduct a transitional medical visit).</td>
<td>Usually</td>
<td>0.0 (0)</td>
<td>17.6 (3)</td>
<td>12.5 (1)</td>
</tr>
<tr>
<td></td>
<td>Sometimes</td>
<td>0.0 (0)</td>
<td>5.9 (1)</td>
<td>0.0 (0)</td>
</tr>
<tr>
<td></td>
<td>Rarely</td>
<td>87.5 (7)</td>
<td>41.2 (7)</td>
<td>37.5 (3)</td>
</tr>
<tr>
<td></td>
<td>Don’t know</td>
<td>12.5 (1)</td>
<td>35.3 (6)</td>
<td>50.0 (4)</td>
</tr>
</tbody>
</table>

52
Table 3 continued

<table>
<thead>
<tr>
<th>Activity</th>
<th>Frequency</th>
<th>Primary Care Only (n=8)</th>
<th>Specialty Care Only (n=17)</th>
<th>Primary and Specialty Care (n=8)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Request that the new adult provider provide you with a follow-up note and/or feedback.</td>
<td>Usually</td>
<td>0.0 (0)</td>
<td>17.6 (3)</td>
<td>0.0 (0)</td>
</tr>
<tr>
<td></td>
<td>Sometimes</td>
<td>0.0 (0)</td>
<td>17.6 (3)</td>
<td>0.0 (0)</td>
</tr>
<tr>
<td></td>
<td>Rarely</td>
<td>87.5 (7)</td>
<td>35.3 (6)</td>
<td>62.5 (5)</td>
</tr>
<tr>
<td></td>
<td>Don’t know</td>
<td>12.5 (1)</td>
<td>29.4 (5)</td>
<td>37.5 (3)</td>
</tr>
<tr>
<td>Receive a follow-up note and/or feedback from the new adult provider provide after the patient is transferred.</td>
<td>Usually</td>
<td>0.0 (0)</td>
<td>17.6 (3)</td>
<td>0.0 (0)</td>
</tr>
<tr>
<td></td>
<td>Sometimes</td>
<td>50.0 (4)</td>
<td>23.5 (4)</td>
<td>12.5 (1)</td>
</tr>
<tr>
<td></td>
<td>Rarely</td>
<td>37.5 (3)</td>
<td>29.4 (5)</td>
<td>62.5 (5)</td>
</tr>
<tr>
<td></td>
<td>Don’t know</td>
<td>12.5 (1)</td>
<td>29.4 (5)</td>
<td>25.0 (2)</td>
</tr>
</tbody>
</table>

The Young Adults’ Healthcare Transition Experience

To understand the experiences of the health care transition experienced by an adolescent living with a chronic illness, young adult participants were interviewed and data were analyzed using content analysis (Hsiu-Fang & Shannon, 2005). The major themes will be shared and grouped under the main objective of this qualitative section: describe the experiences of chronically ill young adults living with sickle cell disease, cystic fibrosis, and/or Type I diabetes while residing in southeast Florida. Each of the themes will be described. Then exemplar quotations from which the themes emerged will be provided.

Demographic Characteristics

Eleven young adults living with chronic illnesses were contacted, with eight participants agreeing to participate in the study. The demographic characteristics of the eight young adults living with cystic fibrosis, sickle cell disease, and/or diabetes are included in Appendix G.
There were seven female and one male participant in this study from various ethnic backgrounds ranging from 18-23 years of age. Two participants classified themselves as Haitian American, two participants as Hispanic, one as African American, one as Asian, one as Caucasian, and one as Guatemalan. Seven participants lived in Palm Beach County, Florida during the transitional process, while one participant lived in Broward County, Florida.

Three participants were diagnosed with sickle cell disease, three with Type I diabetes mellitus, one participant with cystic fibrosis, and one participant with both cystic fibrosis and a mixture of Type I/Type II diabetes mellitus. Participants living with sickle cell disease varied in ages at the time of diagnosis from birth to approximately 8 years of age. Similarly, those living with diabetes mellitus varied in ages, upon diagnosis, from 4 to 13 years of age. The participant living with cystic fibrosis was diagnosed at 18 months. Finally, the participant living with cystic fibrosis and diabetes was diagnosed at 12 years and 16 years of age, respectively.

Four participants began the health care transitional process around the age of 17 years. Conversely, the idea of HCT was introduced to one participant at 19 years and another at 20 years of age while they continued to have their health care managed by the pediatric health care provider. Interestingly, the HCT process did not occur at all for two of the participants. One participant continues to see his/her pediatric health care provider while the other participant did not have a health care provider at the time of the interview.

**Development of Themes**

Throughout the interview process, the young adult participants were asked several questions to gain a better understanding of what the health care transition experience is
like in the southeast Florida region. Their narratives are compelling and revealed several shared themes related to health care transition from the pediatric to adult-oriented care. The final five themes that emerged from the data were transition confusion, familial reliance, lost in transition, fiscal stressors, and transition uneasiness. The themes and codes that arose from the initial data analysis are listed in Table 4.

Table 4

*Final Themes and Codes*

<table>
<thead>
<tr>
<th>Themes</th>
<th>Codes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Transition Confusion</td>
<td>Between the care</td>
</tr>
<tr>
<td></td>
<td>Didn’t know when</td>
</tr>
<tr>
<td></td>
<td>Confused and disappointed</td>
</tr>
<tr>
<td></td>
<td>Kind of confusing</td>
</tr>
<tr>
<td>Familial Reliance</td>
<td>Don’t think about it</td>
</tr>
<tr>
<td></td>
<td>Others handle everything</td>
</tr>
<tr>
<td></td>
<td>Escorted to appointments</td>
</tr>
<tr>
<td>Lost in Transition</td>
<td>Prepared me, but not really</td>
</tr>
<tr>
<td></td>
<td>It never happened</td>
</tr>
<tr>
<td></td>
<td>Never touched base</td>
</tr>
<tr>
<td></td>
<td>No idea about it</td>
</tr>
<tr>
<td>Fiscal Stressors</td>
<td>Not having insurance</td>
</tr>
<tr>
<td></td>
<td>Doctor panicking</td>
</tr>
<tr>
<td></td>
<td>Stress about insurance</td>
</tr>
<tr>
<td></td>
<td>No money for supplies</td>
</tr>
<tr>
<td>Transition Uneasiness</td>
<td>Shocking don’t know doctor</td>
</tr>
<tr>
<td></td>
<td>Bye you’re gone</td>
</tr>
<tr>
<td></td>
<td>Very uncomfortable</td>
</tr>
</tbody>
</table>
Transition Confusion

The data revealed that the participants experienced a lack of preparation for the health care transition process that occurred when moving from a pediatric provider to an adult-oriented provider. The codes contributing to this theme were *between the care, didn’t know when, confused and disappointed, and kind of confusing*. Several participants discussed the bewilderment, uncertainty, and confusion that occurred at the time of the healthcare transition. The confusion often included not knowing the adult provider’s expectations. Others elaborated on the feelings of uncertainty and perplexity once the transition occurred:

“They, they said they told me that they couldn’t see me anymore because of, uh, um, the transfer of insurance and different things like that, so, when it came to the transfer, it was very kind of confusing, trying to figure out what was really going on, between the care.” (Charles, diabetes)

“Um, I guess a little confused and disappointed. Like he was, like I really liked him, like my previous hematologist. And now I was too old to see him…” (Ellen, sickle cell disease)

“…they kinda just told me, you know, you need to see, in the long run you’re gonna have to change from pediatrics to, you know, to an adult doctor. Like, it’s, it has to happen and I knew it was going to; I just didn’t know when, you know. I knew it was gonna happen and they’ve always, they had always told me, you know, this is going to happen so you know, just prepare.” (Fran, cystic fibrosis)
**Familial Reliance**

*Others handle everything, escorts to appointments, and don’t think about it* were the codes that shaped the theme of familial reliance. The participants felt that their parents continued to be significantly involved with management of their health care, even after the health care transition occurred. The following quotations illustrate the ongoing parental dependence:

“But other than that, I mean I just go in you know, get my checkups and usually my mom just handles everything else. So I’ve only just learned how to understand where I should be in my life, my health and my blood and count and everything.” (Ann, sickle cell disease)

Researcher: “Does your mother still go with you to your appointments today?”

“Yeah, whenever she can, she comes, other than that, my sisters or my grandpa comes with me.” (Gina, sickle cell disease)

“Many people you know, I know it gets hard because you know you don’t think about it as much when you make the transition ‘cause your parents are around.” (Charles, diabetes)

**Lost in Transition**

The codes *prepared me but not really, no idea about it, it never happened,* and *never touched base* merged to become the theme lost in transition. There were rich descriptions identifying deficiencies in the long-term planning of the health care transition. The following quotations demonstrate the lack of preparation for the transitional event of changing from the pediatric to adult healthcare provider:
“(The nurse) had prepared me for it but I have a terrible memory and so there’s a lot of things that I actually wasn’t aware of switching over here on, I don’t even know, I don’t even know what to say. They prepared me but not really at the same time.” (Barbara, diabetes)

“when it came down to it, um, the transition from pediatric to a different facility, um, there, at that moment, there wasn’t much talk of anything being transferred, um, so at the moment with the pediatric to when I turned 18, when they transferred me over to Dr. XXX, I had no idea about it.” (Charles, diabetes)

“…we didn’t really touch base on transition, they just mentioned that there’s not that many good endocrinologists once you get out of that doctor’s office because, like everyone I talked to usually knows who the pediatrician endo was, and then I tell them my regular endo that I have now, they don’t really hear about him, um, but they did recommend me to an endo in XXX, or something, but I thought like that was still a drive away, because I was still going to, XXX all the way down (the next county) when I lived up here. So, I made a drive to go down there.” (Delia, diabetes)

“It never happened I guess. Oh, um, I mean my doctor did say I could stay until I became pregnant but it was just awkward, ‘kay, like being in the pediatric section while I’m like over 18 so I just stopped going basically…he never told me of another person that was good that he would
recommend to go see. So I kinda just left and that was it.” (Ellen, sickle cell disease)

**Fiscal Stressors**

Participants identified obtaining and maintaining health insurance as a significant stressor in their lives. There were consistent descriptions detailing the impact of health insurance and how living with a chronic illness affects the entire family. The codes that emerged were *not having insurance, doctor panicking, stress about insurance,* and *no money for supplies.* One participant stated:

“…insurance is the biggest, biggest thing. Because without it no insurance means you have to pay for it or not somehow.” (Charles, diabetes)

A participant acknowledged the emotional and fiscal effects of insurance loss on the health care provider and her parents:

“… I had no insurance and my doctor was panicking. He was like you cannot not have insurance. So we, my dad, was trying to get me onto his insurance for his job and they were like, no we don’t want to. No we don’t want to. My dad’s like, he was fighting it and fighting it. So meanwhile this, it was like a year between, meanwhile I had to go to the healthcare district and get their insurance. So for a while I had their insurance but, you know, they only covered so much, you know.” (Fran, cystic fibrosis)

Participants articulated the inability to purchase medical supplies due to financial constraints:

“Well I cannot get my insulin. I wasn’t aware of ways to get insulin. I’ve been mooching off of my diabetic grandmother and diabetic neighbor. I
haven’t been able to get any of my supplies whatsoever. I have, I didn’t think I could go to the hospital, any doctors. I had, for what I had thought I lost my primary care whose pediatrics and my endocrinologist. As not having insurance pretty much just bunks my whole medical everything. I couldn’t, I couldn’t get any supplies whatsoever as, as far as I was aware unless I paid out of pocket.” (Barbara, diabetes)

**Transition Uneasiness**

The initial codes shocking *don’t know doctor, bye you’re gone*, and very *uncomfortable* collapsed to become the theme transition uneasiness. The participants expounded on the apprehension and discomfort they had personally experienced before the transitional process occurred:

“…I had never met him. It was, um, you know, like I said, I had seen one doctor for like my whole life and then they said, all right, we finally are able to transfer you to adult. I was like, okay, and then it was like a brand new doctor. And to me it was kind of shocking, like, I don’t know this doctor. I’ve known one doctor my whole life. What do I do?” (Fran, cystic fibrosis)

“ Well the way, the way I feel about it is like they, this office, the pediatrician office they actually cared about me until I was right about to like leave and they were just pretty much like bye or whatever you’re gone.” (Barbara, diabetes)

Another participant expressed the reasons that she did not want to transition to an adult health care provider:
“Very, very uncomfortable. I really, I really, really don’t want to switch. Because personally, I don’t like, um, a whole new system of people coming into my life and switching out the old people, like, I wouldn’t be seeing Dr. XXX anymore and it makes me feel really uncomfortable, so, personally I want to stay, because even if, you know, it’s pediatrics, I want to stay, because I can’t, I don’t like the idea of not having them around. They’ve been around for the entire time I’ve had cystic fibrosis, and they’ve really changed my life, like, they pretty much saved my life, so, it’s like, you know, it’s like a personal connection so…” (Helen, cystic fibrosis and diabetes)

Chapter Summary

The results of this study indicated that there are similar and contrasting perceptions of the HCT process between health care providers and the young adults living with a chronic illness who recently underwent HCT or who currently are transitioning from a pediatric to an adult-oriented health care provider. As reflected in the statistics derived from the survey, health care providers vary in their approach to HCT. Similarly, the young adults interviewed voiced feeling of confusion, uncertainty, and fear when reflecting on their HCT experiences.

In Chapter 5, the findings will be discussed from the perspectives of existing literature related to health care transition. Additionally, Meleis et al.’s (2000) transition theory and caring science will provide a framework for presenting implications for education, practice, and research.
CHAPTER 5. DISCUSSION, IMPLICATIONS AND RECOMMENDATIONS

As technology continues to advance and the population of young adults living with a chronic illness increases, the urgency to resolve the present gap in health care transition (HCT) becomes more evident. At the same time that many chronically ill young adults hesitate to transition from pediatric to adult-oriented health care providers, many health care providers waver when transitioning their patients to the adult-oriented health care system. As a result, this population often remains with their pediatric health care providers after the age of 18 years or, due to finances or lack of support, will leave medical supervision entirely.

This chapter presents a summary and analysis of the findings from this study. The results will be discussed and described in relation to the research questions. In addition, the findings will be linked and compared to current literature that focuses on the healthcare transition of adolescents living with a chronic illness. The outcomes of the study will be discussed within the context of a modified framework of Meleis et al.’s (2000) theory on transition using a caring lens. The limitations of this study will be considered as they apply to the interpretation of the results. Finally, the implications of the findings as they relate to education, practice, and future research will be identified.

Discussion of Findings

The dramatic increase in the life expectancy of young people living with chronic health conditions has prompted the urgent need for changes in the current HCT system. Peter et al. (2009) reinforced that a successful HCT requires the comprehensive
understanding of each chronically ill young adult’s needs as they transfer from the pediatric to adult-oriented health care setting. Previous studies have inquired about the views of patients, family members and pediatric health care providers (Modi et al., 2009; Newland, 2008; While & Mullen, 2004). Likewise, other research has evaluated various HCT models that are disease specific in their focus (Crosby et al., 2009; McLaughlin et al., 2008; Newland, 2008). These studies have not given a true picture of the entire HCT process from the perspective of the HCT or the young adult. To expand on these findings, this study sought to identify the current HCT practices offered by health care providers and associate these findings with the viewpoints of the young adult living with a chronic illness who recently experienced or currently is experiencing HCT. In order to determine how health care teams prepare adolescents with chronic illnesses to transition to adult-oriented health care, a survey was distributed to several general and subspecialty health care practices in a region of southeast Florida. Additionally, young adults (18-23 years) were interviewed from the same area, to gain a better understanding of perceptions of the health care transition experiences of the young adult.

The current findings of this study demonstrate that there are, at minimum, three general parts of the HCT process that remain deficient: educational preparation regarding HCT, consistent communication between all parties involved in the HCT process, and the independent negotiation of the present health care system. The findings from this study are congruent with Scal and Ireland (2005), who recognized that in order to develop a standard HCT framework, a comprehensive approach to understanding the causes of unmet health care needs and health care service utilization must occur. The remainder of this discussion will be presented in three general parts.
HCT: Educational Preparation

The results of this study demonstrate that the HCT teams’ educational preparation of the patient regarding the transition process is being addressed inconsistently with patients living with chronic illnesses. The concept of HCT is not always being discussed with the patient/family in a timely manner with only two out of three HCT team members typically discussing the idea of transitioning to an adult-oriented provider. Further supporting this finding was Charles’ statement within the theme of lost in transition, that “…there wasn’t much talk of anything being transferred…I had no idea about it.” If the idea of transition and assessment of the patient/family’s understanding of the HCT process is not introduced when the patient/family is developmentally ready or at the time of diagnosis (whichever comes later), the acceptance of the pending change of providers could be problematic (Reiss & Gibson, 2002; Visentin et al., 2006). This lack of education became evident with 24-year old Fran who was diagnosed with cystic fibrosis at 18 months of age. Within the theme of transition uneasiness, she clearly acknowledged her discomfort with moving from a pediatric to an adult-oriented setting when she stated, “all right, we finally are able to transfer you to adult. I was like, okay, and then it was a brand new doctor. And to me it was kind of shocking, like, I don’t know this doctor… What do I do?” HCT teams must be cognizant of the fact that health care transition is a process that occurs over a period of time, not at the time of transfer from pediatric to adult-oriented health care (Duguépéroux et al., 2008; Peters et al., 2011).

Secondly, the results of this study reinforce that educational materials are not being offered regularly to the patient/family at the time of service. Only one out of five HCT team members consistently offered educational materials to their patients during the
transition process. The need for written material to assist with anticipatory guidance and transition expectations is critical (McPherson et al., 2009). The development of an outline of clear educational goals that can be individualized to the patient, at the time of an office visit, could enhance the promotion of autonomy and the adjustment to the pending transfer of health care providers (Telfair et al., 2004). Yet, less than 10% (n=3) of the health care providers in this study routinely offer a written health care transition plan to their patients. Educational resources of this type would be considered a critical component towards the development of a structured HCT framework.

Finally, many young adults living with chronic illnesses are not prepared for the transfer of care when it occurs. Often, they continue to rely on familial support when managing daily challenges regarding their disease process, and frequently are unaware of future fiscal challenges. Following the theme of familial reliance, Ann, 19 years old, for example, attends her checkup appointments but continues to rely on her mother to “handle everything else.” Likewise, Barbara summarized her unexpected immediate fiscal challenges within the theme of fiscal stressors when she said, “As not having insurance pretty much debunks my medical everything.” White (2002) stated that the lack of planning was the central reason for HCT failure. When preparing for HCT, health care teams must address future expectations regarding the transition process, disease progression/management, and likely fiscal challenges. Recommendations from other studies expand on these topics to include medications and pain management (Modi et al., 2009; While & Mullen, 2004). The integration of “future expectations” into the educational section of a general HCT framework could assist in preventing many untoward outcomes after the transfer of care occurs.
HCT: Communication

A successful HCT occurs with interdisciplinary collaboration and patient participation. Interdisciplinary collaboration starts with intraprofessional and interprofessional communication. However, the challenge remains clear, as a substantial number of health care providers in this study did not speak with the new adult provider, send a discharge summary, or send/receive a follow-up note and/or feedback once the patient was transferred. Throughout the HCT process, it is essential that the team members communicate effectively with one another and with the patient/family. Care coordination that includes the patient/family during the planning stages could enhance the level of the patient’s trust of the newly appointed adult-oriented health care team.

One of the barriers reflected in this study was the lack of pediatric providers routinely scheduling a visit specifically focused on HCT. Many of the providers did not see the patient along with the new adult providers to conduct a transitional visit. Jointly planning the transfer between the pediatric and adult providers would offer all HCT team members an opportunity to explore the attitude and readiness of the patient and to enhance trust of the new providers. Although not currently used by a majority of the providers in this study, the integration of a flexible individualized HCT timeline would enable the team members to anticipate the patient’s level of preparation/knowledge, offer guidance appropriately, and encourage a positive relationship with the patient. At the same time, patients could be given time to accept the pending transfer and offered multiple opportunities to discuss concerns about the HCT. This approach would have assisted Charles in avoiding transition confusion, rather than, as he perceived, he could
not be seen at the pediatric–centered office any longer and feeling confused as he tried “to figure out what was really going on, between the care.”

Only one third of the participants in this study acknowledged that their clinic worked with a designated HCT coordinator. Identifying a HCT coordinator on each team could benefit all HCT team members and patients by offering an organized approach for coordinating issues and planning (Suris, Michaud, & Viner, 2004; Peters et al., 2011). HCT team members from each of the pediatric and adult areas would have a “go to” person to communicate needs, changes, or concerns regarding the patient. At the same time, the patient would have a single resource person in each office who would be familiar with his/her case history.

Many of the young adult participants in this study verbalized a desire to meet the adult health care team before the transfer of care happened. However, according to the participants that completed the survey and the young adults who currently are transitioning or who recently completed the HCT process, this “meeting of the future providers” during the transitional process rarely occurred. The integration of this step into a generalized transition framework would encourage trust of the adult HCT team by allowing the patient to “get to know” the new team members, clarify expectations, and decrease anxiety levels before the actual transfer of care occurs.

**HCT: Negotiation of the Healthcare System**

The present health care system is comprised of multi-layered governmental and health insurance policies, which often present challenges to patients and their families when navigating the health care system while living with a chronic illness. Peters et al. (2011) reinforced that preparation for the transfer of care between the pediatric and adult
providers should not only address the differences in expectations of the patient’s participation, but also include education regarding health insurance/coverage. The results of this study clearly demonstrate the lack of a consistent approach to prepare the patient to meet the challenges of negotiating care within a fragmented health care system.

The challenges of maintaining health insurance often is an overwhelming task for the patient and his/her family. The fiscal guidance within the transition process is regularly overlooked, leaving many young adults to experience termination in health care coverage. Education regarding health insurance options and how to maintain coverage are two necessary components that would not only benefit patients/families, but also prevent patients from delaying or foregoing needed medical care due to a lack of health insurance.

Pai and Ostendorf (2011) recognized that financial barriers frequently contribute to non-adherence during the HCT process; yet only one out of four participants in the survey acknowledged discussing possible changes in eligibility for health insurance coverage when the patient became an adult. The financial burden of chronic disease management can be overwhelming and stressful. Barriers (e.g., medications, testing, attending clinic visits, and seeking care when needed) exist that can cause limited access to health care and can impact the quality of life and ability to follow a prescribed regime for patients living with a chronic illness. These barriers clearly were present in the theme fiscal stressors. Two examples illustrate this. In the first, Fran, when she lost her private health insurance, said: “I had no insurance and my doctor was panicking…So for a while I had (public health insurance) but, you know, they only cover so much, you know.” In the second, Barbara, when explaining her challenges due to lack of health insurance
coverage, commented: “Well I cannot get my insulin…I’ve been mooching off of my diabetic grandmother and diabetic neighbor.”

The urgency for the pediatric and adult HCT teams to recognize the financial barriers and to educate the patient on how to negotiate the current health care system is evident in the results of this study. Every young adult in this study verbalized concern about health insurance maintenance and listed fiscal challenges. Guidance should begin in the pediatric setting and continue as the patient moves into the adult-oriented setting and his/her needs evolve in lifestyle management.

**Theoretical Conceptual Model**

Often the routine and quality of the HCT practice varies depending on the adolescent’s diagnosis, the healthcare provider’s knowledge/educational background, and/or the relationship that is cultivated between the health care provider and the patient/family. These characteristics of HCT are addressed in Meleis et al.’s (2000) middle range theory on transitions. Operationally, the dynamic process outlined in this framework assimilates all types of transitions that nurses may encounter within their practice.

Meleis et al.’s (2000) theory was selected as a framework for providing clarity in understanding the healthcare transition process within the context of young adults living with a chronic illness. While it is important to note that Meleis et al.’s (2000) theory is presented as a nursing theory, the general framework provides direction for many professionals practicing within the health care system (e.g., primary care providers, nurses, dieticians, pharmacists, social workers, and ancillary staff). Along this same vein,
the concept of HCT requires a team of providers from various backgrounds in order to provide the adolescent with a multidimensional comprehensive transition.

The findings of this study support the foundational concepts of the Meleis et al.’s (2000) model. Types, patterns, and properties of transitions were evident within this group of participants. It is obvious from the voice of the participants that Meleis et al.’s emphasis on developmental readiness must be taken into consideration when transitioning from the pediatric to adult healthcare provider. Additionally, the concept of awareness, as outlined by Meleis et al. (2000), was found to be a major factor in the HCT process. Moreover, this model’s component of transition conditions was found to be extremely influential on the HCT process. In particular, one of the most important conditions supported in the healthcare transition process for these adolescents and young adults is the need for preparation and knowledge before the transition from pediatric to adult care occurs. Furthermore, the socioeconomic status transition condition greatly influenced how the participants experienced fiscal stressors. Finally, the findings of the HCTIIS and the voices of the young adults clearly demonstrate that the patterns of the response component of Meleis et al.’s (2000) middle range theory accurately target the necessary areas for healthcare providers to consider when assessing and developing individualized HCT interventions.

Ultimately, the findings of this study led to the development of a healthcare transition model to guide HCPs when transitioning chronically ill adolescents and young adults from pediatric to adult-oriented providers. The concept for the person-centered HCT framework emerged from data that included the survey results completed by HCT team members and the voices of the young adults living with a chronic illness (Figure 2).
Figure 2. The person-centered HCT framework.

This general framework’s purpose is to assist HCT team members to clearly identify and address the individualized needs/anticipated needs of the person transitioning from the pediatric to the adult healthcare world.

The chronically ill adolescent and young adult, along with family members, encounter common transition challenges. For instance, lost in transition, transition uneasiness, transition confusion, familial reliance, and fiscal stressors are all common characteristics that are shared among this population at various times throughout the transitional process. While these traits frequently may be displayed by those living with a chronic illness, the uniqueness and complexity of each transitional experience should be noted by each of the HCT team members working with these individuals.
The HCT team should be obligated to approach each transitional experience in a thorough, individualized, and caring manner. The methodical approach, as outlined in the person-centered framework, includes participating in clear, concise communication with all parties involved with the healthcare transition. Additionally, by identifying a HCT coordinator on each of the pediatric and adult teams, this process can be streamlined and lines of communication between the participating healthcare providers and young adults can be solidified. Second, the inclusion of a written person-centered HCT plan offers each healthcare provider a more structured educational approach when working with young adults living with a chronic illness. This individualized education plan must remain flexible since developmental readiness and acceptance will vary from person to person. The use of written materials to assist adolescents and family members in understanding the process must be included as these materials can be used as additional sources of information that can reinforce pending healthcare changes. Finally, another responsibility of the healthcare providers is to provide guidance throughout the HCT process. This guidance must include teaching the young adult how to navigate the current healthcare system and how to address potential fiscal stressors that may occur during or after the HCT is complete.

The young adult and the team of healthcare providers interact at different times and at various stages throughout the HCT process. Boykin and Schoenhofer (2001) noted that the members of the HCT team have a “caring function; however, caring per se is not their function” (p. 13). When interprofessional teams work with adolescents experiencing a HCT process, they should do so through the use of a caring lens to ensure an individualized person-centered approach and to promote successful outcomes for the
adolescent/family. This single lens should be utilized by each of the HCT team members to assist with the visualization of various perspectives of the adolescent’s needs/calls during this time frame through personal, empirical, and ethical knowing. The use of this lens provides a basic foundation that leads to the development of relationships and connections with others and often guides the adolescent in the direction of a successful HCT outcome (Kralik, Visentin, & van Loon, 2006).

Therefore, the integration of a caring lens provides a solid foundation for a general approach to the HCT process for young adults living with a chronic illness. When a reliable pattern of communication is established and filtered through a caring lens and a caring lens is added early in the HCT process, a higher level of trust is reached between the HCP and the adolescent. Moreover, structured educational outcomes may be enhanced through the use of a person-centered written plan that leads to the transition of care from the pediatric to adult-oriented provider. Lastly, this caring approach enables these young adults to be better prepared for handling future health insurance changes and economic challenges.

In the end, HCT team members have the opportunity to live caring every day in their support of adolescents living with chronic illnesses. This model integrates the longitudinal characteristics and various individual and HCT team factors, and focuses on young adults’ individualized needs while considering potential outcomes. The utilization of the person-centered HCT framework will offer all HCT team members a guide for a caring approach while working with persons experiencing the transition process. The person-centered model provides the entire HCT team guidance so that barriers such as transition confusion, familial reliance, fiscal stressors, and transition uneasiness can be
moderated. In order to move forward with the evolving advancements in healthcare, HCT team members and adolescents must work together symphonically within a caring environment to reach successful outcomes. The use of a caring lens within the person-centered framework allows for recognition and implementation of an individualized approach to communication, education, and guidance while assisting every person transitioning from a pediatric to adult-oriented health care provider.

**Limitations**

This study has several limitations. The small sample size limits generalizability. This study examined various approaches to HCT currently practiced by 33 health care providers in the southeast Florida area. It is possible that only the health care providers with a strong interest in this topic participated in this study. Additionally, the lengthiness of the survey proved to be a challenge for the researcher. Many questions were left unanswered and several potential participants verbally refused to partake in the study due to the length of time required to complete the survey.

Gaining access to interview the young adults (18-23 years of age) living with sickle cell disease, cystic fibrosis, and/or diabetes was challenging, as there are a limited number of health care providers in the southeast Florida region working with this population. In the end, seven of the participants in this study were recruited from Palm Beach County and one from Broward County, Florida. More participant interviews, as well as interviews of adolescents (less than 18 years of age) that are preparing for or who currently are experiencing HCT, would have helped the researcher gain a deeper understanding of the experiences of these young adults as they prepare to move from the pediatric to adult-oriented health care world.
Implications for HCT Education

The findings of this study demonstrate the necessity for both the pediatric and adult-oriented health care providers to engage in a mutually inclusive approach when working with a person experiencing HCT. Moreover, to address the needs of young adults living with chronic illnesses, a national transition policy that incorporates the Person-centered HCT Framework should be introduced to institute general guidelines for health care providers to follow. The integration of this framework into health care practices nationwide would offer all HCT teams a basic model to streamline the approach to the HCT processes and could lead to better HCT outcomes for the chronically ill young adult.

Another tactic that may offer an additional way to streamline the process to ensure ongoing partnership would be to include the school nurse as part of the HCT team. While the role of the school nurse varies nationally, in the southeast Florida area this role is well integrated and respected within the community. Therefore, the school nurse would be well positioned to provide a strong linkage for all parties involved in the HCT process.

Implications for HCT Practice

There are many practice implications from this study. It is important that health care providers recognize that there is an incongruent perception of the HCT process between the health care providers and the chronically ill young adults. The HCT team members are assisting the person/family through the transition process, yet the young adults perceive their transition experience as one that is missing a caring approach and is fragmented. The implementation of the Person-centered HCT Framework could prompt healthcare teams to integrate a caring approach and address what matters most to the
person experiencing the transition, while providing guidance, education, and consistent communication. The addition of a primary HCT liaison (pediatric and adult) to every health care clinic that works with chronically ill young adults experiencing transition would enhance trust and open communication. The use of telecommunication technology could assist in effective implementation of the liaison roles for healthcare transition. Advances in this type of technology could make it possible for P-OPs, A-Ops, and adolescents with their families to interact synchronously while at multiple locations. Providers’ awareness of the types of transitions, transition conditions, and patterns of responses could alter the approach to the patient by individualizing interventions, thereby increasing the potential for successful outcomes. These successful outcomes would be reflected not only in the person’s quality of life, but also in the economic benefits, as healthcare evolves.

**Recommendations for Future Research**

To provide a more solid HCT framework, a prospective longitudinal study of chronically ill adolescents living with various diseases experiencing the HCT process is necessary. Additional research in this area could identify other modifiable factors that occur within the HCT process at various stages. These factors essentially could lead researchers toward improving health outcomes. Expanding on this recommendation, after these factors are identified, the information could be used to create a tool to measure HCT outcomes. Research that explores the use of a primary coordinator/communicator role such as a nurse in the pediatric and adult practice setting might be helpful in creating a more nurturing and caring environment for the person transitioning from the pediatric
to the adult-oriented system. Finally, research should look at the school nurse and how this role could provide a connection between adolescents and HCT teams.

**Chapter Summary**

This mixed methods, descriptive exploratory study was deemed the best way to discern the routine of HCT teams providing care to patients living with cystic fibrosis, sickle cell disease, and/or diabetes, and to gain further knowledge on the perspectives of young adults living with these chronic illnesses on the current HCT practices in the southeast Florida area. The key findings were the lack of a consistent approach to HCT by health care teams throughout the southeast Florida region and the overarching themes of inadequacies regarding the HCT process experienced the young adults within the study.

While the overall findings suggest a need for additional exploration of the health care transition process, this is the first study to describe current practices of HCT health care providers and the views of young adults living with cystic fibrosis, sickle cell disease, and/or diabetes on the HCT transition process. The benefits of developing and implementing a formalized health care transition infrastructure are numerous. Providing continuity of care between pediatric and adult health care providers can improve quality of care and reduce long-term health care costs. Establishing a HCT framework that incorporates consistent communication among team members and patients/families, individualized educational formats, and guidance for navigational skills to negotiate the healthcare system can lead to more successful health transition outcomes.
APPENDICES

Appendix A

FAU IRB Approval

From: Angela Clear [no-reply@irbnet.org]
Sent: Thursday, July 12, 2012 1:24 PM
To: Kelly White; Claire Hanson; Kathryn Keller; Kristine Killip
Subject: IRBNet Board Action

Please note that Florida Atlantic University IRB has taken the following action on IRBNet:

Project Title: [332397-2] The Chronically Ill Adolescent: What is Missing In the Transition of Care?
Principal Investigator: Kathryn Keller, PhD

Submission Type: Response/Follow-Up
Date Submitted: June 25, 2012

Action: APPROVED
Effective Date: July 11, 2012
Review Type: Expedited Review

Should you have any questions you may contact Angela Clear at aclear@fau.edu.

Thank you,
The IRBNet Support Team

www.irbnet.org
Appendix B

Organizational Approvals

FAU
DIABETES EDUCATION
AND RESEARCH CENTER
Christine E. Lynn College of Nursing
Florida Atlantic University
Tel: 561.803.8880 • Fax: 561.803.8899 • www.faudiabetescenter.org

May 15, 2012
To the Florida Atlantic University (IRB):

I am familiar with Kelly N. White’s research project entitled: THE CHRONICALLY ILL ADOLESCENT: WHAT IS MISSING IN THE TRANSITION OF CARE? I understand the Florida Atlantic University’s Diabetes Education and Research Center’s involvement to be contacting/emailing members of the organization to ask if they will complete the survey involved or be interviewed for Ms. White’s research project.

I understand that this research will be carried out following sound ethical principles and that participant involvement in this research study is strictly voluntary and provides confidentiality of research data, as described in the protocol.

Therefore, as the institution authority of the Diabetes Education and Research Center, I agree that Kelly N. White’s research project may be conducted through personal interviews and/or online in collaboration with our agency/office.

Sincerely,

Eugenia Mendez PhD(c), MS, RN, PMHNP, CCRN
Clinical Director
To Florida Atlantic University (IRB)

I am familiar with Kelly N. White’s research project entitled: THE CHRONICALLY ILL ADOLESCENT: WHAT IS MISSING IN THE TRANSITION OF CARE? I understand that Pediatric Endocrine & Diabetes Specialists, PA will be involved in contacting/emailing members of the practice to ask if they will complete the survey involved or allow to be interviewed for Ms. White’s research project.

I understand that the research will be carried out following sound ethical principles and that participant involvement in this research study is strictly voluntary and provides confidentiality of research data, as described in the protocol.

Therefore, as the president of Pediatric Endocrine & Diabetes Specialists, PA, I agree that Kelly N. White’s research project may be conducted through personal interviews and/or online in collaboration with my practice.

Sincerely,

Mary A. Vaccarelo-Cruz, MD
President, Pediatric Endocrine & Diabetes Specialists, PA

https://docs.google.com/document/d/15_fNaSjpvzCziHBFHMeyL94xsdT3KQX1NGTY6T... 5/9/2012
Maurice Cruz, MD, P.A.
500 Federal Highway
Lake Park, Florida 33403

Telephone (561) 6358-1492
Fax: (561) 862-4779

To Florida Atlantic University (IRB)

I am familiar with Kelly N. White's research project entitled: THE CHRONICALLY ILL ADOLESCENT: WHAT IS MISSING IN THE TRANSITION OF CARE? I understand that Maurice Cruz, MD, P.A. will be involved in contacting/emailing members of the practice to ask if they will complete the survey involved or allow to be interviewed for Ms. White’s research project.

I understand that the research will be carried out following sound ethical principles and that participant involvement in this research study is strictly voluntary and provides confidentiality of research data, as described in the protocol.

Therefore, as the president of Maurice Cruz, MD, P.A. I agree that Kelly N. White's research project may be conducted through personal interviews and/or online in collaboration with my practice.

Sincerely,

[Signature]

Maurice Cruz, MD
President, Maurice Cruz, MD, P.A.
Director, Cystic Fibrosis Center at St. Mary's Medical Center

https://docs.google.com/document/d/15_fNsSjpvACziHBFHMeyL94xsdT3KQX1NGTY6T... 5/9/2012
Appendix C

Recruitment Letter

VOLUNTEERS NEEDED FOR A RESEARCH STUDY

Volunteers are needed to participate in a study about working with adolescents living with a chronic illness (cystic fibrosis, diabetes, sickle cell disease) as they transition from the pediatric healthcare setting to the adult healthcare setting. This survey is anonymous and voluntary. Your name or place of employment will not be requested.

In order to participate, you must hold one of the following positions in your office of employment: center director, primary care provider, nurse educator, nurse, nutritionist, doctor pharmacy, social worker, or an office worker without a formal administrative role who is highly involved in working with these adolescents as they transition into the adult healthcare system. You must be in your current position for a minimum of six (6) months. It should take no longer than 30 minutes to complete this study.

To participate in this study or if you have any questions or concerns, you may contact:

Kelly White MSN, ARNP at 561-707-2938, knwhite@fau.edu
Dr. Kathryn Keller PhD, RN at 561-297-2919, kkeller@fau.edu

To take this survey on-line, go to: https://www.surveymonkey.com/

Contact Kelly White for paper and pencil version.
Appendix D

Health Care Transition Survey for Health Care Providers

Title: The Chronically Ill Adolescent: What is Missing in the Transition of Care?

Investigators: Kelly White PhD (c), ARNP and Kathryn Keller PhD, RN

Purpose: The purpose of this research study is to examine current transitional healthcare practices of healthcare workers working with chronically ill adolescents.

Procedures: To participate in this study, you must hold one of the following positions in your office of employment: center director, primary care provider, nurse educator, nurse, nutritionist, Doctor of Pharmacy, social worker, or an office worker without a formal administrative role who is highly involved in working with these adolescents as they transition into the adult healthcare system. You must be in your current position for a minimum of six (6) months.

You will complete a 41-item anonymous survey about working with adolescents living with a chronic illness (cystic fibrosis, diabetes, or sickle cell disease). The survey should take no more than 30 minutes to complete. You will not be asked your name or place of employment. You may skip any question that makes you uncomfortable.

Risks: The potential risks associated with participating in this research could be breach of confidentiality. This risk will be minimized by collecting no identifying data.

Benefits: There is no direct benefit to you for your participation in this study. The potential indirect benefits to patients and society would be the possibility that information obtained from this study could be used to improve the healthcare transitional practice for young adults living with a chronic illness and reduce rates of crisis-centered hospital admissions.

Data Collection & Storage: Your data will be submitted to SurveyMonkey.com server using a secure, encrypted website. Only the researchers working with the study will see your data. All data provided will be kept confidential, unless required by law. We will make every attempt to keep your data secure to the extent permitted by the technology. However, no guarantees can be made regarding the interception of data sent via the Internet by any third parties. Stored data will be deleted from the server and from any computers used in this study five (5) years after the study is completed.

1 Permission to modify and use the HCTIIS survey was obtained from Dr. John Reiss.
**Contact Information:** For related problems or questions regarding your rights as a research subject, contact the Florida Atlantic University Division of Research at (561) 297-0777. For other questions about the study, you should call the principal investigators: Kelly White MSN, ARNP at (561)-707-2938 knwhite@fau.edu or Dr. Kathryn Keller PhD, RN at (561)297-2919 kkeller@fau.edu.

**Consent Statement:**
I have read the information describing this study. All my questions have been answered to my satisfaction. I am 18 years of age or older and freely consent to participate. I understand that I am free to withdraw from this study at any time without penalty. I have printed a copy of this consent form for my records. By clicking the “I consent” button below, I am giving my consent to participate in this research study.

[ ] I consent  [ ] I do not consent
to participate in this research study

**Additional instructions:** We recognize that health care professionals are responsive to the individualized needs of patients and the priorities and preferences of families; and that the health care transition related services and supports provided by your clinic will vary from patient to patient. Therefore, when completing this questionnaire, please answer in terms of the *typical* experience of patients who received care at your practice or clinic.
This survey is to learn what your practice or clinic does in regards to the treatment of individuals with disabilities or special health care needs when they reach adulthood, ages 18-21 and beyond.

**Type of Clinic/Practice:**

- __Broward County
- __Miami Dade County
- __Palm Beach County

**Practice Location:**

- __Urban
- __Rural

**DEMOGRAPHICS**

1. Do you have a Professional License?
   - O Yes    O No

2. If yes, in what area?
   - O Nurse
   - O Physician
   - O Social worker
   - O Therapist
     - Occupational
     - Physical
     - Psychology
     - Speech
   - O Other: _______________________________________

   If no, what type of formal educational training have you had on Healthcare Transition?
   - O Continuing Education Class/es
   - O On the job training only
   - O None

3. What role or title best describes your work in the clinic or practice: (Choose only one)
   - O Director/Administrator
   - O Clinic Coordinator
   - O CMS Nurse Coordinator
   - O Clinic/Staff Social worker
   - O Clinic/Staff Nurse
   - O Therapist
   - O Other (please specify role_________________________)
4. How long have you worked in this position?
   - Less than 1 year
   - 1 – 2 years
   - 3 – 5 years
   - More than 5 years

5. How would you describe the type of care offered by the practice or clinic?
   - Primary care only
   - Specialty care only
   - Primary and specialty care

6. Do you work in a specialty care clinic focused specifically on:
   - Sickle Cell Anemia (Proceed to question 7)
   - Cystic Fibrosis (Proceed to question 7)
   - Diabetes (Proceed to question 7)
   - None of the above (Please answer 6a)

6a. If you answered NONE OF THE ABOVE: What are the five most common chronic health conditions and/or disabilities the adolescents in your clinic present with? Please give an estimated percentage of each chronic health condition.
   a. (most prevalent) / %
   b. / %
   c. / %
   d. / %
   e. (least prevalent) / %

   Please answer the ALL questions on this questionnaire based specifically on the most prevalent diagnosis/population you chose in question 6/6a. (Questions 7-44)

7. What is the total number of patients currently followed by your clinic or practice in each of the following age groups?

<table>
<thead>
<tr>
<th>Age Group</th>
<th>If guess or estimate</th>
</tr>
</thead>
<tbody>
<tr>
<td>0-14</td>
<td>0-14</td>
</tr>
<tr>
<td>15-17</td>
<td>15-17</td>
</tr>
<tr>
<td>18-20</td>
<td>18-20</td>
</tr>
<tr>
<td>21+</td>
<td>21+</td>
</tr>
<tr>
<td>I don’t know</td>
<td></td>
</tr>
</tbody>
</table>

**DISCHARGE STATISTICS**

8. Do you discharge patients because of age?
   - Yes
   - No
   - Sometime

9. At what age are these patients generally discharged?
   ______
10. How many patients are discharged each year because of age (estimated percentage)?
   O 0-25%
   O 26-50%
   O 51-75%
   O 76-100%

11. How many of the total number of patients who are discharged annually from your practice are referred to see an adult oriented provider (estimated percentage)?
   O 0-25%
   O 26-50%
   O 51-75%
   O 76-100%

12. Do you discharge patients because they reach the age of 21?
   Yes____  No____  Sometimes____

13. How many patients are discharged each year because of loss of insurance eligibility upon reaching age 21 (estimated percentage)?
   O 0-25%
   O 26-50%
   O 51-75%
   O 76-100%

14. Do you continue to see older patients after they are no longer eligible for pediatric services after age 21?
   Yes____  No____  Sometimes____

15. What is the number of patients who continue to receive treatment in your practice or clinic after they reach age 21 (estimated percentage)?
   O 0-25%
   O 26-50%
   O 51-75%
   O 76-100%

16. What is the number of patients, annually, who are referred to adult-oriented providers who complete at least one visit with this provider (estimated percentage)?
   O 0-25%
   O 26-50%
   O 51-75%
   O 76-100%
17. What is the number of patients who return after discharge seeking ongoing treatment (estimated percentage)?
   - O 0-25%
   - O 26-50%
   - O 51-75%
   - O 76-100%

POLICY
18. Does your practice or clinic have a policy regarding a ceiling age over which patients will not be seen?
   - O Yes
   - O No

18a. What is that upper age limit? _______

18b. Is this policy written?  
   - O Yes
   - O No
   - O Generally yes with some exceptions.

18c. What are the exceptions: ________________________________

   - O No

19. Does your clinic have a written transition policies or guidelines?
   - O Yes
   - O No
   - If yes, please ask respondent to provide a written copy of the policy or procedure

20. What percentage of all young adults (>18 years old) is this policy applied to (estimated percentage)?
   - O 0-25%
   - O 26-50%
   - O 51-75%
   - O 76-100%

21. What percentage of all pediatric patients (<18 years old) is this policy applied to (estimated percentage)?
   - O 0-25%
   - O 26-50%
   - O 51-75%
   - O 76-100%

PREPARATION FOR TRANSITION
22. Does your practice/clinic provide any services or supports or engage in any activities that prepare adolescent patients for a transition to adult-oriented providers, settings, and/or content of visits?
   - O Yes_______ continue to Question 23
23. Are your transition services, supports or activities part of a formal program to prepare adolescents for transition to adult care?
   _____ Yes we have a formal transition program.
   _____ No we do not have a formal transition program. (Transition is done in an informal fashion)

24. Does your practice/clinic have criteria for assessing a young person's readiness to transfer to adult-oriented health care services?
   Yes _____
   No _____

25. Which of the following criteria are used by your practice or clinic's to assess a young person's readiness to transfer to adult-oriented health care services. Check all that apply
   _____ Patient’s age
   _____ Patient’s knowledge of medication and their function
   _____ Patient’s ability to interact with health care providers independently
   _____ Patient’s ability to attend clinic visit independently
   _____ Patient’s ability to recognize emergent situations and seek care appropriately
   _____ Patient’s knowledge of their health insurance (coverage, how to contact insurer, etc.)
   _____ Patient’s developmental maturity
   _____ Other: (Specify)

26. At what age do you generally start talking about health care transition with your patients?
   _____

27. What percentage of patients in the following age groups receives some preparation for health care transition from your practice/clinic?
   12-14 _____%
   15-17 _____%
   18-20 _____%
   21+ _____%
   _____ I don’t know

28. Does your practice have a primary coordinator for the transitional process in your practice/clinic?
   Yes _____ (proceed to question 29)
   No _____ (skip to question 30)

29. Who is this primary coordinator?
   _____ Nurse
   _____ Primary Care Provider
   _____ Social Worker
   _____ Other : (please specify role: ____________________)

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b. What is this primary coordinator responsible for in the transitional process? (Check all that apply):

_____ Communication between all staff working with the transition process
_____ Communication with the patient/family in the transition process
_____ Communication with the adult care team that will work with the young adult after transfer
_____ Communication with insurance companies supplying coverage for the young adult
_____ Other: Please specify

TRANSITION PRACTICES

30. The following is a list of services, supports and activities that might be carried out to prepare adolescents for transition to adult care. How typical it is for your clinic/practice to do this transition related activity for patients, age 15+?
<table>
<thead>
<tr>
<th>Activity</th>
<th>Usually</th>
<th>Sometimes</th>
<th>Rarely</th>
<th>Don’t Know</th>
</tr>
</thead>
<tbody>
<tr>
<td>Discuss with youth and or families eventually seeing doctors or health providers who treat adults</td>
<td>O</td>
<td>O</td>
<td>O</td>
<td>O</td>
</tr>
<tr>
<td>Talk with youth and/or families about health care needs when patient is an adult</td>
<td>O</td>
<td>O</td>
<td>O</td>
<td>O</td>
</tr>
<tr>
<td>Discuss possible changes in eligibility for health insurance coverage when the patient becomes an adult</td>
<td>O</td>
<td>O</td>
<td>O</td>
<td>O</td>
</tr>
<tr>
<td>Encourage patients to take responsibility for their health care needs?</td>
<td>O</td>
<td>O</td>
<td>O</td>
<td>O</td>
</tr>
<tr>
<td>Schedule a visit specifically focused on transition</td>
<td>O</td>
<td>O</td>
<td>O</td>
<td>O</td>
</tr>
<tr>
<td>Provide educational materials about health care transition to patients</td>
<td>O</td>
<td>O</td>
<td>O</td>
<td>O</td>
</tr>
<tr>
<td>Assess patient’s understanding of the transition process</td>
<td>O</td>
<td>O</td>
<td>O</td>
<td>O</td>
</tr>
<tr>
<td>Ask about patient’s long-term health goals</td>
<td>O</td>
<td>O</td>
<td>O</td>
<td>O</td>
</tr>
<tr>
<td>Involve the family in transition planning</td>
<td>O</td>
<td>O</td>
<td>O</td>
<td>O</td>
</tr>
<tr>
<td>Provide a transition timeline to patient</td>
<td>O</td>
<td>O</td>
<td>O</td>
<td>O</td>
</tr>
<tr>
<td>Designate who is responsible for key elements of transition</td>
<td>O</td>
<td>O</td>
<td>O</td>
<td>O</td>
</tr>
<tr>
<td>Develop a written health care transition plan</td>
<td>O</td>
<td>O</td>
<td>O</td>
<td>O</td>
</tr>
<tr>
<td>Meet with the patient, alone, for at least some of the medical visit.</td>
<td>O</td>
<td>O</td>
<td>O</td>
<td>O</td>
</tr>
<tr>
<td>Discuss plans for higher education, vocational training and/or employment</td>
<td>O</td>
<td>O</td>
<td>O</td>
<td>O</td>
</tr>
</tbody>
</table>

31. Are there additional transition supporting activities not listed above that your clinic or practice does?
   Yes_____
   What are they?
   No______
32. The following is a list of activities that might be included in a protocol for transferring patients to adult-oriented health care services. How often this activity is done as part of the process of discharging and transferring a patient to adult care?

<table>
<thead>
<tr>
<th>Activity</th>
<th>Usually</th>
<th>Sometimes</th>
<th>Rarely</th>
<th>Don’t Know</th>
</tr>
</thead>
<tbody>
<tr>
<td>Assess the patient's readiness to transfer to adult care</td>
<td>O</td>
<td>O</td>
<td>O</td>
<td>O</td>
</tr>
<tr>
<td>Write a discharge summary and include it in the patient's chart</td>
<td>O</td>
<td>O</td>
<td>O</td>
<td>O</td>
</tr>
<tr>
<td>Give the discharge summary to the patient.</td>
<td>O</td>
<td>O</td>
<td>O</td>
<td>O</td>
</tr>
<tr>
<td>Refer the patient to a specific adult provider or practice.</td>
<td>O</td>
<td>O</td>
<td>O</td>
<td>O</td>
</tr>
<tr>
<td>Send a discharge summary to the patient's new adult provider</td>
<td>O</td>
<td>O</td>
<td>O</td>
<td>O</td>
</tr>
<tr>
<td>Talk with the new adult provider by phone or in person</td>
<td>O</td>
<td>O</td>
<td>O</td>
<td>O</td>
</tr>
<tr>
<td>See the patient along with the new adult providers (conduct a transitional medical visit)</td>
<td>O</td>
<td>O</td>
<td>O</td>
<td>O</td>
</tr>
<tr>
<td>Request that the new adult provider provide you with a follow-up note and/or feedback</td>
<td>O</td>
<td>O</td>
<td>O</td>
<td>O</td>
</tr>
<tr>
<td>Receive a follow-up note and/or feedback from the new adult provider provide after the patient is transferred.</td>
<td>O</td>
<td>O</td>
<td>O</td>
<td>O</td>
</tr>
</tbody>
</table>

33. Are there additional processes or protocols for transferring patients to adult care not listed above that your clinic or practice does?

______No

______Yes, if so what are they? (please list below):

34. What proportion of adolescents with chronic health conditions served by your practice or clinic are prepared for transfer to adult care?

______%

35. Listed below are some common factors that contribute to young adult patients leaving pediatric practices or clinics to go to an adult-oriented provider/practice/clinic. Please use the rating to describe how often these factors affect patients leaving your practice or clinic.
Factors | Rarely 30% or less | Approx. 50% | Often 70% or more
--- | --- | --- | ---
The clinic/practice has a policy not to care for patients over a certain age. |  |  |  
Clinic/practice staff/professionals prefer not to care for patients over a certain age. |  |  |  
The young adult prefers to receive care from an adult oriented provider |  |  |  
The young adult’s family prefers to receive care from an adult oriented provider |  |  |  

**OPEN ENDED QUESTIONS**

35. What are the major needs of the parents (and other family members) of patients during the transition process?

36. What are the needs of pediatric health care providers during the transition process?

37. What are the needs of adult health care providers during the transition process?

38. What do you see to be the biggest barriers to Healthcare Transition for individual level care, clinic level care, and systems level care?

1. 
2. 
3. 

39. What would help address these barriers to the transfer to adult services?

40. Please provide any other information you feel is relevant to the issue of health care transition:

41. Are you aware of the Health Care Transition Training Program for Professionals located at: [http://www.aheceducation.com/ELearning/CourseCatalog.aspx](http://www.aheceducation.com/ELearning/CourseCatalog.aspx)?
Yes ______ (Have you completed this course? Yes ___ No___)

No ______

This online training curriculum provides information about how professionals can help prepare youth with chronic health conditions and disabilities for their eventual graduation from pediatrics and transfer to adult health care. Up to 4 free CME credits are available to pediatricians and other care providers in Florida.

Thank you for taking the time to complete this survey and making a difference to future young adults living with chronic illnesses! 😊
Appendix E

Recruitment Flyer for Young Adult Participants

Florida Atlantic University Christine E. Lynn College of Nursing
Study Title: The Chronically Ill Adolescent: What is missing in the Transition of Care?
Participants wanted for a research study…
We are currently recruiting young men and women for a research study that will look at the transitional care experience of moving from a pediatric health care setting to an adult health care setting.

To be eligible for this study, you must:
• You must be between the ages of 18-25 years old
• You must have one (or more) of the following chronic illnesses:
  o Cystic Fibrosis
  o Diabetes Mellitus
  o Sickle Cell Disease
• Be able to speak and read English

Participation in this study will take approximately 30 minutes to 1 hour and will consist of an audio recorded interview which you will be asked to talk about your healthcare transitional experience. The goal of this study is to understand the experience of the transitional process of moving from pediatric-focused care to adult-focused care with hopes that we can improve the current healthcare transitional experience for other young adults living with a chronic illness.
To learn more about this research study or to volunteer to participate, please contact:
 Kelly White, PhD Student
 E-mail: knwhite@fau.edu
 Cell: (561)707-2938
Appendix F

Health Care Transition

Interview for Transitioning Young Adults

**Title:** The Chronically Ill Adolescent: What is Missing in the Transition of Care?

**Investigators:** Kelly White, PhD (c), ARNP and Kathryn Keller, PhD, RN

**Purpose:** The purpose of this study is to understand the experience of young adults living with a chronic illness as they move from pediatric care to adult care.

To be eligible for this study:

- You must be between the ages of 18-25 years old
- You must have one (or more) of the following chronic illnesses:
  - Cystic Fibrosis
  - Diabetes Mellitus
  - Sickle Cell Disease
- You must be able to speak and read English

**Procedures:** Participation in this study will take approximately 30 minutes to 1 hour and will consist of an audio recorded interview which you will be asked to talk about your experiences of moving from pediatric care to adult care. Your participation in this study is voluntary and you will not be paid for participation in this study. Demographic data will be obtained prior to each interview. (i.e.- age, ethnicity, chronic illness/es, age of diagnosis). You may choose not to answer any question asked or withdraw from this study at any time without consequence. Participation in this research study will not affect your care at your primary care provider’s office.

**Risks:** The researchers will maintain all information that is shared by you in confidence. However, there is a risk that your name may be linked to the data gathered during this study. However, since the data will be coded, it is unlikely this information will be linked to your name.

**Benefits:** There is no direct benefit to you for participation in this study. The potential indirect benefits to patients and society would be the possibility that information from this study could be used to improve the lives of young adults living with a chronic illness and reduce rates of crisis-centered hospital admissions.

**Data Collection & Storage:** All collected data will be identified with a participant identification number only to maintain confidentiality. Audiotapes and demographic papers collected from this interview will be stored in a locked box within a locked office that will be accessible only to the investigators of this study. Tapes from the audiotaped interviews will be destroyed when the study is completed. Data will be kept in a locked drawer in the researcher’s locked office for five (5) years. Data may be viewed by the researcher and the researcher’s dissertation committee only.
Contact Information: For related problems or questions regarding your rights as a research subject, contact the Florida Atlantic University Division of Research at (561) 297-0777. For other questions about the study, you should call the principal investigators: Kelly White MSN, ARNP at (561)-707-2938 knwhite@fau.edu or Dr. Kathryn Keller PhD, RN at (561)297-2919 kkeller@fau.edu.

Consent Statement: I have read the information describing this study. All my questions have been answered to my satisfaction. I am 18 years of age or older and freely consent to participate. I understand that I am free to withdraw from this study at any time without penalty. I received a copy of this consent form for my records.

I agree ____ do not agree___ to be audiotaped. _____Initials

I agree to participate in this research study.

_________________________________________  ___________________________________________  ______

Printed Name                     Signature of Participant                  Date

_________________________________________  ______

Signature of Interviewer          Date
Appendix G

Demographics Characteristics of Young Adults

<table>
<thead>
<tr>
<th>Pseudonym</th>
<th>Gender</th>
<th>Chronologic Age/Age at Diagnosis</th>
<th>Ethnicity</th>
<th>Diagnosis</th>
<th>County of HCT</th>
</tr>
</thead>
<tbody>
<tr>
<td>Ann</td>
<td>Female</td>
<td>19 yrs/ birth</td>
<td>Haitian American</td>
<td>Sickle Cell Disease</td>
<td>Palm Beach</td>
</tr>
<tr>
<td>Barbara</td>
<td>Female</td>
<td>19 yrs/ 4 yrs</td>
<td>Caucasian</td>
<td>Diabetes Type I</td>
<td>Palm Beach</td>
</tr>
<tr>
<td>Charles</td>
<td>Male</td>
<td>19 yrs/14 yrs</td>
<td>African American</td>
<td>Diabetes Type I</td>
<td>Palm Beach</td>
</tr>
<tr>
<td>Delia</td>
<td>Female</td>
<td>23 yrs/13 yrs</td>
<td>Hispanic</td>
<td>Diabetes Type I</td>
<td>Broward</td>
</tr>
<tr>
<td>Ellen</td>
<td>Female</td>
<td>22 yrs/6 mos</td>
<td>Haitian American</td>
<td>Sickle Cell Disease</td>
<td>Palm Beach</td>
</tr>
<tr>
<td>Fran</td>
<td>Female</td>
<td>24 yrs/ 18 mos</td>
<td>Guatemalan</td>
<td>Cystic Fibrosis</td>
<td>Palm Beach</td>
</tr>
<tr>
<td>Gina</td>
<td>Female</td>
<td>20 yrs/ 9 yrs</td>
<td>Asian American</td>
<td>Sickle Cell Disease</td>
<td>Palm Beach</td>
</tr>
<tr>
<td>Helen</td>
<td>Female</td>
<td>18 yrs/ 13 yrs CF -16 yrs</td>
<td>Hispanic</td>
<td>Cystic Fibrosis and Diabetes</td>
<td>Palm Beach</td>
</tr>
</tbody>
</table>
REFERENCES


Doulton, D. M. (2010). From cradle to commencement: Transitioning pediatric sickle cell disease patients to adult providers. *Journal of Pediatric Oncology Nursing, 27*(2), 119-123.


