

TRANSITION OF CHRONICALLY-ILL YOUTH TO ADULT CARE: EXPERIENCE OF  
YOUTH WITH HEMOGLOBINOPATHY

A DISSERTATION

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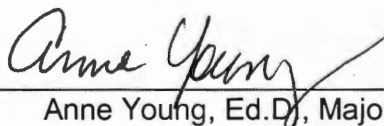
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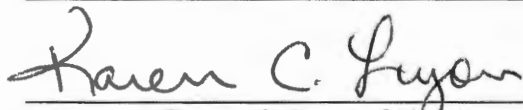
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I am submitting herewith a dissertation written by Rosalind Bryant entitled "Transition of Chronically-ill Youth to Adult Care: Experience of Youth with Hemoglobinopathy." I have examined this dissertation for form and content and recommend that it be accepted in partial fulfillment of the requirements for the degree of Doctor of Philosophy with a major in Nursing Science.



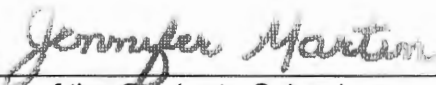
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We have read this dissertation and recommend its acceptance:



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Accepted:



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## DEDICATION

I would like to dedicate this work to my deceased father and sister who always inspired and believed in my ability to accomplish my academic dreams. I wish they were here to see the fruition of the dream. I would also like to dedicate this work to my brother who has been supportive throughout my life as I pursued my goals. I would also like to thank Mamzie, someone very dear to me, who helped to strengthen my fortitude toward the completion of this project by giving me the most precious gift of all, a mother's love. Lastly, this work is dedicated to the chronically ill youth with hemoglobinopathy, who shared their transitional experience from pediatric to adult health care and motivated me to conduct and complete research that may assist all chronically ill youth in their successful transition to adult health care.

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## ABSTRACT

ROSALIND BRYANT

### TRANSITION OF CHRONICALLY-ILL YOUTH TO ADULT CARE: EXPERIENCE OF YOUTH WITH HEMOGLOBINOPATHY

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With the advent of innovative technologies and medical advances, over half million chronically ill youth (CIY) cross the threshold into adulthood yearly. Successful transition of the CIY from pediatrics to adult care continues to be an inconsistent process, especially for CIY with hemoglobinopathy (e.g. sickle cell disease, thalassemia). The transitioning experience to adult care may be interrupted by obstacles such as lack of transition support, limited number of transition programs and resistance toward transfer to adult health care. Since CIY with hemoglobinopathy have a risk of developing severe medical complications (e.g. sepsis, severe anemia), the transitional experience including obstacles must be understood in order to promote an uninterrupted transfer to adult health care.

The purpose of this study was to describe the transition experience, expectations and concerns of the CIY with hemoglobinopathy regarding their transfer to adult health care. The research questions addressed were: 1. What are the experiences of the CIY with hemoglobinopathy who transition from pediatric to adult health care? 2. What are

the expectations and concerns of CIY with hemoglobinopathy regarding their transition experience?

A Husserlian descriptive phenomenological methodology was used to uncover the essential structures of the CIY's transition experience. The study recruited a purposive sample of 14 CIY with hemoglobinopathy from a large medical center's transitional clinic. CIY ranged in age from 18 to 25 years. Colaizzi's method was used to analyze meaning of transition experience. Four themes were identified from the interviews of CIY with hemoglobinopathy which were: Reaction to the transition experience, concerns about the transition experience, getting pushed into transitioning to adult care, and acknowledgement of the transition to adult care. An adjustment process was discovered through the interview meanings and formulated 4 themes that may help to facilitate designing effective interventions to provide uninterrupted medical care as the CIY with hemoglobinopathy transition from pediatric to adult health care.

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## CHAPTER I

### INTRODUCTION

#### Focus of Inquiry

More than 30 years ago, most chronically ill children did not survive into adulthood. With the advent of innovative technologies and medical advances, approximately 750,000 chronically ill youth (CIY) cross the threshold into adulthood yearly (Scal & Ireland, 2005). Successful transition of the CIY from pediatrics to adult care continues to be a difficult and inconsistent process, especially the CIY with hemoglobinopathy (e.g. sickle cell disease, thalassemia).

The transition experience of the CIY may consist of obstacles that interfere or impede the transfer to adult health care. Obstacles identified in the literature include lack of transitional support, limited transitional programs, and transitional resistance to adult care (Fiorentino, Phillips, Walker, & Hall, 1998; Scal, Evans, Blozis, Okinow, & Blum, 1999; Boyle, Farukhi, Nosky, 2001; Reiss, Gibson, & Walker, 2005; Scal, 2002). Often the transitioning experience consists of an abrupt transfer which leaves the youth unprepared for the movement to adult health care (Hauser & Dorn, 1999; Wojciechowski, Hurtig, & Dorn, 2002; Scott, 2006). Consequently, the CIY does not keep follow-up appointments with the new provider and ends up returning to the pediatric provider or the emergency room for health care (Hauser & Dorn, 1999; Lam, Fitzgerald, & Sawyer, 2005). Missed adult care appointments by the transitioned CIY can lead to irreversible, yet preventable complications and even death (Bell, 2007). Therefore, the holistic transition experience including the obstacles must be understood

to promote uninterrupted medical care as the CIY transfer to adult care. To uncover the lived experience, the meaning of the transition experience from the viewpoint of CIY with hemoglobinopathy was explored in this descriptive phenomenological study.

### Statement of Purpose

As the number of CIY living to adulthood increases, effective mechanisms need to be put in place to facilitate transition into adult care. Accurate description of the transition experience will facilitate designing effective interventions to move CIY into adult care. The purpose of this descriptive phenomenological study was to describe the actual transition experience, expectations, and concerns of the CIY with hemoglobinopathy.

### Rationale for the Study

Expert panels, publications, conferences, and policy statements have discussed facilitating an organized, coordinated transition for young people with chronic conditions from child to the adult health care system (McGrab & Millar, 1989; Blum, 1995; Rosen, 1995). In 1984, the United States Surgeon General cohosted a national invitational conference focusing on the needs of older adolescents with chronic and disabling conditions. This conference was the first national focus on health care transition issues (McGrab & Millar, 1989). The Society for Adolescent Medicine addressed the problem of transition in a position paper delineating recommendations for transition funding, research on outcomes of transition programs, investigation of multiple transition models, and the education concerning transition issues among health care trainees and providers (Blum et. al., 1993). The American Academy of Pediatrics (1996, 2002) published policy statements on the importance of health care providers working to

educate and advocate for youth with special health care needs to promote their transition into adult health care. While transitioning to adult care has been identified as a priority, work remains to make a smooth transition a reality.

Only a limited number of empirical studies have been published on transition of the CIY to adult care, especially within the nursing literature. Soanes and Timmons (2004) and Kirk (2008) are among the few nursing studies published on transition to adult care. Concerns about facing transition to adult care were reported by both studies that interviewed chronically ill adolescents (e.g., diabetes, cystic fibrosis, cancer, and other complex health care problems) from pediatric settings (Kirk; Soanes & Timmons). Content analysis of the studies revealed concerns such as: meeting new provider, knowing the expertise of the new provider, being familiarized with adult services, providing an informal adult atmosphere to promote communication, and instituting a gradual individual, flexible transition process with adequate preparation from supportive providers (Kirk; Soanes & Timmons). Both studies cite the concerns of CYI who are primarily speculating about their future transition experience, whereas this study focused on views of CIY who have actually experienced the transition to adult care.

The majority of transitional science consists primarily of medical studies that focus on the parental and providers' view of the transitional expectations or concerns of the CIY who still attend pediatric clinics (Boyle, Frukhi, Nosky, 2001; Peter, Forke, Ginsburg, & Schwarz, 2009; Scal, 2002; Scal & Ireland, 2005; Telfair, Alexander, Loosier, Alleman-Velez & Summons, 2004). McPherson, Thaniel, and Minniti (2009) recently published a study that supported the need to prepare the CIY for transition to adult care based on recognition of transition readiness. A survey on transitional readiness was administered to a purposeful sample of 70 sickle cell disease (SCD)

patients 14 to 21 years old from a children's hospital that reported cognitive readiness developed as the individual aged (McPherson et al.). Another study, using the National Health Interview Survey data from 2000 to 2005, focused on transitional delays of CIY to adult care that compared the responses of 1539 parents of adolescent asthmatics to the responses of 833 young adult asthmatics regarding transitional obstacles (Scal, Davern, Ireland & Kyong, 2008). According to descriptive statistics and bivariate comparisons, financial obstacles delayed transition to adult care among the young adults significantly more often than among the adolescents (Scal et al.). Since financial obstacles were not the sole reason for the high rates of delayed transition to adult care, the investigators recommended further research on health care transition as the literature provides little in the way of in depth description of this problem (Scal et al.).

Telfair, Ehiri, Loosier, and Baskin (2004) reported that published empirical studies offer the most rudimentary issues of transition, especially from the fact that CIY's point of view remains rare. Another study reported that little is known about the health care seeking behaviors of young adults, especially those with childhood-onset chronic conditions (Scal, et al., 2008). A significant awareness of the need for programs aimed at transitioning adolescents from pediatric to adult care exists within the literature (Boyle, Farukhi, Nosky, 2001; Fiorentino, Phillips, Walker, & Hall, 1998; Lotstein et al., 2009; Reiss, Gibson, & Walker, 2005; Scal, Evans, Blozis, Okinow, & Blum, 1999; Scal, 2002). Yet, further research is needed to gain understanding of the transition experience of young adults in order to contribute to successful establishment of transition programs (Telfair, Ehiri et al.).

Information derived from this study focused on the in-depth description of the transition experience as told in the words of the CIY with hemoglobinopathy who

transferred to adult care. Knowledge gained from this study may help to design interventions to facilitate uninterrupted medical care in the transfer of the CIY with hemoglobinopathy to adult health care which will contribute vital and new information to the transitional literature.

### Research Questions

The research questions addressed were: 1) What are the experiences of the CIY with hemoglobinopathy who transition from pediatric to adult health care? and 2) what are the expectations and concerns of CIY with hemoglobinopathy regarding their transition experience?

### Philosophical Underpinnings

The philosophical underpinnings utilized for this study were derived from the work of Edmund Husserl. According to Husserl, phenomenology searches for the meaning of lived experiences from the perspective of those who lived them. The focus of this study was derived from Husserl's (1960, 1962) three tenets that include: (a) return to original awareness, (b) transcendental subjectivity and (c) free agency (Wojnar & Swanson, 2007). Husserl's (1960, 1962) main tenet instructed individuals to go back to the things themselves (*zu den sachen selbst*) to recover the original awareness of the phenomenon through phenomenological reduction. Phenomenological reduction is the process of returning to the original awareness by allowing individuals to describe the experiences as perceived by their consciousness. Consciousness refers to the relationship between the person and the events of their experience, or one's directed awareness of an object or event (Husserl, 1962). In this process, one on one interactions was used to gather accounts of the phenomena under study. As multiple accounts are gathered, multiple universal structures or essences of the phenomena were derived.

Transcendental subjectivity refers to a process in which the investigator sheds preconceptions about the phenomenon and attempts to derive a pure description. Through the process of bracketing past knowledge, the phenomenon may be seen precisely as it presents itself (Giorgi, 1992). Bracketing as described by Husserl occurs when investigators suspend their preconceptions and biases while seeking to discover the true form or essences of things. Utilizing bracketing throughout the interviews aided in the emergence of the essences of the life world. As stated in the interpreted writings of Husserl (1990), the life world (*Lebenswelt*) is what individuals experience pre-reflectively, without resorting to interpretation.

The third tenet is free agency in which individuals are believed to be free agents who are able to influence their environment. The converse, however, that the environment influences lived experiences and individual freedom was a peripheral concept to Husserl's teachings (Deustcher, 2001). Therefore, contexts such as environment, culture, or politics are not crucial to the universality of the experience (Lopez & Willis, 2004).

Utilizing the Husserlian tenets in this study, the investigator gathered the participants' descriptions by guiding the interviewees toward their original awareness of the transition experience. The investigator bracketed preconceptions about the transition process. Through one on one dialogue, the experience unfolded to formulate meanings and identified the universal essences among the participants' transitional experience.

### Summary

There has been little qualitative exploration of the transition experience of CIY published in the literature (Britto et al., 2007). The majority of studies reviewed are quantitative or mixed studies utilizing investigator-constructed scales and surveys or

questionnaire interviews (e.g. P-SCTQ scale) to explore transitional obstacles that include lack of transition support, limited transition programs and resistance to adult health care. With the utilization of standardized surveys or structured scales and instruments by the majority of quantitative studies reviewed, the studies were not able to discuss the youth's transitional experience to adult health care in depth. However, face-to-face interviews gained information using the interviewee's own terms which contributed specific information beyond the yes-and-no responses elicited from surveys and instruments (Betz, 2007). Therefore, information gained from the face-to-face interviews of the CIY with hemoglobinopathy may promote successful adult health care transition.

At present, there has not been a published qualitative study using face-to-face interviews that focused solely on the CIY with hemoglobinopathy who transitioned to adult health care. Scal and associates (2008) assured that uninterrupted access to health care for transitioning youth was a priority among health care providers. Knowledge gained from the CIY's transition experience in this study may facilitate uninterrupted medical care from pediatric to adult health care.



## CHAPTER II

### REVIEW OF THE LITERATURE

This chapter presents an extensive review of the literature related to this study in the form of the following published manuscript. Based on the literature review, the three main transitional obstacles identified were: a) Lack of transitional support, b) limited transition programs, and c) transitional resistance to adult care. The 17 transitional studies are listed in the Literature Review Tables (Appendix A). After the integrated literature review, a critique of the studies with identification of gaps in the literature was included in the discussion. The manuscript also includes clinical recommendations from the studies that were organized according to the related transitional obstacle, study limitations and a brief summary of the content.

Transition of the Chronically Ill Youth with Hemoglobinopathy to Adult Health  
Care: An Integrative Review of the Literature (Bryant, R. & Walsh, T.)

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More than 30 years ago, the majority of chronically ill children did not survive into adulthood. With the advent of innovative technologies and medical advances, approximately 750,000 chronically ill adolescents cross the threshold yearly into adulthood (Scal & Ireland, 2005). Successful transition of the chronically ill youth (CIY) from pediatric to adult care continues to be a challenging process. Often the transitioning experience consists of an abrupt transfer which leaves the youth unprepared for the movement to adult health care (Hauser & Dorn, 1999; Scott, 2006; Wojciechowski,

Hurtig, & Dorn, 2002). Consequently, the adolescent does not keep follow-up appointments with the new provider and ends up returning to the pediatric provider or the emergency room for health care (Hauser & Dorn). Because CIY with hemoglobinopathy have a risk of developing severe medical complications (e.g. sepsis, severe anemia), obstacles that impede transition to adult care must be identified to promote an uninterrupted transfer to adult health care. This comprehensive literature review on the transition of the CIY to adult health care was undertaken to synthesize the transition literature focusing on the youth with hemoglobinopathy (e.g. sickle cell disease [SCD], thalassemia, severe hereditary spherocytosis) and identify related clinical recommendations.

#### Method of Review

A comprehensive exhaustive literature search on the transition to adult health care was conducted by using MEDLINE, Cumulative Index of Nursing and Allied Health Literature (CINAHL), PsycINFO, UpToDate, Agency for Healthcare Research and Quality (AHRQ), MD Consult, Cochrane Database of Systemic Reviews, ProQuest, National Guideline Clearinghouse, Web of Science and several organizational web sites such as American Academy of Pediatrics (AAP), American Heart Association, and Sigma Theta Tau International. The search limitations included children to young adult age bracket, the English language and publication dates from 1980 to 2007. The search strategies also included searching the names of authors that published more than one article on transition to adult health care. The search terms and phrases utilized were: adolescent, young adult, chronically ill youth and hemoglobinopathy, pediatric-oriented care, adult-oriented care, children and special health care needs, transition program,

transfer program, continuity of care, transitional strategy, transitional barriers, transition to adult care, and transfer to adult care.

Initially the inclusion criteria consisted of transition search terms, age range and the English language with the only exclusion criteria being middle to older age individuals. However, after sorting through a plethora of nonempirical literature published on chronically ill youth's transition to adult health care, the exclusion criteria broadened to include commentaries, editorials, and case studies on transition. The reference lists of each research study were perused to identify other related studies. A hand search of nursing, medical and psychological journals, books and position papers and conference proceedings was performed until the references became repetitive in the literature.

#### Historical Aspects

Expert panels, publications, conferences and policy statements have discussed facilitating an organized, coordinated transition for young people with chronic conditions from child to the adult health care system (Blum, 1995; McGrab & Millar, 1989; Rosen, 1995). In 1984, the United States Surgeon General co-hosted a national invitational conference with the Undersecretary of Education focusing on the needs of older adolescents with chronic and disabling conditions. This was the first national focus on health care transition issues (McGrab & Millar). The Society for Adolescent Medicine addressed the problem of transition in a position paper delineating recommendations for transition funding, research on outcomes of transition programs, investigation of multiple transition models, and the education concerning transition issues among health care trainees and providers (Blum et al. 1993). The American Academy of Pediatrics (1996, 2002) published policy statements describing the importance of the health care provider to educate and advocate for youth and family in promoting transition to adult health care.

Since the 1980s, there have been a limited number of empirical studies published on transition of the CIY to adult care, especially for youth with hemoglobinopathies. To compile a comprehensive review of the transition literature, it was necessary to supplement the paucity of hemoglobinopathy studies with transition studies on a variety of chronic illnesses (e.g. cystic fibrosis [CF], diabetes, disabilities). The literature review identified 17 empirical studies that met the inclusion criteria with only five of the studies focusing on hemoglobinopathies (Tables 1-3). All of the transition studies were published in peer-reviewed journals. The studies are listed in Tables 1, 2, and 3, which is divided into five areas: author and date, design and purpose, subjects, key findings and clinical recommendations. In reviewing the 17 studies, the three main transitional obstacles consistently emerged from the literature: (a) five studies that focused on the lack of transitional support (Table 1); (b) six studies that focused on limited transitional programs (Table 2); and (c) the remaining six studies that focused on transitional resistance toward adult health care (Table 3).

#### *Transitional Obstacle: Lack of Transitional Support*

Lack of transitional support was described in the following five studies that focused on the lack of available resources to support transitional programs for the CIY. Scal (2002) surveyed 13 out of 36 health care providers that were nominated by CIY's caretakers. After receiving a mailed investigator-developed survey, the health care providers identified lack of transitional support (e.g. no time for transition planning, no resources, no personnel) and difficulty in finding or communicating with an adult subspecialist medical provider as factors that interfered with the transfer of the CIY (e.g. cystic fibrosis, epilepsy) to adult health care (Scal). Scal's study identified other factors such as lack of time to address transition issues, lack of additional training for the health

care provider in relation to adolescent developmental and emotional issues, lack of utilization of transition services (e.g. insurance coverage, employment and/ or school guidance) and limited community based resources which was also supported in another study by Scal and Ireland (2005).

The lack of transitional support was identified in a cross-sectional study using a random digit-dial method. The study surveyed a sample of 4332 from 4426 eligible parents of youth aged 14-17 years obtained from 2000-2001 National Survey of Children with Special Health Care Needs (Scal & Ireland, 2005). The Health Care Transition (HCT) survey asked the parents if the health care provider (HCP) addressed transition issues during their routine visit with the chronically ill adolescent (see Table 1 for listed questions). Bivariate analyses examined the relationship between factors (e.g. age, gender, and disease severity) and parents' response scores that ranged from 0-3 (negative to positive response) from the HCT survey. Older age, White race, greater number of health care needs, and higher quality of parent-provider relationship were associated with significantly higher scores on HCT survey. Overall, 50% of the parents reported that transition to adult health care was mentioned by the HCP, but only 30% had developed transitional plans. Focusing on the lack of transition support, this study considered health care transition suboptimal in that only 16 % of CIY had health care transition comprehensively addressed by the HCP (Scal & Ireland).

Reiss, Gibson, and Walker (2005) focused on lack of transition support by interviewing 143 participants about their experiences with transition services and health care systems. The participants were distributed into focus groups consisting of 49 youth with chronic illnesses (e.g., asthma, cardiac, and cancer), 44 family members, and 50 health care providers. Reiss and colleagues reported factors such as availability of care,

insurance issues and lack of funding with the automatic discharge to adult care because of age or undesirable behaviors (e.g., pregnancy and criminal activity). The researchers stressed the need for further exploratory research on health care transition and the need for documentation of the transition experience (Reiss et al.). The 2002 study by Wojciechowski, Hutig, and Dorn identified lack of transitional support from the questionnaire responses of 18 participants aged 18-24 years with SCD. Pediatric and Adult Site Review Forms (PASR), SCD Compliance Questionnaire (Cronbach  $\alpha=0.56$ ) and SCD Self-efficacy Scale (Cronbach  $\alpha=0.84$ ) questionnaires were used. Supporting each other's findings, these studies identified the following: automatic discharge from pediatrics (because of events such as age  $\geq 18$  years, pregnancy, criminal activity or other behaviors), lack of continuation of funding and insurance, lack of practitioner training and experience with disabled youth, and the lack of transition preparation as contributing to the lack of transitional support (Reiss et al.; Scal; Scal & Ireland, 2005; Wojciechowski et al.).

Hauser and Dorn (1999) also focused on the lack of transitional support. The pilot study consisted of a purposive sample divided into three focus groups comprising 22 youth with SCD aged 13-21 yrs, 22 parents and 8 health care providers. Hauser & Dorn's content analysis identified the following themes: unfamiliar adult provider, lack of pre-transition education, lack of preparation in assuming an adult role, which has been supported by other studies (Reiss et al., 2005; Scal, 2002; Scal & Ireland, 2005; Wojciechowski et al., 2002). Hauser and Dorn developed a draft framework as part of the pilot study. The framework, developed to guide a successful transition program for youth with SCD to adult care, has not been empirically evaluated. Of the five studies reviewed, two studies focused on the CIY with hemoglobinopathy. All five studies

reported that transition programs are necessary to promote the successful transfer of chronically ill youth to adult care.

#### *Transitional Obstacle: Limited Transitional Programs*

The following six studies focused on the limited number of transition programs for CIY and the necessity for these programs. Out of the six studies reviewed on the limited number of transition programs, two focused on CIY with hemoglobinopathy. However, the majority of studies focused on a variety of other chronic illnesses (Table 2). The first cross-sectional study published on transition programs documented that 47% (170 out of 360) of youth aged 19-21 years with congenital heart defects successfully transferred to adult care in a timely manner (Reid et al., 2004). Yet, the measurement of successful transfer for the study was limited to keeping one appointment in the adult clinic or any adult-related test. Using an investigator-developed questionnaire, another study on transition programs evaluated the views of 40 health care professionals regarding transitional preparation for adolescents with a chronic condition (e. g., CF, asthma, diabetes) to adult health care (Por, Golberg, Lennox, Burr, Barrow & Dennard, 2004). Based on the content analysis, the providers supported the need for transition programs, but revealed only 10% of their adolescents with chronic conditions were prepared adequately for transitional care (Por et al., 2004). Both of these studies supported the need for transitional planning and transition programs.

Another study supporting the need to plan for transitional programs was reported by Fiorentino, Datta, and colleagues (1998). An interview was conducted of 87 out of 206 eligible disabled youth (e.g., youth with cerebral palsy, spina bifida, and juvenile arthritis) and / or their caregivers from the registry of organizations such as Cerebral Palsy Association (Fiorentino, Datta et al.). Using content analysis and statistical

software program for analysis, the study compared the legislation guidelines for good transition practice to the youth's transition experience to adult health care. The disabled youths' perceptions of the transition process was correlated with type of school the youth attended. The severe learning disabled youth in a special school usually had a transition plan, whereas the mild or moderate disabled youth in a mainstream school did not have a transition statement or plan. Therefore, the more severe physically disabled youth were more apt to be transferred to adult specialist which speaks to the quality of the transition experience. In contrast, the mild or moderate physically disabled youth usually remained with their general practitioner (Fiorentino, Datta et al.). Fiorentino, Datta, and associates concluded transitional practices did not correlate with the legislature transition guidelines and problems exist in the transition process, which subsequently interfere with the transition of the disabled youth to adult health care.

The 2005 study by Lotsein, McPherson, Strickland, and Newacheck added transition questions to an existing national survey. Using a random-digital dial questionnaire created by an expert panel associated with the Maternal Child Health Bureau, 5,533 out of 13,885 youth aged 13-17 years with special health needs and their parents answered transition questions. All analyses were conducted by using a statistical software program by the Stata Corporation. The study reported that transitional planning with a medical transition goal was performed in only one of seven youth with special health care needs and even lower results in youth from ethnic minorities. Lotsein and colleagues noted that 20 % of youth with a medical home met the medical transition goal compared to the 11 % of youth without a medical home. The medical home is defined as an approach to providing continuous and comprehensive pediatric care from infancy to adulthood (AAP, 2002). Not only have studies focused on



the youth and families' transitional needs and the concerns of the health care providers, but also stressed the need for transitional planning. Clearly obstacles exist that impede the transfer from pediatric to adult care setting, which include the limited number of evaluated transitional programs.

Transitional programs are considered necessary as reported by a cross-sectional study of 224 adolescents with SCD who were selected from Sickle Cell Centers in United States and a center in the United Kingdom (Anie, Telfair & Sickle Cell Disease Transition Study Working Group [SCDTSWG], 2005). The focus of the study was to predict that self-efficacy and self-management skills in adolescents were influenced by age, educational level and gender. Validated disease specific instruments [Sickle Cell Disease Psychological Symptoms Scale (SCDPYS), Sickle Cell Disease Efficacy Questionnaire (SCDEQ), and SCD Adolescent Readiness Scale (SCDARS)] were used in the study (Anie et al.). The instruments were used to assess the adolescents' perceptions of physical and psychological symptoms, self-efficacy, and self-management skills that were correlated with demographic factors (Anie et al.). Using analysis of variance, there were no significant differences between the 2 countries on the demographic factors (Anie et al.). Using hierarchical regression analysis on SCDEQ and factor analysis of SCDARS, both analyses indicated that older adolescents with higher educational level tend to report more physical and psychological symptoms related to SCD according to SCDPYS results (Anie et al.). The researchers of this study recognized the importance of demographic factors as a part of the transition program. They also recommended the need for further qualitative research to explore the transitional views of the CIY and their parents.

In another cross-sectional survey, the majority of the providers (89%) of youth with hemoglobinopathy supported the need for a transition programs (Telfair, Alexander, Loosier, Alleman-Velez, & Simmons, 2004). Two hundred and twenty-seven randomly sampled health care providers of youth with SCD from two medical centers and from the National SCD Center (NSCDC) database was surveyed using an investigator-developed questionnaire: Sickle Cell Transfer Questionnaire-provider version (P-SCTQ). After two Delphi rounds reviews, a pilot draft of P-SCTQ was developed and tested by 10 providers (Telfair, Alexander et al.). Using the bivariate and comparative content analyses, the results of the P-SCTQ denoted that majority of providers (70%) serving both adolescent and adult populations expected the patient to be seen with the parent or guardian. Conversely, 67% of adult-only providers expected the patient to be seen without the parents present (Telfair, Alexander et al.). To diminish these inconsistencies among adult providers' expectations, the literature supports the need for transition programs that incorporate the expectations of the not only the provider but the parent and CIY.

#### *Transitional Obstacle: Transitional Resistance to Adult Health Care*

Transitional resistance was reflected in six studies that focused on the concerns of youth, parents, and health care providers regarding the transfer of the CIY to adult health care. Of the six studies reviewed that related to transitional resistance to adult health care, only one study focused on the CIY with hemoglobinopathy. Telfair, Myers and Drezner (1994) used a cross sectional survey to determine issues, concerns and expectations of the 36 adolescents with SCD in pediatric care, 60 SCD young adults and 25 primary caretakers and providers. The investigator-developed Sickle Cell Transfer Questionnaire (SCTQ) was mailed to providers of two major medical centers

(Telfair, Myers et al.). The providers either administered the questionnaire using the interview method or mailed the questionnaire to study participants. Using the bi-variate analyses, the study reported that the caretakers and youth were primarily concerned about how they would pay for the medical care, what would the adult setting be like for them and how to manage their mixed feelings about leaving the pediatric provider (Telfair, Meyers et al.).

Fiorentino, Phillips, Walker, and Hall (1998) also recognized mixed feelings of the disabled youth and their caregivers about their transfer to adult care in a descriptive study. Using a pre-existing database, a survey of 50 out of 159 physically disabled youth aged 16 to 24 years old and their caregivers was conducted (Fiorentino, Phillips et al.). The content analysis noted that the participants felt angry and distressed about unexpected transfers and none of the participants reported a smooth transfer to adult services due to lack of transitional preparation (Fiorentino, Phillips et al.). Christian, D'Auria and Fox (1999) supported study results from Fiorentino, Philips and colleagues regarding the need to prepare the CIY based on readiness for the transfer to adult health care. A retrospective review of a purposeful sample of four teens with diabetes identified that cognitive readiness can begin as early as 12 years in the preparation for transition to adult care (Christian et al., 1999).

Boyle, Farukhi, and Nosky's (2001) also focused on transition preparation of the youth with CF to adult care. The researchers surveyed 52 CF youth and 38 parents prior to transition to adult care (pre-transition group) and 60 participants 8-12 months after transition to adult care (post-transition group). Comparison of survey responses between the two groups demonstrated significantly lower levels of concerns in all areas for participants who had previously met the adult team prior to transition (Boyle et al.).

The investigator-developed survey revealed the areas of concerns were: leaving health care providers, meeting a new team, and the infection control policies in adult programs (Boyle et al.). The investigator-developed survey was based on the review of previous CF studies and tested by CF experts and 4 CF patients. In all these studies, the parents, youth and providers surveyed had a positive attitude toward the establishment of a transition program as long as the program was based on their concerns.

Concerns about facing transition to adult care was shared by seven 12-17-year old chronically ill youths (e.g., with diabetes, chronic renal failure, and cancer) in a qualitative study (Soanes & Timmons, 2004). Content analysis of the interview transcripts revealed concerns regarding the importance of a familiar face, an informal adult atmosphere to promote communication, and a gradual individual/ flexible transition process with adequate preparation from supportive providers (Christian et al., 1999; Soanes & Timmons). In these studies, transitional resistance was identified by the concerns regarding leaving health care provider, meeting new provider and lack of adequate transition preparation.

A retrospective chart review of 247 chronically ill young adults exhibited transitional resistance by reporting a significant increase in admissions of these adults to pediatric hospitals(e.g., to endocrine, oncology, neurosurgery services) over a 10 year period (Lam, Fitzgerald, & Sawyer, 2005). Almost half (49%) of the adults admitted to the hospital had severe complications of their illness and had been previously transferred to adult care provider or had a documented transition plan (Lam et al.). Regardless of whether the CIY had a documented transition plan or had been previously transferred to adult health care, many of the CIY continued to return to pediatric care.

Resistance toward transition to adult health care is an area that needs further research especially in the CIY with hemoglobinopathy.

### Discussion

Of the 17 empirical transition studies reviewed, only 5 studies focused on CIY with hemoglobinopathy. Therefore, this comprehensive literature review was supplemented with other studies that focused on CIY with a variety of chronic illnesses (e.g., diabetes, cystic fibrosis, and neurological disabilities). Also no studies addressed similarities and differences in the transition experience among various cultures (e.g., Asian, Latino, and Native American). Most of these studies were conducted in the United States and the United Kingdom with the remainder in Canada and Australia. The majority of studies reviewed were quantitative or mixed studies utilizing investigator-constructed scales and surveys or validated questionnaires (e.g., the P-SCTQ scale). The transitional obstacles identified in the literature included the lack of transition support, limited transitional programs and transitional resistance to adult health care. Clinical recommendations from the studies are organized in the following section according to the related transitional obstacle.

#### *Transitional Obstacle: Lack of Transitional Support*

Several studies reported the lack of transition support was comprised of the difficulty in finding adult providers, no transition planning with abrupt transfer to adult care, no transition resources, no transition personnel, and the lack of communication between the pediatric and adult health care providers (Reiss et al., 2005 ; Scal, 2002 ; Wojciechowski et al.,2002). Clinical recommendations by researchers included viewing transition as a continuum and starting the process early, working as a team, recognizing transitional readiness in CIY, emphasizing the importance of having an adult provider,

training the adult health care provider in adolescent health, and obtaining transition support (e.g., funding) from the institution (Reiss et al.; Scal; Scal & Ireland, 2005; Wojciechowski et al.). In all these studies, the adult and pediatric providers, parents and CIY supported the need for transition programs.

#### *Transitional Obstacle: Limited Transitional Programs*

Very few transition programs identified in the research literature. Only one program was evaluated in the transition literature with successful transfer of CIY to adult care. However, the successful transfer was based on CIY attending one adult clinic visit or adult related test (Reid et al., 2004). Clinical recommendations for transitional programs included establishing comprehensive goals, educating of the health care providers, parents and youth on transfer issues, providing a medical summary from the pediatric provider and promoting collaborative interaction between adult and pediatric subspecialist (Fiorentino, Datta et al., 1998; Telfair, Alexander et al., 2004). Other clinical recommendations included the formulation of a transition program to include orienting youth to adult clinic and utilizing consistent provider (e.g., advance practice nurse) to introduce the CIY and parent to adult care system prior to the transfer (Lotsein et al., 2005; Por et al., 2004).

#### *Transitional Obstacle: Transitional Resistance to Adult Health Care*

Several studies have identified resistance by the providers, parents and the CIY toward transition to adult care. Parents may interfere with the transition to adult care because they do not want to let go of their control over their CIY's health care or they may feel excluded from participating in the medical decisions (Telfair, Myers et al., 1994). Studies have reported that providers, parents and CIY have mixed feelings about the CIY leaving pediatric care. The studies suggested clinical recommendation such as

establishing collaborative relationship between pediatric and adult health care providers (Fiorentino, Phillips et al., 1998; Soanes & Timmons, 2004; Telfair, Myers et al.).

Researchers suggested to start the transition process when CIY is developmentally ready and to provide education regarding their diagnosis, treatment and preventive measures which tend to encourage self-care responsibility in the CIY (Boyle et al., 2001; Christian, D' Auria, & Fox, 1999; Fiorentino, Phillips et al.; Telfair, Meyers et al.). Betz and Redcay (2005) suggested that the health care provider begin the transition process by exploring with the youth their transition expectations and experiences. Enhancing the youth's participation in the transition process can be facilitated best by encouraging the youth's verbal input regarding their transition experience. Information gained from the CIY can contribute to the transition plan to facilitate transfer to adult health care.

### Limitations

The limitations of this integrated review are based on the limits of the individual studies reviewed. Small sample size, purposive samples, no mention of validity or reliability on some of the investigator-developed instruments, the need to replicate study on a larger scale, retrospective and cross-sectional data and nonrandom samples were some of the limitations. The use of nonspecific sampling strategies, majority of providers interviewed were pediatric providers, that ethnic minorities underrepresented and the lack of sample characteristics in some studies (education, illness severity, gender, types of chronic illnesses) also limited study comparisons.

### Summary

There has been little qualitative exploration of the transition experience of CIY published in the literature (Britto et al., 2007). Telfair, Ehiri, Loosier, and Baskin (2004)

reported that published empirical studies offer the most rudimentary issues of transition, especially from the fact that chronically ill youth's point of view remains rare. Of the 17 studies reviewed, the majority were quantitative and mixed studies that were not able to discuss the youth's transitional experience to adult health care in depth. Further research is needed to gain understanding of the transition experience of young adults in order to contribute to the establishment of transition programs. It is evident in this review of literature that there is limited research in the area of transition and chronic illness especially CIY with hemoglobinopathy. This empirical review contributes significant knowledge to the transition literature by identifying three transitional obstacles that emerged from the literature. The obstacles were categorized as lack of transition support, limited transition programs and transitional resistance to adult health care with associated clinical recommendations. Most of the clinical recommendations were based on speculation and experience rather than empirical evaluation, which are areas for needed research. Therefore, to promote successful transition to adult care, further research is needed to explore the transition experience of the CIY especially in the area of hemoglobinopathy and to evaluate transition programs based on clinical outcomes.



## CHAPTER III

### PROCEDURE FOR COLLECTION AND TREATMENT OF DATA

The purpose of this descriptive phenomenological research was to describe the transitional experiences of CIY with hemoglobinopathy (e.g. sickle cell disease, thalassemia). Phenomenological research attempts to understand the meaning of human experience by grasping the lived experience of those being studied (Lopez & Willis, 2004). Therefore, this methodology explored the meaning of the transition experience through the voices of the CIY with hemoglobinopathy who have been transferred to adult health care. The aim of this approach was to gain understanding of the lived transitional experience as revealed through interviews of the CIY with hemoglobinopathy. This chapter contains information regarding the study setting, participants, protection of human subjects, data collection methods, and methods for data analysis.

#### Setting

Data were collected from a transitional clinic (TC) in a southwestern medical center. The clinic was established in January, 2005 with the goal of providing a medical home for chronically ill patients. Presently the clinic cares for more than 200 young adults with neurological, endocrine, pulmonary, hematological and oncological disorders (e.g. spinal bifida, cystic fibrosis, cancer, sickle cell). The director of the TC granted approval for the investigator to invite eligible patients with hemoglobinopathy to participate in this study (Appendix B).

## Participants

A purposeful sample of 14 English-speaking CIY aged 19 to 25 years with hemoglobinopathy (e.g. sickle cell disease, thalassemia) was recruited from a list obtained from TC and the children's hospital electronic medical records that identify individuals who transferred to the TC. Inclusion criteria for this study were: 1) English-speaking youth with hemoglobinopathy, 2) youth aged 18 to 25 years, 3) youth transitioned to adult health care, and 4) youth that could give informed consent. Exclusion criteria included: 1) Non-English speaking youth and 2) youth unable to give informed consent. A sample size of 14 was based on the literature recommendation of 10-15 participants to gain saturation of the phenomenon (Kvale, 1996). Sampling ended when data saturation occurred.

## Protection of Human Subjects

This study was approved by the institutional review boards of Baylor College of Medicine and Texas Woman's University (Appendix B). Participants were recruited via a letter informing them of the study. Potential participants indicated their interest verbally or by returning a post card and were contacted during clinic visit or phone by the investigator who set a mutually agreed meeting time. Informed consent was obtained in clinic prior to data collection. Participants were made aware that the study involvement was voluntary. Participants were informed that they may elect not to answer interview questions or discontinue participation in the study without penalty.

Every effort was made to maintain the confidentiality of the study's participants. Each participant's audiotape was assigned a study number upon transcription and only the investigator had access to participant's identification. Demographic information sheets and audiotapes of the interviews and transcripts were stored in a locked cabinet

accessible only to the investigator. At the completion of the study, the audiotapes were destroyed. A password-protected computer was used for stored data. In future publications, composite data will be presented and individual identifiers will be omitted from the findings presented.

### Data Collection

A letter describing the study, length of time for the interview, and inviting participation in the study was mailed or hand delivered to the prospective participant by the investigator, social worker or medical provider during a clinic visit (Appendix B). Included with the letter was a stamped addressed postcard that offered participation in the study by returning the postcard or calling the investigator. After receiving the postcard or a telephone call, the investigator and the eligible participant scheduled the study interview, if possible, on the same day as the clinic appointment. Using a script to guide the consent process, the investigator discussed the study and answered questions (Appendix D). The investigator informed the participant that the interview would be audiotaped. After written consent was obtained from the youth, a copy of the consent was given to the participant.

Demographic data consisting of age, ethnicity, diagnosis, and other data were obtained prior to beginning the taped interview (Appendix E). The face-to-face interview was conducted using semi-structured questions to guide the collection of data (Appendix F). Each study participant was interviewed within the clinic in a quiet, private room with the door closed. The audiotaped interview averaged 45 minutes (30-60 minutes). If unable to validate the themes at the completion of the initial interview, participants were requested to return for a 15 minute follow-up audiotape interview for the purpose of

validating the emerging themes. Probes were used to elicit more information if respondent answers were vague.

### Data Analysis

The goal of the analysis was to discover the meaning and achieve understanding of the holistic transitional experience including obstacles as expressed by CIY with hemoglobinopathy. Audiotapes of each interview were transcribed verbatim after the interview session. Following transcription, audiotapes were played while reviewing the printed text to verify accuracy. Following accuracy verification, transcripts were read to begin pulling out key ideas expressed in the interview. Through repeated readings, the themes were derived. Thematic clusters were identified, grouped and analyzed according to Colaizzi's procedural steps. The steps include:

1. Describe the phenomenon of interest
2. Collect participant's description
3. Read all participant's descriptions
4. Return to original transcripts and extract significant statements
5. Spell out meaning of each significant statement
6. Organize aggregate formalized meanings into clusters/themes
7. Write exhaustive description and validate data at the end of each interview or during a follow-up interview with the participants (Colaizzi, 1978).

Trustworthiness is comprised of credibility, transferability, dependability, and confirmability which were incorporated in this study. Credibility of the study was supported by the thick descriptions (intense dialogues) from the interviews and member checks. As a part the analysis, member checks from transitioned participants were conducted by sharing the identified themes with the participants at the end of the

interview or returning to the participant for a follow up audiotape interview. The 4 themes were validated by 12 of the 14 participants who all agreed the themes captured elements of their transitional experience. Two of the participants were not included in the validation of the themes because one had a stroke after the interview and the other was unavailable for a follow-up interview.

True analysis of the experience is achieved by identifying the facts of the situation by Husserlian phenomenological reduction (Walters, 1995). Bracketing was performed throughout the research process as the researcher maintained a list of suspended biases and preconceptions while reading, rereading and reflecting on the participants' lived experiences. Dependability was demonstrated in the consistent use of step-by-step data collection and data analysis with use of an ongoing audit trail. Audit trail was maintained throughout the analysis as the researcher recorded a systematic documentation of the data. Transferability may be demonstrated by the in-depth understanding of the CIY's transition experience which may have meaning for others in similar situations. All of the interviews were compared to each other to identify universal essences or themes and to determine an overall picture of the transitional lived experience.

## CHAPTER IV

### ANALYSIS OF DATA

The following manuscript consists of a descriptive phenomenological study that explored the transition experience from pediatric to adult health care of the chronically ill youth with hemoglobinopathy (CIYH) through interviews. The philosophical underpinnings utilized for this study were derived from the work of Edmund Husserl. Colaizzi's method was used to analyze the CIYH's meaning of the transition experience. This chapter consists of a manuscript that includes an abstract, succinct literature review, methodology, findings in response to the research questions, discussion, implications, limitations, and recommendations. Verification of article submission is in Appendix G.

#### Transition of Chronically Ill Youth to Adult Health Care:

##### Experience of Youth with Hemoglobinopathy

The life expectancy of children with chronic illnesses has increased dramatically over the past decades with greater than 90% surviving beyond their 20<sup>th</sup> birthday (The American Academy of Pediatrics, 1996). However, successful transition of the chronically ill youth (CIY) from pediatrics to adult care continues to be a difficult and inconsistent process, especially for the CIY with hemoglobinopathy (e.g., sickle cell disease, thalassemia). Transitioning of CIY to adult care may be interrupted by obstacles such as lack of transitional support, limited transitional programs and transitional resistance to adult care (Bryant & Walsh, 2009). Often the transitioning experience consists of an abrupt transfer which leaves the youth unprepared for the movement to

adult health care (Hauser & Dorn, 1999). Consequently, CIY do not keep follow-up appointments with the new provider and end up returning to the pediatric providers or the emergency room for health care (Hauser & Dorn, 1999). Missed adult care appointments by transitioned CIY can lead to irreversible, preventable complications and even death (Bell, 2007). In order to promote uninterrupted medical care as CIY with hemoglobinemias transfer to adult care, it is important to understand the holistic transition experience including the obstacles. To uncover the lived experience, the meaning of the transition experience from the viewpoint of chronically ill youth with hemoglobinopathy (CIYH) was explored in this descriptive phenomenological study. As the number of CIY living to adulthood increases, effective mechanisms need to be put in place to promote transition into adult care. Accurate description of the transition experience may facilitate designing effective interventions to provide uninterrupted medical care in the transfer of the CIYH to adult health care, therefore contributing vital and new information to the transitional literature.

### Literature Review

In 1984, the first national focus on health care transition issues (McGrab & Millar, 1989) was presented by the United States Surgeon General during a cohosted conference focusing on the needs of older adolescents with chronic and disabling conditions. The problems of transition were further addressed in a position paper by the Society for Adolescent Medicine (Blum et al., 1993). Also, the American Academy of Pediatrics (1996, 2002) published policy statements emphasizing the importance of the health care providers educating and advocating for youth and family in promoting transition to adult health care. A significant awareness of the need for programs aimed at transitioning adolescents from pediatric to adult care exists within the literature (Boyle,

Farukhi, & Nosky, 2001; Fiorentino, Phillips, Walker, & Hall, 1998; Lotstein et al., 2009; Reiss, Gibson, & Walker, 2005; Scal, Evans, Blozis, Okinow, & Blum, 1999; Scal, 2002). Yet, further research is needed to gain understanding of the transition experience of young adults in order to contribute to establishing transition programs (Telfair, Ehiri et al., 2004).

Even though transitioning to adult care has been identified as a priority, only a limited number of empirical studies have been published on transition of the CIY to adult care, especially within the nursing literature. Kirk (2008) and Soanes and Timmons (2004) are among the few qualitative nursing studies published on transition to adult care. Concerns about facing transition to adult care was reported by both studies that focused on chronically ill adolescents with diabetes, cystic fibrosis, cancer, and complex health care problems from pediatric settings ( Kirk; Soanes & Timmons). These studies revealed concerns about leaving pediatric health care providers, meeting new providers, the expertise of the new providers, continuity of care, and flexibility of the transition process including adequate preparation from supportive providers (Kirk; Soanes & Timmons). Both studies focused on the concerns of CYI who are primarily speculating about their future transition experience, whereas this study focused on views of CIYH who have actually experienced the transition to adult care.

The majority of transitional science consists primarily of medical studies focusing on the parental and providers' view of the transitional expectations or concerns of the CIY attending pediatric clinics (Boyle, Frukhi, Nosky, 2001; Lotstein et al., 2009; Peter, Forke, Ginsburg & Schwartz, 2009; Scal, 2002; Scal & Ireland, 2005; Telfair, Alexander, Loosier, Alleman-Velez, & Summons, 2004). McPherson, Thaniel, and Minniti (2009) recently published a study supporting the need to prepare the CIY for transition to adult



care based on recognition of transition readiness. A survey on transitional readiness was administered to a purposeful sample of CIY from a children's hospital that reported that cognitive readiness developed as the individual aged (McPherson et al.).

Another study, using the National Health Interview Survey data from 2000 to 2005, focused on transitional delays of CIY to adult care that compared the responses of parents of adolescent asthmatics to the responses of young adult asthmatics regarding transitional obstacles (Scal, Davern, Ireland & Kyong, 2008). According to descriptive statistics and bivariate comparisons, financial obstacles delayed transition to adult care among the young adults significantly more often than among the adolescents (Scal et al.). Other transitional obstacles reported in the literature were the parent's reluctance in relinquishing control over their CIY's medical care and finding an adult provider to care for the CIY (Scal, 2002; Telfair, Meyers, & Drezner, 1994). Since finding an adult provider, parent's reluctance to release medical control over CIY, and financial obstacles were not the sole reasons for the high rates of delayed transition to adult care, the investigators recommended further research on health care transition as the literature provides little in the way of in-depth description of this problem (Scal et al.).

Telfair, Ehiri, Loosier, and Baskin (2004) reported that published empirical studies offer the most rudimentary issues of transition, especially from the fact that CIY's point of view remains rare. Another study reported that little is known about the health care seeking behaviors of young adults, especially those with childhood-onset chronic conditions (Scal et al., 2008). The purpose of this study was to gain understanding of the lived transitional experience as told in the words of the CIYH who transferred to adult care.

This is the first study to focus solely on experience of the CIYH who have transitioned to adult health care to obtain an in-depth description of the transitional experience. The research questions addressed in this study were: (a) What are the experiences of the CIYH who transition from pediatric to adult health care? and (b) what are the expectations and concerns of CIYH regarding their transition experience?

## Methods

### *Research Design*

The philosophical underpinnings utilized for this descriptive phenomenological study were derived from the work of Edmund Husserl. According to Husserl, phenomenology searches for the meaning of lived experiences from the perspective of those who lived them. The focus of this study was derived from Husserl's (1960, 1962) three tenets that included: (a) return to original awareness, (b) transcendental subjectivity and (c) free agency (Wojnar & Swanson, 2007). Husserl's (1960, 1962) main tenet instructed individuals to go back to the things themselves (*zu den sachen selbst*) to recover the original awareness of the phenomenon through phenomenological reduction. Phenomenological reduction is the process of returning to the original awareness by allowing individuals to describe the experiences as perceived by their consciousness. Consciousness refers to the relationship between the person and the events of their experience, or one's directed awareness of an object or event (Husserl, 1962). As multiple accounts of the phenomena under study were gathered, universal structures or essences were derived.

Transcendental subjectivity refers to a process of bracketing which is described by Husserl as occurring when investigators suspend their preconceptions and biases while seeking to discover the true form or essences of things. Through the process of

bracketing past knowledge, the phenomenon may be seen precisely as it presents itself (Giorgi, 1992). The third tenet is free agency in which individuals are believed to be free agents who are able to influence their environment. Through one on one dialogue, the experience unfolded to formulate meanings and identified the universal essences of the CIYs' transitional experiences.

### *Setting and Sample*

The setting was in the transitional clinic (TC) of a large southwestern medical center. The TC was established in January, 2005 with the goal of providing a medical home for chronically ill patients. A purposeful sample of 14 English-speaking eligible CIY aged 19 to 25 years with hemoglobinopathy (e.g. sickle cell, thalassemia) were recruited from a list obtained from TC and the children's hospital electronic medical record that identifies individuals who transferred to the TC. A sample size of 14 was selected based on the literature recommendation of 10-15 participants needed to gain saturation of the phenomenon (Kvale, 1996).

### *Data Collection Procedure*

Following approval by the institutional review board, a recruitment letter describing the study, length of time for the audiotaped interview and inviting participation in the study was either mailed or hand delivered to prospective participant during a clinic visit. Included with the mailed letter was a stamped addressed postcard offering participation in the study by either returning the postcard or calling the investigator. After receiving a positive response from the participant, an interview appointment was scheduled that usually coincided with the clinic visit. Following written consent, semi-structured interviews averaging 45 minutes were conducted.

## *Data Analysis*

Audiotapes of each interview were transcribed verbatim after the interview session. Audiotapes were played while reviewing the transcription to verify accuracy, thoughts, and ideas. Through repeated readings, thematic clusters were identified, grouped, and analyzed according to Colaizzi's procedural steps. The steps included: (a) Describe the phenomenon of interest, (b) collect participant's description, (c) read all participant's descriptions, (d) return to original transcripts and extract significant statements, (e) spell out meaning of each significant statement, (f) organize aggregate formalized meanings into clusters/themes and validate data, and (g) write exhaustive description (Colaizzi, 1978).

Bracketing was performed throughout the analysis as the researcher suspended biases and preconceptions while reading, rereading and reflecting on the lived experiences of each participant. All of the interviews were compared to each other in order to determine universal essences or themes and the overall picture of the transitional lived experience. The goal of the analysis was to discover the meaning of the transitional experience in order to achieve understanding of the holistic transitional experience as perceived by CIYH.

Credibility of the study consisted of thick descriptions (intense dialogues) from the interviews and member checks. As a part of the analysis, member checks from transitioned participants were conducted by sharing the identified themes with the participants at the end of the interview or returning to the participant for a follow-up audiotape interview. The 4 themes were validated by 12 of the 14 CIYH who all agreed the themes captured elements of their individual transitional experience. Two of the CIYH were not included in the validation of the themes because one had a stroke

several weeks after the interview and other was not available for a follow-up interview. An audit trail used in the data analysis showed the steps from significant statements of the participants to the formulation of meanings around 4 themes.

### Findings

The sample consisted of eight (57%) females and six (43%) males aged 19-25 years with mean age of 21 years (SD=1.60). Thirteen (93%) participants were African-American and one (7%) Hispanic with all diagnosed with Sickle Cell Disease. Seven (50%) participants were college students, two (14%) were sales associates, one (7%) worked at a manufacturing company, one (7%) was on disability, two (14%) were looking for a job and one (7%) participant did not record any occupation on the demographic form. All participants had insurance with majority (12 or 86%) enrolled in Medicaid and others (2 or 14%) enrolled in private insurance. All but one of the youth was transferred from pediatric provider to adult care within two months to two years of their interviews. One participant had transitioned 4 years prior to the interview.

Significant statements pertaining to the transition experience were extracted from the transcriptions. Meanings were formulated and organized into 4 major themes that described the essence of the CIYH's transition experience. The themes included: (a) reactions to the transition experience, (b) concerns about the transition, (c) pushed into transitioning to adult health care, and (d) acknowledgement of the transition to adult care. One participant best described the holistic transition experience as "an adjustment process." Themes clearly exemplified this adjustment process as the participant expressed reactions and concerns of reluctance to transition with recognition that the movement was inevitable as they were pushed into adult care and finally accepting the transition to adult care as beneficial.

### *Reactions to Adult Care Transition: I Don't Want to Go.*

Reactions to the transition to adult care encompassed feelings of sadness, not wanting to leave pediatric providers and apprehension about unfamiliar new adult environment. Participants expressed feeling scared when asked to move out of their comfortable pediatric environment to the new adult environment. Transitioning into an unfamiliar adult environment was instrumental in promoting anxiety and fear of the unknown as reported by the participants. With lack of readiness to transition, the participants perceived the sudden request to move to adult health care as the loss of their life-long relationship with their pediatric providers and were reluctant to leave pediatrics. Not wanting to leave pediatrics, sadness was expressed as participants perceived not only the loss of the pediatric provider, but the feeling was compounded by the sense that the pediatric provider did not want to care for them anymore as they moved into adulthood. Participants felt abandoned by their pediatric providers as they moved alone into adult care. As participants expressed in the following statements, these feelings contributed to their arduous transition toward adult health care.

I was kind of scared at first cause I was so used to going to children's. It was kind of fun being there (children's). You know, I didn't want to leave from under the doctor at children's and I felt like they (pediatrics doctors) didn't want me there no more. I felt bad.

Well, I was scared. I didn't really want to transfer. I was not ready to leave children's; I wanted to stay at children's. It was difficult and hard... made me feel sad and anxious.

It (adult care) is different, it is a new environment. That's what scares me, the new environment. Cause I knew it was going to be different people, new people and different doctors. I did not want to leave children's.

### *Concerns about Transition Experience: What's Going to Happen to Me?*

Concerns about transition experience consisted of worrying about selecting an appropriate adult provider and what is going to happen to them in the care of the adult provider which tended to aggravate the initial feelings of fear, anxiousness and nervousness. All participants, who were at or near their 18<sup>th</sup> birthday, were informed to transfer to adult care either during a clinic visit, in the emergency room or during hospitalization. Most were given a list of adult providers and instructed to make an appointment. Participants who received a list of adult providers expressed concerns about selecting the best adult doctor that would provide the best care for them as two CIYH stated in the following statements: “ most difficult finding the best doctor for me” and “ was he (adult doctor) going to be a good doctor and want the best for me?” Without information about what transition to adult care entailed, participants perceived the transition experience as difficult to switch to adult care. Expressed by a participant “Switch doctors that was difficult...a lot of new doctors...the switch from my pediatrician...the switching to a new doctor, that was difficult.”

Participants were clueless about what their future health care entailed. They lacked information about adult providers and the adult care environment which created worry about the type of care that they would receive and how they would be treated as individuals and patients. Participants expressed these worries and concerns in the following statements and questions:

I was like, would they take care of me the right way like Children's do? Is it going to be different over there? Will they you know, about my sickle cell ... know as much as children's? Will they know to get me well...help me?

I was worried about is how the doctors were how they (adult providers) were going to treat me, what's going to happen? Getting ready to be in a new

atmosphere and meet new people. I hope the people (adult providers) are like the people at children's.

Is the adult doctor going to be hands on as my old doctor (pediatric doctor)? That is talk to me and my family about my care.

Is he (adult provider) going to be a suitable doctor that is attend to my needs? Is he going to be a stable doctor...that is he going to be there for me?

### *Pushed into Transitioning to Adult Care: Facing the Music*

Getting pushed into transitioning to adult care consisted of being forced into adult care without transitional preparation and was often accompanied by an abrupt movement from pediatrics into adult health care. Participants perceived that they were tossed out of pediatrics into an unfamiliar adult health care environment as described by participant who stated "...[it] felt like I was being put out (pediatrics) or something."

Participants also voiced difficulty in severing ties with the pediatric providers by returning to the children's emergency room when ill after being transitioned to adult care.

Returning to pediatrics after being transferred to adult care was illustrated by a 22 year old female with sickle cell disease complicated by a stroke during childhood:

I used to go back to children's hospital emergency room(ER) even though my adult doctor told me not to... I did that like three times after I was transitioned. They (pediatric doctors) would treat me and then transfer me to the adult hospital. Finally I talked to my adult doctor about how I felt and she told me about behaving as an adult, so I decided not to back to the children's ER.

Although participants in this study were told to move to adult care without any prior preparation, they began to adjust as they recognized that transition to adult care was inevitable which was illustrated by a participant who stated "I knew I was getting older and they were going to kick me out, eventually." Recognizing the inevitability of transitioning to adult care was also aptly expressed by a youth as "when they told me I was going over to the adult doctors, I just had to face the music and went on because I



couldn't stay there forever." Since each participant was either an adult or approaching adulthood when asked to transfer to adult care, they perceived that they had no choice but to transition to adult provider as expressed in the following statements:

Well, the next time I got sick and went to children's, the people in the emergency room told me that I was too old to be a patient in the children's hospital. They admitted me at that time, but told me to find an adult doctor.

They (pediatric doctors) threw me to somebody (adult providers). I was pushed into being an adult because my age speaks for itself.

They (pediatric doctors) started telling me and my family that we needed to transfer to adult care when I turned 18 but we did not go...so we just ignored them...until Mom called for an appointment one day and was told to make an appointment with adult doctor.

Kicking me out...I knew pediatrics was for kids and I was turning 18.

#### *Making the Adult Care Transition: Accepting That I Had to Leave*

Making the transition to adult care reflected the adjustment process as the CIYH accepted the transition to adult health care. Accepting transition to adult care encompassed an introduction to the adult provider and environment, informative interaction with the adult provider about their medical care, and recognized being treated as an adult. One CIYH equated acceptance of transition to adult care with becoming an adult as stated "Maybe it (transitioning) made me become my age...it made me become a woman. It made me show my age a lot...and letting me know that I am not a child any more. I am an adult."

Participants perceived the adult provider and their environment as welcoming, informative, interactive, and more importantly being treated as adults and felt in control of their medical care. CIYH became more knowledgeable about their illness as reflected by the comment " I know more about my health than I did at first." With recognition of an inevitable transition accompanied by knowledge of the adult environment and interaction

with the adult providers dissipated the reluctance to transition and perpetuated the acceptance of transitioning to adult care that exemplified by adjustment process as illustrated by the following responses:

The best thing about transitioning was being treated like an adult. For me I'm the baby of the family, my grandmother had 12 grandkids and I'm number 12. So my family can see that she (referring to herself) drives now, she graduated from high school, and she is in college. Just becoming an adult... for me was the best thing (participant raised by her grandmother).

They basically go how you feel and you know, you basically can discharge yourself as far as, you know, if you're feeling... if you tell them that you're feeling better, obviously you're of age, so there are going to just gonna go by what you're saying.

Well, is definitely different...as far as being hospitalized cause the wait is a lot longer (than in pediatrics).

They (adult doctors) do a good job by explaining everything to me, answering my questions and let me explain my thoughts and feelings.

Made me more independent... happier being more independent. Shared my medical information with my adult doctor.

More control over my medical care and see the doctor less often.

However the adjustment process was not without obstacles, the participants reported difficulties such as completing excessive amount of paperwork and long waits for medical care, especially in the adult emergency room. CIYH voiced "When I finally accepted that I had to leave, it was hard getting all the paperwork and sending it to the new adult doctor." Participants perceived movement into adult care as positive experience and wanted to share advice with individuals facing transition. A 20 year old CIYH who wanted to give advice to those planning to transition to adult care stated "I know they're going to be nervous at the beginning of it (transition to adult care), but it's

going to work...it's a fast process, it's going to work." Delaying transition to adult care for two years, a CIYH did not receive the preventive care that could have avoided severe hip damage who now is faced surgical replacement of his hip and shared these comments:

If I could do it over again, I would have done it (transition) as soon as they (pediatric providers) mentioned transition. I would do it a lot sooner than I did it, instead of waiting. I guess if I didn't wait... there is more that could've been done instead of surgery.

## Discussion

Utilizing the Husserlian tenets in this study, the investigator gathered the CIYHs' descriptions by guiding the interviewees toward their original awareness of the holistic transition experience. The 4 themes that emerged from the interviews exemplified the adjustment process. Parts of the themes have been reported in the literature, but the holistic transition experience as illustrated by the adjustment process has not been reported. The adjustment process was initiated as the participants expressed that they did not want to leave pediatric care. Studies have identified reluctance of the CIY to leave pediatrics and feeling angry and distressed to make the transition (Boyle et al., 2001; Fiorntiono et al., 1998; Telfair, Myers et al., 1994). All of the participants in this study stated that either they did not want to leave pediatrics or were not ready to leave pediatrics. Feelings of fear, sadness and "being put out" of pediatrics were expressed by the participants in this study and may contribute to CIY's reluctance to leave pediatrics. Although fear has been mentioned rarely in the transition literature, the majority of participants expressed fear of transitioning to adult care which was aptly conveyed by a participant who stated "scary not knowing my options."

Participants' verbalization of fear, anxiety and sadness overlapped their concerns about switching to new adult provider and being worried about the type of care that they will receive from the adult provider. Several studies have reported concerns from CIY facing transition or a combination of concerns from both CIY and their parents, or pediatric providers about the type of care that CIY would receive from unfamiliar adult providers (Boyle et al., 2001; Fiorentino et al., 1998; Soanes & Timmons, 2004; Telfair, Myers et al., 1994). This study confirmed CIYH's worries experienced during their transition to adult care and the mechanisms that moved youth beyond their worries and concerns into actual transition.

Ongoing adjustment was the key in the transition process by the CIYH's sense of getting pushed into adult care without any preparation leading to the eventual recognition of the inevitable movement into adult care. An initial lack of adjustment contributes to resistance toward transitioning to adult health care. The abrupt transfer to adult care has been reported in the several studies that focused on lack of transitional guidelines (Boyle et al., 2001; Florentine et al., 1998; Lam et al., 2005). Not only was the abrupt transfer to adult care recognized in this study, but an additional finding was the worry CIYH expressed regarding the adult doctors' response to them as patients and as individuals.

Making the transition to adult care consisted of accepting the transition, albeit reluctantly as evidence by the repeated attempts to receive care from the familiar pediatric providers. Returning to pediatrics after transition to adult care has been reported in the literature (Hauser & Dorn, 1999). As the adjustment process continued, CIYH moved completely into adult care, regardless of obstacles including finding an adult provider, completing excessive paperwork, and prolonged waiting for medical

treatment. A positive finding of this study is that CIYH finally accepted the transition to adult care. This transfer of care ushered in a sense of adulthood and a sense of greater responsibility toward managing their own health care. Even with the acknowledgement of adjustment difficulties, this study reported an overall positive adjustment and acceptance of the transition to adult care by the CIYH.

In summary, the adjustment process began with initial reactions of fear, anxiety and sadness of CIYH accompanied with their postponing or hindering the transition to adult care (e.g., ignoring request to transition, not keeping adult care scheduled appointment). Overlapping of these initial reactions was concerns or worries regarding their unknown medical fate (e.g., worried about the type of care will receive) with an unfamiliar adult provider. Pushed into adult care exemplified the CIYH's adjustment as they recognized their inevitable movement into adulthood and adult health care (e.g., forced into adult care without preparation). As the adjustment process progressed, the CIYH moved into adult care by deciding to transition (e.g., actively searching for adult provider, locating and making appointment with adult provider), and accepting transition to adult care (e.g. keeping appointments with the adult provider, completing the paperwork for transition). Knowledge of this adjustment process is helpful information that can be utilized in the formation and implementation of interventions in transitional preparation of CIY for adult health care.

### Implications

Advanced practice pediatric nurses and other medical providers must incorporate transitional preparation to adult health care into their practice, particularly for CIYH who require uninterrupted medical care. As stated by one of the study participants, the transition to adult care “need to be talked about at a younger age instead of starting at

18 years when you are shocked and don't wanna leave.” This study identified that CIYH are shocked by the abrupt mention of transition that create a feeling of not wanting to leave pediatrics and supports the need for transitional preparation long before transfer to adult care. Findings support the literature in the recommendation of preparing the CIY for transition to adult care based on readiness and starting as early as 12 to 14 years of age (Christian, D'Auria, & Fox, 1999; McPherson et al.).

Participants of this study suggested “...to meet the doctor or their assistants before I went to the new hospital and ...by meeting the new doctor, I would not feel so scared.” This study reported that the majority of participants were afraid of being transitioned to adult care, most likely because they were informed about transitioning without any knowledge of what comprised the movement into adult health care. Not only was fear identified in this study but also feelings of anxiety, sadness and worries associated with the transition that may be dissipated by providing knowledge of the unfamiliar adult provider and environment.

The transition to adult care as an adjustment process for CIYH exemplified by progressing from fears, anxieties, and worries to being pushed into adult care with the recognition of an inevitable transition into acceptance of transition to adult health care. Viewing transition as an adjustment process allows pediatric providers to plan interventions, such as establishing of transitional plans or programs that incorporate:

1. assessing CIY's transitional readiness.
2. having portion of medical visit without parent present.
3. encouraging the expression of fears and anxieties related to adult care transition

4. educating CIY regarding their diagnosis, treatment, and preventive measures to encourage responsibility for their medical care (Boyle et al., 2001; Christian, D'Auria, & Fox, 1999; Fiorentino, Datta, Gentle et al., 1998).
5. encouraging participation in discussions regarding medical treatment and transition to adult care.
6. educating CIY and parents on transition issues (e.g. insurance, medical documents).
7. assisting the CIY with their paperwork prior to transition and the selection of an adult provider (e.g., hospital affiliation, clinic location).
8. orienting the CIY and their families to the adult system (e.g. introduction to provider or representative, inform of the adult clinic routine).

Knowledge of the adult system may alleviate fears, anxieties and worries of CIYH which may help to eliminate resistance or reluctance toward transitioning to adult health care.

Findings in this study are the first to acknowledge that the benefits (e.g., being treated as adult, having more control over medical care, being more independent) of transitioning to adult care outweigh the difficulties (e.g., completing excessive paperwork, finding an adult provider, long waits for medical care) by the CIYH. Since the majority of transitioned CIYH view adult health care system as primarily beneficial, reluctance to transfer to adult care may be reduced by matching a CIYH facing transition to adult care with a transitioned CIYH who would share their adult care experience which may assist in promoting a positive adjustment to adult care. With knowledge of the adjustment process, pediatric providers may be able to design effective interventions that provide uninterrupted medical care as the CIYH transition to adult health care.

Health care providers need to change the way they approach the transition process. In addition to developing education programs and becoming more proactive about introducing the concept of adult transition at an earlier point in care, creative strategies to promote successful transition should be considered. One such strategy would be developing articulation agreements between pediatric clinics and adult care clinics to facilitate a seamless transition in care. Another possibility is developing a transitional care nursing role. The transitional care nurse would be responsible for developing and coordinating programs of care that includes (a) proactive conversations regarding care transition; (b) education for CIY and their families, (c) assistance with completion of insurance and other medical documents needed for transition, and (d) follow-up with CIY to ensure that successful transition has occurred.

During the exploration of the holistic transition experience, the meaning from the CIYH's interviews unfolded the adjustment process leading to implications for potential interventions that may provide uninterrupted medical care as the CIYH transition to adult health care. Difficulty experienced by the CIYH during the adjustment process suggest the importance of further research to examine interventions based on transitional preparation that will successfully move CIY into adult health care.



## CHAPTER V

### SUMMARY OF THE STUDY

Since life expectancy of chronically ill youth with hemoglobinopathy (CIYH) has increased, the issue of transition from pediatric to adult health care has become a major issue. Multiple obstacles prevent successful transition leading to missed adult care appointments that can potentially lead to irreversible, but preventable complications. The holistic transition experience must be better understood in order to promote uninterrupted medical care as the CIY transfer to adult care. The purpose of this descriptive phenomenological study was to describe the transition of CIYH to adult health care. This chapter will provide a summary of the study, conclusions, nursing implications, and recommendations.

#### Summary

The purposive sample of 14 English-speaking participants consisted of eight females and six males aged 19-25 years. One participant was Hispanic, while the remainder was African American and all participants were diagnosed with Sickle Cell Disease. Half of the participants were college students, while the remainder either worked, were looking for employment, or on disability. All the participants completed high school, except one participant who completed the 11 grade. All of the participants had insurance with almost all enrolled in Medicaid and the remainder enrolled in private insurance. All but one youth had transferred from pediatric provider to adult care within

two months to two years of their interviews. One participant had transitioned four years prior to the interview.

Two research questions were explored in this study. The first question explored the experiences of the CIYH who transitioned from pediatric to adult health care. The second research question explored the expectations and concerns of the CIYH regarding their transition experience. As the experiences were explored through interviews, meanings were formulated and organized into 4 themes that described the essence of the CIYH's transition experience. The themes included: (a) reactions to adult care transition, (b) concerns about the transition experience, (c) pushed into transitioning to adult care, and (d) making the adult care transition. One participant best described the holistic transition experience as "an adjustment process." The themes clearly exemplified this adjustment process as the participant expressed reactions and concerns of reluctance to transition with recognition that the movement was inevitable as they were pushed into adult care and finally accepting the transition to adult care as beneficial.

Reactions to the transition to adult care was expressed by all the CIYH as "I don't want to go", accompanied by feelings of fear, sadness, and anxiousness and nervousness. Transitioning into unfamiliar adult environment was instrumental in promoting anxiety and fear of the unknown as reported by the participants. With lack of readiness to transition, the CIYH perceived the sudden request to move to adult health care as the loss of their life-long relationship with their pediatric providers and were reluctant to leave pediatrics. Not wanting to leave pediatrics, sadness was expressed as CIYH perceived not only the loss of the pediatric provider, but it was compounded by the sense that the pediatric provider did not want to care for them anymore as they moved into adulthood.

Overlapped by the reactions of fear, anxiety and sadness, the concern about the transition experience as expressed by the CIYH was “what’s going to happen to me?” CIYH were worried and apprehensive about the change of moving from pediatrics to the new adult provider. All CIYH, who were at or near their 18<sup>th</sup> birthday, were informed to transfer to adult care either during a clinic visit, in the emergency room or during hospitalization. Without information about what transition to adult care entailed, CIYH voiced worry about the type of care that they would receive and how they would be treated as individuals and patients.

Getting pushed into transitioning to adult care was expressed by the CIYH as “facing the music.” CIYH perceived that they were tossed out of pediatrics into unfamiliar adult health care and also voiced difficulty in severing ties with the pediatric providers by returning to the children’s emergency room when ill after being transitioned from pediatrics. Recognizing the inevitability of transitioning to adult care was also aptly expressed by a CIYH as “when they told me I was going over to the adult doctors, I just had to face the music and went on because I couldn’t stay there forever.”

Making the transition to adult care reflected the adjustment process as the CIYH accepted the transition by expressing “I finally accepted that I had to leave.” All the CIYH accepted transition to adult care but they all delayed their transition to adult care from 3 months to 2 years. Following transitioning, CIYH stated that if they had an opportunity to change anything about the experience that they would transition earlier, in order to limit the gap in their medical care and prevent progression of disease-related complications. Obstacles encountered during transition included completing excessive amount of transitional paper work and having long waits for medical care especially in the adult

emergency room. The 4 themes exemplified the adjustment process which reflected the exploration of CIYH's holistic transitional experience from pediatric to adult health care.

### Conclusions and Implications

Conclusions of this study are:

1. Transition of CIYH to adult care is an adjustment process comprised of four stages beginning with reluctance to leave, uncertainty about what lay ahead, getting pushed into transition followed by the acceptance of actual transition.
2. Lack of preparation of the CIYH's for transition to adult care creates fear, anxiety, sadness and worries about the unknown adult provider and their environment.
3. Abrupt transfer to adult care from pediatrics may potentially delays the transition into adult care by generating adult care avoidance behaviors.
4. Successful transition leads to greater independence and greater assumption of care responsibilities by CIYH.

Knowledge of the adult system may alleviate fears, anxieties and worries of CIYH which may help to eliminate resistance toward transitioning to adult health care. Implications of this study are:

1. Pediatric medical providers must incorporate transitional preparation to adult health care for CIY (e.g. transitional plan or program) into their practice, particularly for CIYH who require uninterrupted medical care.
2. Avoid abrupt transition into adult care by discussing transition to adult care regularly beginning at an early age incorporating the CIY's transitional readiness.

3. Providers need to increase awareness of the CIYH's adjustment process, attending to fears, anxieties and worries related to transitioning.
4. Educate CIY and parents on the mechanics of transition issues such as insurance selection and completing the necessary medical documents.
5. Orienting the CIYH and their families to the adult system (e.g. introduction to provider or representative, exposed to adult clinic routine) prior to transitioning to adult health care may reduce fears and worries associated with lack of transitional preparation.
6. Since transitioned CIYH view adult health care system as primarily beneficial and positive, reluctance to transfer to adult care may be reduced by matching a CIYH facing transition to adult care with a transitioned CIYH who would share their adult care experience which may assist in promoting a positive adjustment to adult care.

#### Recommendations for Further Studies

Difficulty experienced by the CIYH during the adjustment process suggest the importance of further research focusing on interventions to promote smoother transitions culminating with the successful movement of the all CIY into adult health care.

Potential research studies include:

1. Test the effectiveness of early and ongoing preparation for adult transition.
2. Examine the effectiveness of education programs designed to reduce obstacles to transition such as adult provider orientation and/or programs to assist with insurance issues and provide uninterrupted medical care as the CIY transition to adult health care.

3. Research examining the effectiveness matching CIYH facing transition to adult care with a transitioned CIYH who would share their adult care experience that may assist in promoting a positive adjustment to adult care.
4. Conduct qualitative studies with more racially and geographic diverse sample of CIY with a variety of chronic illnesses that have transitioned to adult health care.
5. Study CIYH that did not make a successful transition to adult care.

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APPENDIX A  
LITERATURE REVIEW TABLES

Table 1

*Transitional Obstacle: Lack of Transitional Support*

| Author / Date    | Design / Purpose  | Subjects   | Key Findings   | Clinical Recommendations   |
|------------------|---|--|--|--|
| Scal, P. (2002). | Survey Design: mailed investigator developed survey to nominated health care providers by families of patients (e.g., cystic fibrosis, epilepsy, others); purpose of this study was to describe transition services provided by primary care physicians | 13/36 nominated health care providers completed the 53 forced response & 8 open ended items on the survey (survey reviewed by 6 researchers prior to distribution) | Summarized responses on transition were: (a) ambivalence, (b) transition is a process, (c) focus on youth future, (d) family physician view, (e) transition as part of care, (f) identify adult provider, (g) lack institutional support (no planning time/ no personnel), and (h) community resources | Recommend individualized care to transition; view transition as a continuum; start early and work as a team; identify & train adult providers to care chronically ill youth; obtain institutional support for transition services (planning time /resources/ personnel (most significant/ study); seek community resources (school/employer) |

Table 1, *continued*

| Author / Date                 | Design / Purpose  | Subjects  | Key Findings   | Clinical Recommendations   |
|-------------------------------|---|---|--|--|
| Scal, P. & Ireland, M. (2005) | Cross-sectional design using a random digit-dial method to generate sample; purpose was to determine from surveyed parents if the health care provider addressed transition from child to adult health care for youth with special health needs | Data from 4332 /4426 youth 14-17 year old from 2000-2001 National Survey of Children with Special Health Care Needs via 3 questions: (a) Have providers talked about health care needs changing when adult? (b) Has a plan that addressed changing needs been developed with provider? (c) Have provider discussed transfer to adult health care? | 50% parents reported discussion of transition issues with doctor. Health care transition (HCT) was discussed comprehensively with 16% of youth. Condition complexity, older age, White race, high quality relationship with provider significantly addressed HCT issues / bivariate analysis. To date, no outcome studies on transition interventions in literature to substantiate the value HCT services | Discuss transition process early with youth & family; work as a team with adult provider, youth & family; establish transitional plan with the team; facilitate HCT services (insurance coverage, employment/ school guidance) |

Table 1, *continued*

| Author / Date  | Design / Purpose   | Subjects   | Key Findings   | Clinical Recommendations  |
|--|--|--|--|---|
| Reiss, J.G.,<br>Gibson, R.W. &<br>Walker, L.R.<br>(2005) | Qualitative design; purpose was to address the need for exploratory research on Health care transition (HCT) & documentation of the transition experience. It is widely known that HCT is often unsuccessful, few empirical data have been collected to help understand & explain the difficulties | 143 participants in 34 focus groups almost evenly distributed: youth/young adults(49), family members(44) & health care providers (50); ages range 13-35 yrs with variety chronic illnesses (e.g. asthma, cardiac, cancer); focus groups and interviews conducted separately using a standard protocol | Two factors with significant effect were cognitive ability of patient & progressive nature of the disability. Stages of transition: (a)envisioning a future, (b) age of responsibility, (c) age of transition allow for developmental delays, age of transition is completed by age 21 yr. Transitional barriers: (a) aging out of treatment,(b) insurance/ funding availability of care, & (c) practice differences | Incorporate developmental readiness into transition plan; avoid automatic transfer to adult care; institute therapeutic termination of pediatric relationships; aid with continuation of insurance/ funding for youth health care |



Table 1 *continued*

| Author / Date                                   | Design / Purpose   | Subjects   | Key Findings   | Clinical Recommendations   |
|---|--|--|--|--|
| Wojciechowski, E., Hutig, A., & Dorn, L. (2002) | Nonexperimental descriptive design used to collect historical data; purpose of study was to obtain database to understand natural history when adolescent/young adults (AYA) with sickle cell disease (SCD) make the transition from pediatric centered care(PCC) to adult centered care (ACC) | 18/35 participants ages 18 -24yrs were chosen from 3 mid-western hospitals; using Compliance Questionnaire (Cronbach's $\alpha=0.56$ ) & Self-efficacy Scale for managing SCD ( $\alpha=0.84$ ), the correlation between dependent variables (uninterrupted care, compliance, self-efficacy,independence) & independent variables (preparation, gender, pediatric patient care) was questionable | AYAs with chronic illness are transferred to ACC abruptly with little preparation or opportunity to practice managing own care; follow-up ceases once AYA leave PCC; transfer is often initiated because of the AYAs age/ pregnancy rather than on youth's readiness; many of AYAs remain on public insurance and have jobs; lack of communication between PCC & ACC providers | Transfer to adult care based on readiness (educational/ developmentally);increase communication between adult & pediatric providers; verbally communicate between providers regarding transfer information; provide a medical summary for the adult provider |

Table 1, *continued*

| Author / Date                | Design / Purpose   | Subjects   | Key Findings  | Clinical Recommendations  |
|------------------------------|--|--|---|---|
| Hauser, E. & Dorn, L. (1999) | Exploratory nonexperimental design; purpose was to develop framework to guide the transition of sickle cell disease (SCD) patients from child-centered care to adult- centered care and to provide knowledge useful to nurses working with SCD adolescents & other chronic illnesses | Purposive sample from 4 SCD pediatric centers in Midwestern city comprised 3 groups: 22 adolescences age 13-21yrs, 22 parents / caregivers with mean age of 45.7 yrs and 8 practitioners who completed open-ended questions /interview via audiotape & notes | Focus group indicated the concerns, expectation and needs of the parents & adolescents were parallel (e.g. lack transition preparation, unfamiliar provider); transition framework was recommended & formed based on focus group results; with abrupt transfer, adolescent tend not to keep follow-up appointments with new adult provider and may return to pediatrics | Avoid abrupt transfer to adult health care if possible; establish a transition program based on research; provide & evaluate transition framework |

Table 2

*Transitional Obstacle: Limited Transitional Programs*

| Author / Date                | Design / Purpose   | Subjects   | Key Findings   | Clinical Recommendations  |
|------------------------------|--|--|--|---|
| Reid, G.J., et al.<br>(2004) | Cross-section study from entire cohort;<br>Purpose was to determine percent of young adults with complex congenital heart defects (CHD) who successfully transferred from pediatric to adult care & examine correlates of successful transfer; successful transfer defined as keeping 1 adult appt. of any type (e.g., clinic, surgical, adult test) | 234/360 eligible youth aged 19-21yrs with complex congenital heart defects (CHD) from a pediatric tertiary center database completed questionnaire | Based on multivariate analysis, successful transfer was significantly related to more pediatric surgeries, older age & recommendation from pediatric cardiologist; first study to document the percent of youth with chronic illness successful transfer to adult care in timely manner; no formal transition program in place other than transfer of record | Establish a transition program well before transfer of the youth begins; provide a medical summary for the adult provider |

Table 2, *continued*

| Author / Date           | Design / Purpose   | Subjects  | Key Findings   | Clinical Recommendations   |
|-------------------------|--|---|--|--|
| Por, J.et al.<br>(2004) | Survey design used to collect descriptive data; purpose was to explore the views/needs of health care provider (HCP) regarding transition of care for adolescents with chronic illness to adult services | Data collected by 120 anonymized mailed investigator-developed questionnaires to HCP from the same hospital. 40 of 120 questionnaires were returned. Content validity was established by expert panel & piloted with 5 subjects to test questionnaire | Maturity rather than age is main criteria for assessing youth readiness for transfer to adult care: anxiety ,concerns of transition to adult care; concerns about paying for adult services, time to meet adult provider, support need for transition program, but only 10% of their youth with chronic conditions were adequately prepared for transition to adult services | Provide multidisciplinary approach to formulate a clear written transfer plan; establish a transition program utilizing a consistent provider; orient youth/family /provider to adult clinic before transfer (meet with adult provider team). Discuss insurance / medical funds for adult care within transfer program |

Table 2, *continued*

| Author / Date                                | Design / Purpose   | Subjects   | Key Findings  | Clinical Recommendations  |
|--|--|--|---|---|
| Fiorentino, L,<br>Datta, D, et al.<br>(1998) | Mixed study design; purpose was to examine the assumption that improves transitional process and reflects improved outcomes for young disabled youth (YDY) & caregivers; transition experience of youth was compared to legislative practice guidelines of good transition practice. | 87 / 206 individuals aged 16-25 yrs agreed to participate. YDY were from several registries & had cerebral palsy, spina bifida, & other diagnoses; hypotheses focus: (a) Handover to adult services differ between schools,(b) experiences of YDY depend severity of disability, (c) quality handover process affect perceptions of service received | An ethnographic qualitative analysis of the interview material & quantitative data analyzed using SPSS. YDY handover experience to adult services related:(a) type of school & severity of disability, (b)perception of service (unexpected transfers cause distress/ anger),(c)usual hand-over is 16 yrs, (d) YDY leave pediatrician and medical care declines | Establishment of transition program to include:<br>identification all YDY early & formulate plan, maintain a flexible age for transition train adult providers in developmental care of YDY |

Table 2, *continued*

| Author / Date  | Design / Purpose   | Subjects   | Key Findings  | Clinical Recommendations  |
|--|--|--|---|---|
| Lotsein,D.S.,<br>McPherson, M,<br>Strickland, B., &<br>Newacheck, P.W.<br>(2005) | Descriptive study using<br>nation-wide random<br>telephone survey;<br>purpose was to describe<br>current planning practices<br>of health care providers<br>nation-wide for youth with<br>special health care needs<br>from perspective of<br>parents & guardians | Of the 373,000 youth<br>in all 50 states, the<br>final sample included<br>38,865 children with<br>health care needs<br>(CSHCN);<br>questionnaire created<br>by Maternal Child<br>Health Bureau & used<br>during 10/2000-<br>4/2003 3 transition<br>questions were added<br>after the study started<br>so 5533/ 13885 youth<br>aged 13-17 were<br>asked transition<br>questions | In the first national<br>Survey of CSHCN, the<br>overall rates of transition<br>planning are<br>relatively low, particularly<br>for youth from ethnic<br>minorities; a multivariate<br>logistic-regression model<br>found that older age with<br>medical home were more<br>likely to receive transition<br>planning; pediatric<br>providers wanted to know<br>the "right" age to transfer | Formulate transition<br>plan encompassing<br>shift to adult health<br>care; identify when the<br>youth is physically,<br>medically & socially<br>prepared for transition;<br>discussion of transition<br>with providers, youth &<br>family prior to transfer ;<br>discuss change in<br>health care needs as<br>an adult |

Table 2, *continued*

| Author / Date   | Design / Purpose   | Subjects  | Key Findings   | Clinical Recommendations   |
|---|--|---|--|--|
| Anie, K., Telfair, J. & Sickle Cell Disease (SCD) Transition Study Working Group (2005) | Cross-sectional survey design employed; purpose is to identify similarities in two countries with different health services; study predicted self-efficacy & self-management skills in adolescents are influenced by age, educational level and gender | 224 SCD adolescents from SCD centers in United States & 1 center from United Kingdom were surveyed; validated SCD Psychological Symptom Scale/ SCD Efficacy questionnaire (SCDEQ) /SCD Readiness Scale (SCDARS) were used | Using analysis of variance, no significant differences between the 2 countries; using the hierarchical regression on SCDEQ & factor analysis of SCDARS, analysis indicated that older adolescents with higher educational level tend to report more physical & psychological symptoms related to SCD based on SCDPYS | Provide SCD knowledge and promote self-care skills in the SCD adolescent; orient the youth and family to adult care system prior to transfer |

Table 2, *continued*

| Author / Date  | Design / Purpose   | Subjects   | Key Findings  | Clinical Recommendations  |
|--|--|--|---|---|
| Telfair,J.,<br>Alexander,L.,<br>Loosier,P.,<br>Alleman-Velez,&<br>Summons,J.<br>(2004) | Cross-sectional, multi-format survey in confidential mailed questionnaires to 3 sample populations of Health Care Providers (HCP) of Sickle Cell Disease (SCD) patients; purpose to focus on opinions/insights of HCP from multiple disciplines regarding transition to adult care from pediatric care of SCD adolescents age 12 years & older | 227 pediatric and adult medical psychosocial health care providers sampled in 3 waves: (a) sample of HCP at 2 Sickle Cell Programs;(b) sample of private providers likely care for SCD patient ; (c) national sample of all SCD providers Investigator-developed provider-version Sickle Cell Transfer Questionnaire(P-SCTQ) $\alpha = 0.80$ | 89% of respondents indicated a need for systematic transition; providers significantly believed a systematic transition program provide more support in meeting youth needs than would the absence of such a program; good transition program include:comprehensive/ clear goals & education/ discussion/ support / HCP | Establish comprehensive clear transition goals; recognize transition youth readiness & start preparation of youth for transition; educate the HCP |



Table 3

*Transitional Obstacle: Transitional Resistance to Adult Health Care*

| Author / Date                                  | Design / Purpose   | Subjects  | Key Findings   | Clinical Recommendations  |
|--|--|---|--|---|
| Telfair,J.,<br>Myers,J. &<br>Drezner, S (1994) | Cross-sectional survey;<br>purpose was to<br>determine the issues,<br>concerns &<br>expectations of<br>adolescents, young<br>adults and primary<br>caretakers with regard<br>to transfer to adult care | Volunteer participants<br>included 36<br>adolescents (13-19<br>yrs), 60 young adults<br>(21- 30yrs) & 25<br>adolescent primary<br>caretakers from 2<br>Pediatric & Adult Sickle<br>Cell Programs;<br>respondents either<br>completed 67 item<br>mailed Sickle Cell<br>Transfer Questionnaire<br>(SCTQ) or used the<br>interview method with<br>the SCTQ | Bivariate statistics used<br>to examine that 44% of<br>adolescents, 50% of<br>young adult & 68% of<br>caretakers had concerns.<br>Adolescents/ young<br>adults concerned about<br>payment of medical care<br>& treatment by adult<br>providers. All groups<br>concerned about teens<br>leaving pediatric care;<br>caregivers concerned<br>about being excluded<br>from medical decisions | Start transition process<br>when youth is<br>developmentally ready;<br>establish transfer<br>program; encourage<br>youth, parents &<br>provider's verbal<br>participation in the<br>establishment of a<br>transfer program<br>(express concerns/<br>expectations);listen &<br>demonstrate respect<br>for opinions, concerns<br>of the youth; allow<br>youth to participate in<br>decision making during<br>the transition process |

Table 3, *continued*

| Author / Date  | Design / Purpose  | Subjects  | Key Findings   | Clinical Recommendations   |
|--|---|---|--|--|
| Fiorentino, L. ,<br>Phillips, D.<br>, Walker, A., & Hall,<br>D. (1998) | Descriptive study using a semi-structured interview; purpose was to describe the procedures in place to facilitate transition from pediatric services to adult services | Utilized the Sheffield Case Register updated every 3-5 years (yrs.) that include young people with physical & learning disabilities; compiled a database of 159 people between the ages 16-24 yrs of which 50 were interviewed.; excluding people with profound multiple disabilities | Data from precoded questions & from postcoded open ended questions were analyzed using SPSS statistical package; none of the young people experienced a smooth transition from pediatric to adult care; transition program consisted of: Impersonal formal letter through the post & pediatrician informed youth at final annual meeting to transfer to 1 of 3 hospitals | Prepare youth for transition; establish a specific transition policy for pediatric/specialty clinics; establish a formal transition program, teach youth the skills needed to function in adult clinic, encourage advance practice nurses to act as a facilitator of youth's transition to adult care; develop links between adult & pediatric clinics; evaluate transition programs |

Table 3, *continued*

| Author / Date   | Design / Purpose  | Subjects   | Key Findings  | Clinical Recommendations   |
|---|---|--|---|--|
| Christian, B. J.,<br>D'Auria, J. P., &<br>Fox, L. C. (1999) | Exploratory, qualitative pilot study; purpose of this study was to explore the meaning of chronic illness experience for adolescents with diabetes (DM) in relation to taking responsibility for their own care | Purposeful sampling 4 adolescents ages 14-18 years(yrs.) diagnosed with diabetes at least 4 yrs & were recruited from a pediatric diabetes center;a retrospective semi- structured interview to explore meaning of self-responsibility for diabetes care | 3 themes marked the process: making DM fit within life activities, being ready /willing to transition, & having a safety net of friends. Acceptance of self- responsibility varied based cognitive & emotional readiness. This study indicated cognitive readiness & willingness to learn knowledge of disease/problem-solving skills was identified as early as age 12 years | Incorporate youth developmental needs & readiness into the transition preparation; provide opportunities to practice independence guided by a consistent provider (e.g. advance practice nurse ) |

Table 3, *continued*

| Author / Date                                    | Design / Purpose   | Subjects   | Key Findings   | Clinical Recommendations  |
|--|--|--|--|---|
| Boyle, M.,<br>Farukhi, Z., &<br>Nosky, M. (2001) | Descriptive design;<br>purpose was to<br>identify concerns &<br>expectations of parent<br>& patients prior to/after<br>transitions then<br>develop strategies for<br>the future needs of<br>patients/family<br>members; develop<br>database of patient (pt.)<br>concerns & pt. profile to<br>formulate a customized<br>transition protocol | 52 CF patients (age<br>18-63 years) & 38<br>parents who<br>volunteered to<br>complete an open-<br>ended survey 3 months<br>pretransition & 60 CF<br>pt. completed<br>posttransition interview<br>8-12 months | Investigator-developed<br>survey revealed areas of<br>concerns which were<br>leaving caregivers,<br>meeting new caregivers,<br>& exposure to infection; a<br>significant lower level of<br>concern noted in all areas<br>of concerns with a prior<br>introduction to adult CF<br>team in posttransition<br>group | Transition process<br>need to be<br>implemented between<br>the ages of 15-25<br>years; transition<br>education should<br>include youth, parent<br>and providers; develop<br>a transition program to<br>adult care, introduce<br>youth to adult team<br>prior to transfer,<br>incorporate the<br>concerns of the<br>youth/families into a<br>customized transition<br>protocol |

Table 3, *continued*

| Author / Date                         | Design / Purpose  | Subjects   | Key Findings   | Clinical Recommendations  |
|---------------------------------------|---|--|--|---|
| Soanes,C. ,&<br>Timmons, S.<br>(2004) | Qualitative design;<br>purpose was to<br>examine the attitudes of<br>young people with<br>chronic illness who<br>were facing transition | Purposive sample of 7<br>adolescents (aged 14-<br>17) were interviewed;<br>the chronic illnesses of<br>the adolescents<br>consisted of 4 with<br>diabetes, 2 with chronic<br>renal failure, & 1 with<br>cancer | Data collected via semi-<br>structured interviews.<br>Five themes identified:<br>Flexibility ,informality /<br>formality ;comfort/<br>familiarity, ready<br>prepared support | Prepare youth for<br>transition by assessing<br>readiness then<br>disseminate transition<br>information (diagnosis /<br>medication / preventive<br>actions ), schedule and<br>informal day with adult<br>provider; employ a<br>flexible, supportive<br>provider to direct the<br>transition program |

Table 3, *continued*

| Author / Date                                     | Design / Purpose  | Subjects   | Key Findings  | Clinical Recommendations  |
|---|---|--|---|---|
| Lam, P.,<br>Fitzgerald ,B., &<br>Sawyer,S. (2005) | Retrospective chart review;purpose was to explore the extent to which disease complexity & failure of transition planning may contribute to young adults' healthcare who continue to be based at a children's hospital. | Sample consisted of 247 individuals 57% were 18-20 yrs, 35 % were 20 –25 yrs & 8% were 25- 45 yrs.; sixty-eight % admitted to surgical unit (e.g. orthopedic, neuro. surgical) 52% admitted to adolescent unit (cardiac endocrine & others) 27% had more than 1 admit and 17 % was admitted the following year | Significant increase in admission over 10 year period ( $p < 0.001$ ) & 3/6 of the surgical units had significant increase in admissions; both disease complexity & failure of transition planning contribute to the increase admissions to hospital; need greater focus on support of youth with chronic illness during transition to adult care using transition planning | Focus of transfer age to adult care expects to occur at completion of high school ; establish a transition plan; provide continuous education of the youth regarding diagnosis, medications & preventive measures |

APPENDIX B  
APPROVAL LETTERS



Baylor College of Medicine

**COMBINED MEDICINE-  
PEDIATRICS PROGRAM**

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HOUSTON, TEXAS 77030  
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**Cynthia Peacock, M.D.**  
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Faculty  
713-798-0199  
713-798-0198 Fax

January 8, 2009

**Cynthia Peacock, M.D.**  
Program Director for Medicine Pediatric  
Residency Program  
Assistant Professor  
Baylor Department of Medicine  
Director of Baylor Transitional Clinic

Dear Dr. C. Peacock,

I am matriculating in the PhD program at Texas Woman's University. My topic of interest is the transition of the hematology youth to adult care. The purpose of my study is to explore the transition experience of the transferred hematology youth to adult health care. There is a limited amount of published qualitative literature on the transitioned experience as voiced by the hematology youth. The knowledge gained from face-to-face interviews with the transitioned hematology youth about their transition experience would provide essential information needed for a transition program to be successful. I am requesting permission to contact your patients to ask if they would participate in an interview focused on their transition experience. Please sign this letter if you agree that I may contact your patients regarding the participation in an interview focused on their transition experience.

Thank-you,

Rosalind Bryant, M.N.

Cynthia Peacock, M.D.



September 24, 2008

ROSALIND BRYANT  
BAYLOR COLLEGE OF MEDICINE  
PEDIATRICS: HEMA & ONCOLOGY



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**H-21802 - TRANSITION OF CHRONICALLY ILL YOUTH TO ADULT HEALTH CARE: EXPERIENCE OF YOUTH WITH HEMOGLOBINOPATHY**

**APPROVAL VALID FROM 9/24/2008 TO 9/23/2009**

Dear Dr. BRYANT

The Institutional Review Board for Human Subject Research for Baylor College of Medicine and Affiliated Hospitals (BCM IRB) is pleased to inform you that the research protocol and consent form(s) named above were approved.

The study may not continue after the approval period without additional IRB review and approval for continuation. You will receive an email renewal reminder notice prior to study expiration; however, it is your responsibility to assure that this study is not conducted beyond the expiration date.

Please be aware that only IRB-approved informed consent forms may be used when written informed consent is required.

Any changes in study or informed consent procedure must receive review and approval prior to implementation unless the change is necessary for the safety of subjects. In addition, you must inform the IRB of adverse events encountered during the study or of any new and significant information that may impact a research participants' safety or willingness to continue in your study.

The BCM IRB is organized and operated according to guidelines of the International Council on Harmonization, the United States Office for Human Research Protections and the United States Code of Federal Regulations and operates under Federal Wide Assurance No. 00000286, issued April 30, 2001. Affiliated hospitals include: the Michael E. DeBakey Veterans Affairs Medical Center, St. Luke's Episcopal Hospital, The Methodist Hospital, Texas Childrens Hospital, Texas Institute for Rehabilitation and Research, and the Harris County Hospital District.

Sincerely yours,

RAYAN KAMAL AL JURDI, M.D., B.S.

Institutional Review Board for Baylor College of Medicine and Affiliated Hospitals





Office of Research  
6700 Fannin Street  
Houston, TX 77030-2343  
713-794-2480 Fax 713-794-2488

December 11, 2007

Ms. Rosalind Bryant  
College of Nursing-Anne Young, Faculty Advisor  
6700 Fannin Street  
Houston, TX 77030

Dear Ms. Bryant:

Re: *"Transition of chronically ill youth to adult health care: The experience of the youth with hemoglobinopathy"*

The above referenced study has been reviewed by the TWU Institutional Review Board (IRB) and was determined to be exempt from further review.

Any changes in the study must receive review and approval prior to implementation unless the change is necessary for the safety of subjects. In addition, you must inform the IRB of adverse events encountered during the study or of any new and significant information that may impact a research participant's safety or willingness to continue in your study.

Sincerely,

Dr. William P. Hanten, Chair  
Institutional Review Board - Houston

APPENDIX C  
RECRUITMENT LETTER

## RECRUITMENT LETTER

Hello,

My name is Rosalind (Roz) Bryant. I am a doctoral student at Texas Woman's University College of Nursing and a nurse practitioner at Texas Children's Cancer and Hematology Center. I am conducting a research study about transition of youth with inherited blood disorder to adult health care. As one of the many youth that transferred to adult health care, you are invited to participate in this study to help us learn more about your transition experience. To understand your experiences surrounding the movement from pediatric to adult health care, this study will consist of interviewing you about your views, concerns and expectations of the transition experience. Information gained from interviewing you can help to provide smooth transfer from pediatric to adult health care for other youth with inherited blood disorders.

If you volunteer to participate in the study, you will be asked to sign an informed consent giving us permission to have you as a participant. After signing the informed consent, you will be asked to complete information such as your age, diagnosis, and occupation on a demographic information sheet. You will be interviewed from 60-90 minutes in a private room within the clinic. Your interview information will be kept confidential and private. You and any other person mentioned in the interview will not be identified by name.

Would you like to participate? If yes, you need to return the enclosed stamped postcard or telephone me. I will schedule a mutually agreed upon date and time for the interview.

Thank you,  
Roz Bryant

APPENDIX D  
IN-DEPTH INTERVIEW GUIDE

## IN-DEPTH INTERVIEW GUIDE

Transition of chronically-ill youth to adult health care :  
Experience of youth with hemoglobinopathy

Date: \_\_\_\_\_ Interviewer: \_\_\_\_\_

Statements in bold titles are instructions/comment given to the participant via interviewer  
[statements in brackets and caps are instructions for the interviewer only]

### **Introduction**

Thank you for agreeing to be interviewed. Your assistance and comments are valuable and important in understanding your transitional experience. This is an informal interview which is like a conversation.

### **Purpose**

I am interested in all your concerns, comments, and experiences related to your transfer from pediatric to adult health care. There are no right or wrong answers. I welcome you to share both good and bad parts of your transition experience. The results from this interview will be combined with other interviews to understand the transition experience to adult health care.

### **Interview procedure**

The interview will last an hour to an hour and half. I will be audiotaping this interview and taking notes. The interview will be confidential. You may stop the interview at any time. As previously indicated, I will need you to read and sign this informed consent form. The permission for the interview is included in the consent form. [GIVE HIM/HER THE CONSENT FORM, HAVE HIM/HER READ AND SIGN, THEN YOU SIGN.OFFER A COPY OF THE CONSENT FORM.]

Prior to the interview, I would like you to complete the demographic/transition history information sheet of questions [GIVE INFORMATION LIST OF QUESTIONS]

We have a lot to cover, but let me know if you want to add something during the interview. [ASK INTERVIEW QUESTIONS]

APPENDIX E  
DEMOGRAPHIC INFORMATION SHEET

## Demographic Information Sheet

Please fill in the blank in each item to indicate your response.

Gender: Female \_\_\_\_\_  
Male \_\_\_\_\_

Age: \_\_\_\_\_

Ethnicity: African American \_\_\_\_\_  
African \_\_\_\_\_  
Asian/Pacific Islander \_\_\_\_\_  
Caucasian/White \_\_\_\_\_  
Hispanic/Latino \_\_\_\_\_  
Native American \_\_\_\_\_  
Other \_\_\_\_\_

Diagnosis: \_\_\_\_\_

Occupation/student: \_\_\_\_\_

Marital status: single \_\_\_\_\_  
married \_\_\_\_\_  
divorced \_\_\_\_\_  
separated \_\_\_\_\_

Children: yes \_\_\_ How many? \_\_\_\_\_  
no \_\_\_\_\_

Highest level of education completed: \_\_\_\_\_

Method of financing health care:  
Private insurance \_\_\_\_\_  
Medicaid \_\_\_\_\_  
Other \_\_\_\_\_

### Transition history information:

How old were you when you transferred to the adult provider? \_\_\_\_\_

How often are your appointments scheduled with the adult provider? \_\_\_\_\_

Have you missed any of your scheduled adult appointments? \_\_\_\_\_

How many appointments missed? \_\_\_\_\_

Did you reschedule the missed adult appointments? \_\_\_\_\_

Did you keep the rescheduled appointments? \_\_\_\_\_

How many times have you been in the hospital emergency room since transferred to adult provider? \_\_\_\_\_

How many times have you been in the hospital since transferred to adult provider? \_\_\_\_\_



APPENDIX F  
INTERVIEW QUESTIONS

## Interview Questions

1. Tell me about the your transition or transfer from pediatric to adult health care
2. What was your health care like when you were younger?  
How does this compare to your care now?
3. How did you react to the transition or transfer experience?
4. Tell me what you expected from the transition or transfer experience?
5. Tell me what was good about the transition or transfer experience to adult care?
6. What do you remember was the most difficult part of the transition or transfer experience?
7. Tell me what were your concerns about the transition or transfer experience?
8. What would you change about the experience you went through?
9. Is there anything else that you would like to share about your transition or transfer experience to adult health care?

Probes are used throughout the interview such as repeat unusual terms, strong intonations and rephrase for clarification or elaborate further.

APPENDIX G  
VERIFICATION OF ARTICLE SUBMISSION

**A manuscript number has been assigned: JPHC-D-09-00122**

ees.jphc.19a.3a951.45009681@eesmail.elsevier.com

[ees.jphc.19a.3a951.45009681@eesmail.elsevier.com] on behalf of Martha Swartz [martha.swartz@yale.edu]

Sent: Saturday, September 12, 2009 10:48 PM

To: Bryant, Rosalind

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\*\*\*Please note: if you have received this email, and you are an author for a Special Feature article submitted for Departments and Clinical Reports, please ignore this notification, as the Editor is currently uploading your manuscript for final approval. If you are an author for an Original Article, please read below.\*\*\*

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EXPERIENCE OF YOUTH WITH HEMOGLOBINOPATHY

Journal of Pediatric Health Care

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