

---

Electronic Theses and Dissertations, 2004-2019

---

2016

## Perceived readiness to transition to adult health care for youth with cystic fibrosis and congruence with their caregivers' views

Valerie Lapp  
*University of Central Florida*



Part of the [Nursing Commons](#)

Find similar works at: <https://stars.library.ucf.edu/etd>

University of Central Florida Libraries <http://library.ucf.edu>

This Doctoral Dissertation (Open Access) is brought to you for free and open access by STARS. It has been accepted for inclusion in Electronic Theses and Dissertations, 2004-2019 by an authorized administrator of STARS. For more information, please contact [STARS@ucf.edu](mailto:STARS@ucf.edu).

---

### STARS Citation

Lapp, Valerie, "Perceived readiness to transition to adult health care for youth with cystic fibrosis and congruence with their caregivers' views" (2016). *Electronic Theses and Dissertations, 2004-2019*. 4923. <https://stars.library.ucf.edu/etd/4923>

PERCEIVED READINESS TO TRANSITION TO ADULT HEALTH CARE  
FOR YOUTH WITH CYSTIC FIBROSIS AND CONGRUENCE WITH THEIR  
CAREGIVERS' VIEWS

by

VALERIE LAPP

B.S.N. University of Central Florida, 1999

M.S.N. University of Central Florida, 2009

A dissertation submitted in partial fulfillment of the requirements  
for the degree of Doctor of Philosophy  
in the College of Nursing  
at the University of Central Florida  
Orlando, Florida

Spring Term  
2016

Major Professor: Susan Chase

©2016 Valerie Lapp

## ABSTRACT

Youth with cystic fibrosis must gradually assume considerable self-care management skills in order to optimize longevity and quality of life, and healthcare providers and caregivers play a role in youth gradually assuming these skills. The purpose of this study was to determine how youth with cystic fibrosis perceive their self-care management skills required for transition to adult healthcare, the relationship between age and skill acquisition, youth and caregiver congruence on perceived transition readiness, and frequency of transition discussion with provider. In this descriptive, correlational, cross-sectional design, 58 youth ages 14-22 rated their skill ability in managing cystic fibrosis using the Transition Readiness Assessment Questionnaire (TRAQ) during visits to the cystic fibrosis clinic. Using an adapted version of the questionnaire, the TRAQ-C, 52 caregivers also rated youth readiness to transition to determine congruence in self-care management ability. Five simple regressions were calculated to determine age effects for the self-care management skills. Independent t-tests were used to compare mean scores of youth and caregiver perceptions of self-care management skills. Age predicted youth perception of readiness for self-care management skills. Youth scored significantly higher than their caregivers did in perception of self-care skill management. Study findings suggest that preparation for transition to adult care should begin at an earlier age to prepare youth to assume self-care. Including transition discussion with youth and caregiver assessments using questionnaires such as the TRAQ and TRAQ-C may guide learning of skills and timing of transition to adult health care.

*Keywords:* Transition, self-care management skills, TRAQ, youth, adolescent, caregiver, parent, congruence, cystic fibrosis

## ACKNOWLEDGEMENTS

I would like to thank my advisor and committee chairperson Dr. Susan Chase for guidance in the design and completion of this study. I would also like to thank my committee members, Dr. Karen Aroian, Dr. Josie Weiss, Dr. Xin Yan, and Dr. Patricia Robinson for their support and feedback, along with a University of Central Florida dissertation completion Fellowship. Furthermore, I would like to express my gratitude to Chief Nursing Officer Louise Kaigle for her generous flexibility in my work schedule required for execution of this study. I am very appreciative of the physicians, nurse practitioners, nurses, social workers, respiratory therapists, dietary nutritionists, and medical assistants at the four cystic fibrosis clinics whose collaboration was essential in completion of this project. In addition, I would like to acknowledge the youth and their caregivers whose participation in this research made this study possible.

Thank you to my youngest son David, who was the impetus behind my journey through the concept of child autonomy in the health care setting, and to my other children, Barbara, Michael, and Jennifer who have supported me throughout this process. Additionally, thanks to my late mother, who raised me to believe in the nonexistence of the word *cannot*, and to my late father for his bestowed gift of patience and tenacity; the foundation that framed completion of this journey. It is with much joy and appreciation that I dedicate this manuscript to all of you.

## TABLE OF CONTENTS

LIST OF FIGURES .....	ix
LIST OF TABLES .....	x
CHAPTER ONE: INTRODUCTION.....	1
Cystic Fibrosis.....	3
Self-Care Management.....	5
Managing Medications .....	5
Appointment Keeping .....	6
Tracking Health Issues .....	7
Talking With Providers .....	8
Managing Daily Activities .....	8
Transition Readiness, Planning and Policy .....	9
The Stages of Change Model .....	11
Age .....	13
Caregiver Perception .....	14
Research Questions .....	15
Significance of the Problem .....	15
Summary.....	16
CHAPTER TWO: REVIEW OF RELEVANT LITERATURE; THEORETICAL FRAMEWORK.....	18
Literature Review .....	18
Variables Related to Transition Readiness .....	19
Relationship between Readiness to Transition and Age .....	20

Greater Transition Discussion and Involvement in Self-Management .....	23
Youth Uncertainty in Assuming Self-Management .....	25
Caregiver Relinquishing of Control .....	26
TRAQ Development Using Stages of Change Theory .....	28
Stages of Change Model .....	28
Stages of Change.....	31
Precontemplation Stage.....	31
Contemplation Stage .....	31
Determination Stage (or Preparation Stage).....	32
Action Stage .....	32
Maintenance Stage.....	33
Regression .....	33
Processes of Change.....	34
Gaps in Clinical Practice .....	35
<b>CHAPTER THREE: RESEARCH METHODS .....</b>	<b>37</b>
Setting .....	37
Sample .....	38
Inclusion Criteria.....	38
Exclusion Criteria.....	38
Measures .....	39
Demographics.....	39
Transition Readiness Assessment Questionnaire (TRAQ).....	39
Data Collection Procedures.....	43

Data Analysis .....	44
Protection of Human Participants .....	46
CHAPTER FOUR: RESULTS .....	47
Sample Size, Response Rate, and Missing Data .....	47
Demographics .....	47
Mean Scores for TRAQ and TRAQ-C.....	50
Statistical Analysis .....	52
Research Question 1 .....	52
Research Question 2 .....	53
Research Question 3 .....	58
Research Question 4 .....	62
CHAPTER FIVE: DISCUSSION AND CONCLUSION .....	65
Study Findings Extending the Literature .....	66
Recommendations for Future Practice .....	75
Recommendations for Future Research .....	78
Policy.....	79
Limitations of Study.....	80
Self-report.....	80
Sample Size .....	81
Conclusion.....	81
APPENDIX A: TRANSITION READINESS ASSESSMENT QUESTIONNAIRE (TRAQ) ...	83
APPENDIX B: TRANSITION READINESS ASSESSMENT QUESTIONNAIRE-	
CAREGIVER (TRAQ-C).....	86



APPENDIX C: ARNOLD PALMER HOSPITAL FOR CHILDREN IRB APPROVAL LETTER .....	89
APPENDIX D: NEMOURS CHILDREN’S HOSPITAL FLORIDA IRB APPROVAL LETTER .....	92
APPENDIX E: UNIVERSITY OF FLORIDA SHANDS HOSPITAL IRB APPROVAL LETTER.....	95
APPENDIX F: UNIVERSITY OF CENTRAL FLORIDA IRB APPROVAL LETTER.....	98
APPENDIX G: LETTER OF APPROVAL TO USE TRAQ.....	100
APPENDIX H: LETTER OF APPROVAL TO ADAPT TRAQ FOR CAREGIVER USE.....	102
APPENDIX I: ADOLESCENT DEMOGRAPHIC COLLECTION FORM .....	105
APPENDIX J: PARENT/CAREGIVER DEMOGRAPHIC COLLECTION FORM.....	107
APPENDIX K: FLYER TO ADVERTISE STUDY ARNOLD PALMER HOSPITAL, ORLANDO AND SHANDS, GAINESVILLE .....	109
APPENDIX L: FLYER TO ADVERTISE STUDY NEMOURS, ORLANDO AND PENSACOLA .....	111
LIST OF REFERENCES .....	113

## LIST OF FIGURES

Figure 1. The Stages of Change Model .....	12
Figure 2. The Stages of Change Model .....	33
Figure 3. All Youth (n = 58) Participants Rated Stage of Change for Each Subscale.....	53
Figure 4. Youth Age 14-15 Years (n = 19) Rated Perceived Stage of Change .....	55
Figure 5. Youth Age 16-17 Years (n = 24) Rated Perceived Stage of Change .....	55
Figure 6. Youth Age 18-22 Years (n = 15) Rated Perceived Stage of Change .....	56
Figure 7. All Caregivers Rated Perceived Youth Stage of Change for Each Subscale .....	61

## LIST OF TABLES

Table 1. Cronbach's Alpha for TRAQ 5.0 Subscales .....	42
Table 2. Demographic Characteristics of Youth Participants.....	49
Table 3. Demographic Characteristics of Caregiver Participants.....	50
Table 4. Comparison of Youth (TRAQ) and Caregiver (TRAQ-C) Mean Scores .....	51
Table 5. Effects of Age on Stage for Specific Skills .....	58
Table 6. TRAQ 2-tailed Paired t-Test.....	59
Table 7. TRAQ Subscales 2-tailed Independent t-Test .....	60
Table 8. Age of First Transition Discussion .....	63
Table 9. Frequency of Transition Discussion with Provider/Year .....	64

## CHAPTER ONE: INTRODUCTION

Health care transition is an active, purposeful planned process spanning several years. During transition, youth with chronic conditions progress through adolescent-focused health care to adult-focused health care. The American Academy of Pediatrics (AAP) position statement entitled *Age Limits of Pediatrics* defined the scope of pediatrics as beginning with the fetus and continuing through age 21 years (AAP et al., 1988). Special exceptions such as chronic condition and disability, if mutually agreeable to pediatrician, patient, and family could extend pediatrician services beyond the age of 21 years. The term transfer is used to describe the actual shift to adult health care, whereas, the term transition is used to define the process occurring prior to and after transfer (Kennedy & Sawyer, 2008).

Healthy youth transfer from their pediatric health care provider to an adult health care provider usually in one single event. Typically, youth visit their pediatric health care provider once a year for a well check-up and transfer to an adult health care provider when reaching their eighteenth birthday. However, the situation differs considerably with youth with chronic conditions.

Youth with chronic conditions, such as cystic fibrosis (CF) may see the pediatric pulmonologist up to six times a year (Reiss, Gibson, & Walker, 2005; Zack et al., 2003). The pediatric pulmonologist may have cared for the child since birth and oftentimes becomes the main pediatric health care provider, thus contributing to a strong bond between youth, caregivers and pediatric pulmonologists (Binks, Barden, Burke, & Young, 2007; Bryant, Young, Cesario, & Binder, 2011; McCurdy et al., 2006; Peter, Forke, Ginsburg, & Schwarz, 2009; Reiss, et al., 2005; Tuchman, Slap, & Britto, 2008). This bond may inadvertently delay transition from

pediatric to adult health care. Furthermore, over protectiveness from caregiver may keep youth in a dependent sick role.

Youth with CF transfer to adult health care later than youth with other chronic illnesses. In a study describing age limits in 116 pediatric emergency departments in the United States, youth with CF were found to exceed age-limit policies more than other diagnoses (Dobson, Bryce, Glaeser, & Losek, 2007). It is unknown whether late transfer is related to inability to self-manage CF care. Transferring at a late age may send a message to the youth that he or she is different from his or her peers without a chronic condition, which are feelings most patients with CF strive to avoid (Flume, Anderson, Hardy, & Gray, 2001).

Recommendations for transition from the US Department of Health (2011) include an algorithm attaching specific ages for preparing youth for the transition process. Although an algorithm may be convenient for clinicians, youth differ in their development toward adulthood and may vary considerably in their ability to complete self-care activities. An unplanned transfer without adequate preparation for transition leaves youth unprepared for success with self-care and may result in a traumatic experience for youth. Determining the relationship between age and the various self-care activities will guide clinicians in knowing where and when to intervene to promote optimal timing for assumption of self-care, and move understanding of this field forward.

Successful transition encompasses uninterrupted health care requiring an increase in independent behavior and assumption of autonomy. Independent behavior entails the acquisition of skills in self-care, health care decision-making, and self-advocacy. Transition readiness reflects the stage at which the youth is ready to adopt the self-care management skills necessary for assuming responsibility for adult independent care while at the same time their caregiver

relinquishes control. All youth transitioning to adult health care require these self-management skills in order to maximize health. In particular, youth with CF require multiple skills in self-management of their illness in order to successfully transition to adult health care. Acquisition of these skills requires frequent discussion and planning. However, findings from The National Survey of Children with Special Health Care Needs portrayed youth affected with more severe conditions as no more likely to have received transition planning than youth with less harmful conditions (Lotstein, McPherson, Strickland, & Newacheck, 2005).

Discussions in this chapter include the specific illness and challenges for youth with CF, self-care management skills, guidelines of transition, planning, policy, and a brief introduction to the model guiding the study. Further discussion explores significance of age relating to transition readiness, and caregiver perceptions relating to youth self-care management. Research questions and significance of the study will conclude discussion in this chapter.

### Cystic Fibrosis

CF is the second most common inherited disorder in the United States following sickle cell disease (American Lung Association, 2010). CF affects 30,000 people in the United States, occurring in one in 3,400 births, with approximately 1,000 new diagnoses per year (American Lung Association, 2010). Because of differing gene mutations, birth prevalence varies with race and ethnicity. Based on newborn screening, which is now mandatory in every state, birth prevalence among non-Hispanic whites is 1 in 2,500 - 3,500 births, among Hispanics 1 in 4,000 - 10,000 births, and among non-Hispanic blacks 1 in 15,000 - 20,000 births (American Lung Association, 2010). Although CF occurs across all races and ethnicities, it is most common in

Caucasians of Northern European ancestry with one in 29 whites carrying the autosomal recessive genetic disorder (American Lung Association, 2010).

When CF was first recognized, children died in infancy, but with improved care the predicted median age of survival today is in the early 40s (Cystic Fibrosis Foundation, 2014). The increase in the number of youth with CF surviving beyond childhood is likely a result of detection of the diagnosis earlier in childhood, advances in medical treatments, antibiotics, improvements in nutrition, and aggressive chest physical therapy, along with improved health service systems (Lotstein, et al., 2005; Viner, 2001).

Due to increasing longevity of patients with CF, there is increasing need to study how this population transitions from youth into adulthood. At present, there is no cure for CF and daily burden for maintenance requires life-long self-care management that includes completing a daily therapeutic regimen. Daily tasks include chest physical therapy, inhalation therapy, antibiotic therapy, ingestion of pancreatic enzymes, vitamins and minerals, and possible insulin injections. In childhood, caregivers complete this daily regimen but youth must gradually assume responsibility as they mature into adulthood.

Besides the medical treatment burden incurred with a diagnosis of CF, there is a huge psychological burden. At a developmental time in the lives of youth when it is critical to be like peers, youth with CF are set apart from their peers by their physical appearances (i.e., barrel chest, clubbing of nails, and short stature), chronic 'CF' cough, diminished physical endurance and treatment regimens (Christian & D'Auria, 1997). Given the enormity of complications and daily burden of CF, which begin in childhood, subsequent self-care management of this chronic illness for lifelong care requires extensive evaluation for transition readiness from youth into adulthood.

### Self-Care Management

Health care transition for youth with CF consists of three-interrelated processes. Transitions encompass the transition of *daily care* for their diagnosis from caregiver to self, and as youth take on more responsibility, their caregiver transitions by *relinquishing care* and letting go. The final step involves the *actual movement* from pediatric health care to adult health care. Readiness to transition from the caregiver perspective may differ from the perspective of youth. Youth in transition may not be prepared to assume all requisite self-management skills, and according to developmental stage, some skills may require longer to attain. Youth will ultimately be responsible for self-care management of their health once they reach adulthood. This responsibility includes increasing their self-care management skills in managing medications, appointment keeping, tracking health issues, talking with providers, and managing daily activities.

### Managing Medications

Managing medications entails taking medications correctly, reordering before they run out, filling of prescriptions, and determining what to do if experiencing an untoward reaction to a medication. Knowledge about medications was considered the most important step in transition by youth in a study with recipients of liver transplants (Fredericks et al., 2011). Previous researchers have found that medication adherence in CF is approximately 50% (Eakin & Riekert, 2013). Furthermore, medication adherence has been demonstrated to decline in youth (Zindani, Streetman, Streetman, & Nasr, 2006), with the lowest adherence occurring in young adulthood (Eakin, Bilderback, Boyle, Mogayzel, & Riekert, 2011). Poor adherence to medication therapy



is associated with an increased number of pulmonary exacerbations requiring intravenous antibiotics, and lower baseline lung function (Eakin et al., 2011).

Medication adherence also includes accepting the chronic illness rather than hiding it. One of the most visible aspects of CF - the taking of multiple medications throughout the day and at every meal, may incur visits to the school nurse, which youth may consequently conceal. This can lead to medication nonadherence (Lindsay, Kingsnorth, & Hamdani, 2011). A main characterization of patients living with CF is a desire to keep up as normal a life as possible, in a phenomenon often called normalization (Badlan, 2006; Gjengedal, Rustøen, Wahl, & Hanestad, 2003; Jedeloo, van Staa, Latour, & van Exel, 2010; Knafl & Deatrck, 1986). Therefore, during the transition-planning period towards adult health care, when the responsibility shifts from caregiver to youth, investigation of adherence to medication becomes important for potential intervention.

### Appointment Keeping

Increasing responsibility is required when moving from family-centered care, in which the family is central to the child's life. The expectation in a patient-centered adult care model is for the patient to assume responsibility. Taking responsibility for healthcare appointments is a major skill youth must acquire for a successful transfer given the differences between expectations of pediatric and adult self-care for appointment keeping.

Appointment keeping in youth is often poor. Failure to keep follow-up appointments in a study with chronically ill youth with sickle cell and thalassemia resulted in visits to the emergency department for emergent health care (Bryant et al., 2011). Youth reported in a study by McCurdy et al., (2006) the need to take responsibility and be proactive in setting up and

keeping appointments. Youth described that as they aged, caregivers were no longer responsible for arranging and keeping appointments, and in contrast to their pediatric practice, most adult health care teams did not send reminders. High no-show rates elicited comments by health care providers in the Netherlands who noted that chronically ill youth tended to be ‘pampered’ and ‘somewhat spoilt’ with everything arranged for them, and that patients “fall into a deep hole when they have to do things for themselves” (van Staa, Jedeloo, van Meeteren, & Latour, 2011a, p.826).

### Tracking Health Issues

Tracking health issues includes completion of the medical history form, and knowledge of allergies. When youth finally complete transition and transfer to adult health care, the initial visit often incurs a new baseline medical history assessment (Reiss et al., 2005). Usually, the adult health care physician will examine the youth privately but youth may not be able to provide their medical history. Typically, in the past caregivers completed prior clinic paperwork, circumventing the need for the youth to have knowledge of self and family medical history. Allergies to medication may have presented early in childhood and likewise youth may be unaware. Oftentimes, requests for updated histories and allergies occur during the first yearly visit, or when relocating to a different practice. Furthermore, ability to recall medical information is of great importance during emergent care. Accurate recall and ability to complete patient registration and medical forms describing medical history, family medical history, and knowledge of medication allergies is of great importance during visits to clinic and hospital.

## Talking With Providers

Youth must gradually assume the role of talking with providers alone, which includes describing how they feel, along with the ability to answer questions posed by the health care team. Authors found in a qualitative study of pediatric practitioners that greater parental involvement inhibited successful transition; that caregivers “wouldn’t let go” and would keep their child “in the sick role” (Huang et al., 2011, p. 998e2). Providers recommended reducing the role of the caregiver during clinical visits with suggestions to separate the dyad or not allow the caregiver to talk. Furthermore, adult health care providers believed that youth transitioning needed to be encouraged to stand alone from their caregiver as adult practitioners were not used to including a third party in clinical visits (van Staa et al., 2011a)

## Managing Daily Activities

Daily activities, such as the independent living skills of planning and preparing meals, maintaining a clean house, and using neighborhood stores for groceries and pharmaceuticals are described as critical developmental tasks required in the transition to adulthood (Arnett, 2000). Competence, and likely successful transition to adult independent self-care for youth with chronic illness, is presupposed in youth who complete home-based chores and responsibilities (Blum, 1995; Reed-Knight, Blount, & Gilleland, 2014). Furthermore, internalization of skill in independent living has been associated with greater mastery of skills related to self-care management among people with chronic illness (Ryan & Deci, 2000; Williams et al., 2011).

The gradual acquisition of self-care management skills necessary for independent adult living with CF includes the aforementioned managing of medications, appointment keeping,

tracking of health issues, talking with providers, and managing daily activities. Acquisition of these skills is a gradual process spanning several years in preparation for transition to adult health care.

### Transition Readiness, Planning and Policy

Surviving into adulthood is relatively new for youth with CF. Thus; the need to study how they transition successfully has become an important focus of policy. According to the latest guidance in a clinical report by The American Academy of Pediatrics (AAP, 2011), for transition planning to succeed, both the physician and the caregiver “must view the youth as the driver in the process [of transition] to assume increasing responsibility for his or her own health care to the fullest extent possible” (AAP, 2011, p. 188). In order to become the driver in the transition process, youth need to feel empowered through participation in the process. They are more likely to adhere to self-care management if they feel they participate in decision-making regarding their own care (Lubkin & Larson, 1998).

Although self-care management skills are required for all youth transitioning to adult care, youth with chronic illness such as CF must maintain therapy for lifetime. Therefore, it is essential for these youth to adopt self-care management skills in order to increase longevity and sustain life. The gradual process of transition readiness should begin with provider, youth, and caregiver discussion planning for transition.

Many consensus statements and policy papers of professional organizations in recent years have suggested guidelines to frame the transition process. However, in clinical practice application of these policy statements and guidelines consistently fall short of goals. Healthy People 2020 (Barriers to Health Care, DH-5) increased the 2010 goal of 41.2 % to 45.3% of youth with special needs that had a health care provider who discussed transition planning.

However, youth with chronic conditions in Florida appear to fall short of this Healthy People goal, particularly for low-income families. Findings from a telephone survey in 2006 administered to 376 youth with chronic conditions aged 15-18 years, who were recipients of Medicaid in Florida's Children's Medical Services Network (CMS), found discussion planning rates with their physician, nurse, or parent at 33.8%, lower than the nationwide goal set by Healthy People for 2010 (Knapp, Huang, Hinojosa, Baker & Sloyer, 2013).

Other attempts to improve transition for youth with chronic conditions have included a general agreement statement from AAP, The American Academy of Family Physicians, and The American College of Physicians-American Society of Internal Medicine. In 2002, this group formed a consensus statement calling for a written health care transition plan created by age 14 and updated yearly, in order to ensure a successful transition from pediatric health care to adult-oriented health care. However, in actual practice only half of all 195 Cystic Fibrosis Care Centers (CFCC) in the US (87% response rate) consistently assess transition readiness with less than 10% of all responses observing a written list of desirable self-management skills (McLaughlin et al., 2008). Furthermore, McLaughlin et al., found that in the CFCC, where 85% percent of individuals with CF receive care, the median age for transition for patients with CF occurred at age 19 (range 14-30 years). Initial discussion of transition did not occur until a median age of 17 years leaving only two years to complete the transition process (McLaughlin et al., 2008).

In recent literature, the AAP developed a health care transition-planning algorithm incorporating action steps for specific age ranges for youth with special health care needs (AAP et al., 2011). According to the authors, this algorithm is based on expert opinion and general agreement recommendations rather than science. The initial first step in the health care

transition planning process recommended in the algorithm was an introduction to transition discussion by the age of 12, with some families, especially those with special needs, benefiting from starting this process earlier. According to the AAP, discussions should be individualized, with the beginning discussion determined by age, although timing for some may require modification based on stage of cognitive and social development (AAP et al., 2011). Further action steps in the algorithm include delineation of youth/caregiver responsibilities, and initiation of a formal transition plan incorporating a readiness-assessment tool. This readiness tool may reveal areas for improvement with education and future goals reviewed and updated on at least a yearly basis. These assessments would then accompany youth when they transition to an adult provider in order to portray any deficiencies they may have which require further guidance.

Policy suggestions for beginning transition include discussion between youth, parent, and healthcare provider, followed by a written plan. Transition is a process, which occurs over time, with some youth requiring more time than others to complete some areas of self-care management. This gradual acquisition of new skills requires changes in behavior. While some youth may excel in some areas, other areas of their stage of readiness may require a longer time to adopt. One appropriate way to study youth with CF transitioning to adult health care is through the Stages of Change Model (Prochaska & DiClemente, 1986).

### The Stages of Change Model

Because youth with CF must assume self-care management skills in order to care for their health, the Stages of Change Model, otherwise known as the Transtheoretical Model of Behavior Change (Prochaska & DiClemente, 1986), is well suited to study the stage at which they are ready to change behavior and assume care (see Figure 1). The stages of change begin with the

precontemplation stage when no consideration of adopting the behavior has been deliberated and continues through contemplation or awareness of change required, followed by the determination stage when learning to adopt the change occurs. The action stage designates acquisition of skill management and the final stage of maintenance concludes stabilization of the skill behavior.

Relapse may occur at any stage where the individual may revert to a previous stage.

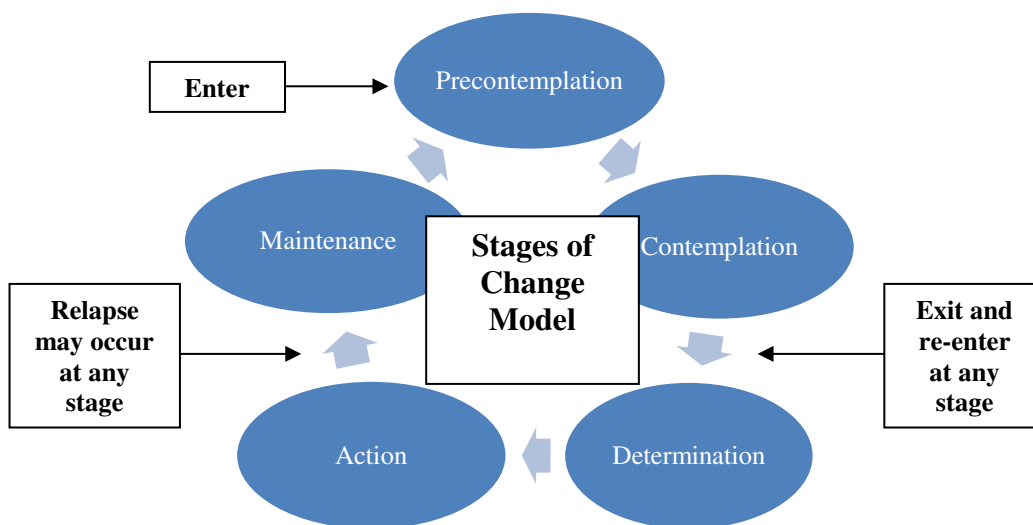


Figure 1. The Stages of Change Model

Application of the Stages of Change Model serves as a useful approach for studying the process of transition to self-care management in CF. Each area of self-care management is a separate path. Some self-care requisites might have reached the maintenance stage, whereas others may still be in contemplation. Youth just attaining their 14<sup>th</sup> birthday may be able to perform some skills alone and no longer rely on their caregiver. On the other hand, at the same age some skills may elude them and require gradual assumption of responsibility. Furthermore,

independence in self-care management is probably not driven by age, and may depend on individual developmental ability. By studying self-care management through the Stages of Change Model, stage of readiness to perform a range of self-care activities will determine if age is the best criterion and how age as a criterion might differ according to type of self-care activity.

### Age

The US Department of Health and Human Services' (USDHHS) Maternal and Child Health Bureau (2011), recommends use of a standardized transition assessment tool completed by youth starting at age 14 to assess and reassess their ability to successfully transition to adult health care. According to the USDHHS the standardized tool should address knowledge and skills to include "health condition(s), symptoms requiring quick medical attention, what to do in case of medical emergency, making appointments, and refilling medications." Furthermore, the transition planning is broken into age specific steps. By ages 12 and 13, the Department of Health issued guidelines to begin the health care transition process by informing youth and their caregiver about the practice's policy for eventual transfer to an adult doctor.

Distinguishing between chronological age and level of maturity may require further assessment from clinicians to determine a timeline for beginning self-care management and successful transition to adult health care. During the course of development, the child at the age of seven to 11 views the world with a concrete logical sequence and is able to make reasoning-based decisions tied to experience. Cognitive and affective developmental theorist Piaget attributed that children move through the stage of concrete operations into the stage of formal operations around the age of 11 or 12 (Wadsworth, 2004). As the child moves into adolescence, formal operations reasoning using hypothetical problems evolve. Development through these



stages of operation is not automatic. Half of adults do not fully develop formal operational reasoning (Wadsworth, 2004). Logic is also heavily influenced by culture (Berk, 2010). Given differing developmental maturity in youth and the influence exerted by caregivers, it is important to assess transition readiness through both youth and caregiver perception.

### Caregiver Perception

Caregivers' transfer of youth daily health care management must occur with clear understanding for youth to assume self-care. Previous researchers have found that youth with chronic conditions are often overprotected and unsure of their role in health self-management (Brunfield & Lansbury, 2004). Both youth and their caregiver may perceive different accountability for individual tasks. Therefore, it is important to determine the delineation of responsibilities from both the caregiver and the youth's perspective. In order to achieve a successful transition to adult health care, congruence in skill acquisition is important so that caregivers feel able to relinquish control of youth health care management.

According to some experts, transition should begin to occur near the time of diagnosis, with consensus that starting the process in adolescence is too late (Binks, et al., 2007; Reiss & Gibson, 2002; Watson, 2005). Since the discovery of the diagnosis of CF occurs during infancy or early childhood, the caregiver has carried out the management of their child's medical care. The gradual assumption of self-care management required for managing CF, transitions from caregiver to youth occurs as youth gain more maturity and responsibility for their health.

Studies of youth with CF and caregiver congruence of skill management incorporating use of a valid and reliable assessment tool, have not previously been published. When comparing youth (age 12-21) and caregiver perceptions of responsibility in recipients of liver

transplants, youth determined that they had responsibility for medication taking. However, there were significant differences between youth and caregiver reports in allocation of responsibility for other self-care management activities, such as calling in prescription refills, scheduling appointments and lab draws, and calling the doctor or nurse with questions (Fredericks et al., 2011).

### Research Questions

1. What stage of change of transition readiness related to self-care activities of managing medications, appointment keeping, tracking health issues, talking with providers, and managing daily activities do youth with cystic fibrosis report?
2. Is level of transition readiness in youth with cystic fibrosis related to age for each of the various self-care activities (managing medications, appointment keeping, tracking health issues, talking with providers, and managing daily activities)?
3. How congruent are youth with cystic fibrosis and caregivers in reporting perceptions of level of transition readiness related to managing medications, appointment keeping, tracking health issues, talking with providers and managing daily activities?
4. How congruent are youth with cystic fibrosis and caregivers in reporting transition discussions with provider? (4a) At what age do youth with cystic fibrosis and caregivers report discussions with provider? (4b) How often do youth with cystic fibrosis and caregiver report discussions with provider?

### Significance of the Problem

In 2002, members of the American Academy of Pediatrics, the American Academy of Family Physicians and the American College of Physicians-American Society of Internal

Medicine, recommended a written transition plan initiated by the age of 14 for youth with chronic illness. Policy statements call for a baseline transition readiness assessment at ages 14-15 (USDHHS, 2011). However, recent literature portrays that the majority of youth with chronic illness appear to have *no* plan in place, and few recall a transition discussion (Knapp et al., 2013; McLaughlin et al., 2008). The national rate reported for transition discussion is 41% (Knapp et al., 2013), with a Healthy People 2020 goal of 41.2%. However, for youth in Florida receiving Medicaid through CMS, the rate is 33.8% (Knapp et al., 2013). In addition, youth with more severe conditions do not discuss transition planning any more than youth with less severe conditions do (Lotstein et al., 2005). The diagnosis of CF, which may incur severe conditions, is the oldest diagnostic group to seek care in pediatric emergency departments, more than any other chronic condition (Dobson, et al., 2007). Moreover, half of all CFCC programs assess transition readiness at a median age of seventeen with less than 10% reporting a written list of desirable self-management skills (McLaughlin et al., 2008). Given these recommendations and contradictory clinical findings, conducting research to understand readiness to transition to adult health care in youth with CF, incorporating age and caregiver congruence, using a standardized validated assessment tool is necessary.

### Summary

Findings from this study will be shared in the literature to support improved practice wherever youth with CF receive care. The researcher will determine how youth with CF perceive their self-care management skills required for transition to adult health care and predict the relationship between age and skill acquisition. Further analyses will determine youth and caregiver congruence on perceived transition readiness, and frequency of transition discussion

with provider. Stage of change readiness and transition discussion with provider, as perceived by youth and their caregiver may reveal areas lacking congruence and guide providers in appropriate interventions for successful transition care.

## **CHAPTER TWO: REVIEW OF RELEVANT LITERATURE; THEORETICAL FRAMEWORK**

Discussions in this chapter focus on the background to the proposed study. A review and evaluation of the literature pertinent to youth perception of transition readiness will be examined. Concepts investigated include the variables related to youth transition readiness. The relationships between readiness to transition and age, perceived barriers to transition including the need for greater transition discussion and involvement in the process, youth uncertainty in assuming self-management, and caregiver reluctance to relinquish control are discussed. Examination of the measure used in this study, The Stages of Change Model guiding this study, and gaps in clinical practice will complete this chapter.

### Literature Review

Although articles written by researchers studying transition to adult health care are in abundance, findings from their studies center on transition readiness through the perception of the caregiver or physician. Little research has been conducted determining transition readiness from the perspective of youth.

A systematic review of findings in the literature that explored how youth with CF perceived their readiness to transition to adult health care was conducted using the search terms adolesc\* or youth or “young adult” AND transition AND “chronic illness” or “chronic condition,” using OneSearch which is composed of multiple databases. This comprehensive search included the limiters of scholarly journals/peer reviewed published in the years of 2003 through 2014. The review spanned twelve years on the basis that the AAP position statement

encouraging a written transition plan for youth appeared in the literature in December 2002.

Following elimination of duplicates, the search yielded 321 articles.

Next, titles and abstracts were scanned for relevancy and articles obtained for further investigation. Empirical studies retained included youth with somatic illnesses, were written in English, and emphasized youth perception of readiness to transition to adult health care prior to the actual transfer event (instead of caregiver and healthcare providers' perceptions). A final 17 studies met these criteria. The reference lists of the 17 articles acquired were searched manually for retrieval of nine further relevant articles. Youth interviewed or surveyed ranged from 12 to 25 years of age. CF was the most commonly studied chronic condition followed by sickle cell disease and other blood disorders, diabetes mellitus, asthma, HIV, congenital heart disorders, epilepsy, inflammatory bowel disease, spina bifida, renal failure, liver transplant, thyroid disease, neuromuscular disorder, cancer, juvenile rheumatoid arthritis, and other chronic somatic conditions. The majority of the studies were conducted in the USA. Researchers in other countries' exploration of youth readiness to transition to adult health care included studies from Canada, Ireland, The United Kingdom, The Netherlands, Sweden, Australia, and Hong Kong. Research articles from several countries were considered to determine if youth perception of readiness transition to adult health care transcended differing healthcare structures.

#### Variables Related to Transition Readiness

Transition readiness has been examined by studying its relationship with age, and themes of perceived facilitators and perceived barriers to transition. Facilitators to transition include greater discussion from care providers related to transition and youth involvement in the process.

Barriers from the perspective of youth included uncertainty of when self-care begins as well as caregiver reluctance to relinquish control.

#### Relationship between Readiness to Transition and Age

The timing of transition to self-care has been studied in several different chronic conditions. Using a transition survey distributed by mail or in person at a sickle cell disease clinic in the United States, 240 youth aged 14 through 20 years were asked about their knowledge of the steps in transition of care, prior thought about transition, interest in learning more about transition, and anticipated difficulty about the process (McPherson, Thaniel, & Minniti, 2009). Seventeen to 20 year-olds demonstrated greater knowledge, thought, and interest in transition and decreased anticipated difficulty in transition than 14 to 16-year-olds. Increasing age was found to predict transition readiness. However, it is difficult to appraise these results as the response rate was poor, with 66 surveys completed in the hospital setting and only six surveys returned by mail. In contrast, in a Dutch study, youth aged 12 through 19 years of age with chronic conditions completed a web-based questionnaire that assessed their perception of readiness to transition through questions asking about self-efficacy in coping with the condition, knowledge of the condition, and skills for independent hospital visits (van Staa, van der Stege, Jedeloo, Moll, & Hilberink, 2011b). Once again, the response rate of 30% was low and there was no indication of how the tool was developed. These researchers determined that although higher transition readiness was associated with older age, other variables such as greater self-efficacy were of more importance.

Many youth with chronic conditions linked transition to adult health care services to a life event such as turning twenty-one when they believed that they faced ‘deadlines’ (Tuchman et al.,

2008). In the United States, Tuchman and colleagues examined expectations and concerns regarding transition to adult health care during semi-structured individual interviews with 22 youth with chronic conditions. Most of the youth, ages 15-21 years, identified negative feelings, being unprepared, and feeling forced to transition. Suggestions for improvement from the youths' perspective included beginning the transition process at an earlier age of 15 or 16.

Age was not a determining factor in a study conducted in Hong Kong with 137 youth ages 16 through 19 years (Wong et al., 2010). This sample included youth with chronic conditions including asthma, diabetes, epilepsy, and thyroid disorders. Patients completed a transition questionnaire at outpatient clinics. The authors developed the questionnaire, based on a review of four previous studies because no validated questionnaire on transition existed. Psychometric analysis was not performed. Attitude to transition was very positive with 85% of the youth expecting to transition when reaching adult age. Detailed explanations by doctors were the major facilitating factor that helped youth accept transition care. Not wanting to change was the only significant barrier that both youth and caregivers determined would stop consideration of transition care. The majority of youth considered age of adulthood to be 18 years. Perhaps because these chronic illnesses are generally not as debilitating and life limiting as others, transition is accepted. Furthermore, cultural expectations may differ across countries.

Using a 24-item questionnaire developed and validated in Canada, 36 youth with CF answered questions regarding their disease knowledge, management, medication knowledge and compliance behavior (Capelli, McDonald, & McGrath, 1989). Use of experts in development of the questionnaire provided construct validity; however, this did not include youth input. The questionnaire consisted mostly of disease knowledge questions in multiple-choice format, with compliance behavioral questions in yes/no response option. A scoring protocol allocated points



for correct responses or responses indicating readiness to assume behavior necessary to transition. Each participant was rated by his or her caregiver on a Likert-type scale of whether they would or would not be able to successfully cope with transfer to an adult CF clinic. The caregiver independently rated them without knowledge of youth responses to the questionnaire. Seventy-eight percent of caregiver and youth scores agreed about transition readiness. Congruence with higher scores obtained and caregiver perception of youth readiness to transition better predicted transfer success rather than age.

In a further study conducted in Canada, the researchers determined that the association between age and medical self-management skills was minimal. In this preliminary study, Williams and colleagues (2011) developed a self-management skills assessment guide that was administered to 49 youth ages 11 through 18, from neurology clinics and youth transition clinics. Subspecialties included chronic illnesses from cardiology, gastroenterology, chronic pain, and rheumatology clinics. Caregivers completed the same guide. Youth mean scores for medical self-management skills were higher than caregiver mean scores. There was little discussion of measurement development and no further exploration of validity or reliability studies.

In a few studies, but not all, researchers found correlations between transition readiness and increasing age. However, studies varied by disease category with health conditions ranging from acute to chronic along with variance in geographical location. Furthermore, inconsistencies in methods, a lack of psychometrics for instruments utilized, and differing questions posed, make it difficult to compare the relationship between transition readiness and age across studies and hinders analysis (van Staa et al., 2011b; Wong et al., 2010; McPherson et al., 2009; Capelli et al., 1989).

## Greater Transition Discussion and Involvement in Self-Management

Few researchers have explored youth and their perception of readiness to transition prior to the actual event. The majority have explored the phenomenon through the eyes of the caregiver, the health care provider or from the youth's retrospective standpoint following the completion of transfer.

In studies considering youth perceptions, youth who felt able to transition, were involved with the transition planning and took part in more discussions related to future transition (Karlsson, Arman, & Wikblad, 2008; Kirk, 2008; Soanes & Timmons, 2004; van Staa et al., 2011b). Further findings of transition readiness included youth possessing individual self-reliance, a perception of responsibility, and a level of self-efficacy in managing self-care (van Staa et al., 2011b; Wong et al., 2010).

In a Dutch study, youth ( $n = 964$ ) aged 12-19 years, participated in a web-based questionnaire which assessed their personal views of self-management competencies required for transition readiness (van Staa et al., 2011b). Facilitators to transition readiness included a more positive attitude towards transition and greater discussion related to transition. This study was one of a few studies in which researchers investigated transition readiness to align with a conceptual model. Bandura's self-efficacy theory framed the belief in confidence questions. The authors developed the unnamed web-based questionnaire with no reported follow-up. Questions were developed from a literature review and analysis from previous interviews with chronically ill youth, along with pilot tests of the questionnaire with five youth and four caregivers. Greater readiness to transition was found with perceived independence during consultations. Youth described independence during consultations as actively participating in treatment decisions and conversing with physicians on their own. Likewise, as no published,

validated questionnaire on transition for chronically ill youth was found, Wong et al. (2010) developed their own questionnaire based on reviews of previous studies, discussion with pediatric and adult providers, and youth who were patients. The questionnaire was fielded to 137 youth with chronic conditions in Hong Kong. Findings from this instrument, demonstrated that perception of personal responsibility towards chronic condition was positively associated with transition readiness (Wong et al, 2010).

The importance in discussing transition planning was described in several other studies. In-depth interviews in the homes of youth in England focused on the experience of transitioning to adult health care in addition to the experience of transferring responsibility from caregiver to self-care. Both caregiver and youth expressed concerns because of a lack of involvement in the transition planning when moving to adult health care (Kirk, 2008). Although discussion had occurred, formalized transition planning was absent. Youth described three inter-related transition processes (1) the abrupt ending to pediatric health care and expectations of assumed self-management from clinicians in adult health care (2) gradual acquisition of self-management skills in health care and assuming independence from caregiver and (3) caregiver relinquishing care. This transition of self-management health care skills encompassing unclear planning was expressed with comments made by a fifteen-year-old in a phenomenological study in Sweden of lived experiences of transition towards autonomy in self-management of type 1 diabetes

Karlsson, et al., (2008) noted the following:

In the beginning when I got diabetes it was mostly Mum and Dad who got the information . . . I was too small then . . . and then I was supposed to start taking care of everything myself . . . now I'm almost completely responsible for my own diabetes . . . but then it feels like I haven't had the time to get the information my parents got (p. 566)

In another qualitative study in England, researchers studied the attitudes of youth with chronic conditions who faced transition. Participants aged 14 through 17 during semi-structured interviews described that transition should be flexible, individualized, and not dependent on age. Youth detailed the need for a gradual process; with time to build self-care management skills and the degree of preparation and readiness should be the determining factor for transition (Soanes & Timmons, 2004). The prominent theme in these studies, which transcend geographical locations, is youth need for greater involvement, preparation for successful transition, and clear guidelines of care assumption of responsibility.

#### Youth Uncertainty in Assuming Self-Management

Findings from the literature review demonstrated that many youth are resistant to transition to adult health care. Barriers identified in qualitative studies include uncertainty of assumption of self-management skills and unwillingness of caregiver to relinquish control and welcome youth autonomy. The majority of youth voiced resistance to transition to adult care with few welcoming the autonomy that adult health care brings. Perhaps youth find the challenge of accepting the move to adult health care and the ownership of health care responsibility overwhelming (Knauth, Verstaphehn, Reiss, & Webb, 2006).

Several studies reflect youth uncertainty about when autonomous care begins. Youth characterize this as they hover between self-care and reliance on caregivers. Several youth with diabetes, when interviewed in a phenomenological study in Sweden, felt a sense of relief when responsibility for self-management of medical care became too burdensome and could be transferred back to their caregiver (Karlsson et al., 2008). In a qualitative synthesis of findings from 34 empirical studies conducted in The United States, The United Kingdom, Canada, and

The Netherlands examining barriers and facilitators of self-management among youth with chronic illnesses, authors found that one of the main barriers for youth in assuming self-care was shared management with caregivers (Lindsay et al., 2011). Findings included how and when youth take ownership for their condition, which encompassed inappropriate delegation by caregiver, hovering between self and shared responsibility, willingness to assume responsibility, and differing perceptions of responsibility between youth and caregiver. This oscillating back and forth with few clear guidelines for responsibility opens uncertainty about independency and could be addressed during transition preparations during bi-annual health care visits.

#### Caregiver Relinquishing of Control

Over protectiveness from caregivers may contribute to encouraging youth to disengage from the transition process (Anthony et al., 2009). Excessive assistance, over vigilance, coupled with nagging and constant reminders contribute to over-protection (Bregnballe, Schiotz, & Lomborg, 2011; Michaud, Suris, & Viner, 2007). The caregiver often knows the youth's history better than the youth and becomes hesitant to begin the process of transition or relinquish control of decision-making once the topic of transition to adult care is discussed. If caregivers feel excluded from all decision-making in the new setting, it is possible they will "sabotage transition" (Viner, 2001, p. 2). Furthermore, caregivers may be reluctant to relinquish control of daily access of their youth's medical records and treatment plans (Wiener, Battles, Ryder, & Zobel, 2007).

During semi-structured interviews conducted in The United States, discussion about expectations towards transition took place with 22 youth aged 15-21 years with CF, sickle cell disease, juvenile rheumatoid arthritis and inflammatory bowel disease. Youth mostly felt

unprepared to transition and identified negative expectations. Caregiver reluctance to accept role change was depicted in this youth's comment "My mom doesn't want to let go. She has flat out told me, 'You put 18 years into your child's health and it becomes your health too'" (Tuchman et al., 2008, p. 560). This caregiver attitude may inadvertently suggest that transition to adult health care is unwelcome by the caregiver, giving the youth a sense that they are taking on an unsupported chapter in their lives. Resistance by the caregiver is likely filtered down to youth and may leave youth with mixed messages regarding their transition (Knauth, et al., 2006). This unclear communication may encourage ambivalence and withdrawal from the transition process.

Some youth, on the other hand, expressed a desire to become independent. During focus group interviewing with youth age 18-25 following transition to adult health care, one participant wished for caregiver withdrawal "I preferred going on my own . . . It forced me to take more of an active role in caring for myself. I would have appreciated maybe not her (my mother) leaving, but just maybe like backing down a little bit and like letting me like (answer my own questions a little more) . . ." (Huang et al., 2011, p. 998e1). Youth experience with caregiver over-vigilance or support requires individualized management during the transition process.

In qualitative studies of readiness to transition, researchers have addressed questions about concerns or problems related to the transition process. This type of research has elicited the aforementioned barriers including uncertainty of care assumption, and caregiver over involvement. Discerning the barriers to adult care transition youth perceive, does not necessarily determine their readiness to transition. A structured transition readiness assessment tool examining the self-care management perceptions of youth and caregiver may aid in determining transition readiness.

### TRAQ Development Using Stages of Change Theory

As previously described, there is a paucity of validated measures available with which to study the readiness of youth with chronic health conditions to transition to adult health care. Furthermore, few transition readiness studies have been developed based on theory. One exception is the development and on-going validation of the *Transition Readiness Assessment Questionnaire 4.1* (TRAQ) in which Sawicki and colleagues (2011) used the Stages of Change theory (Prochaska & DiClemente, 1986) to frame development of this questionnaire.

The aim of the researchers in the Sawicki et al. (2011) study was to develop and validate the *Transition Readiness Assessment Questionnaire 4.1* (TRAQ) as a measure of transition readiness from pediatric to adult health care of youth with chronic illness. Following reassessment of the TRAQ's item performance and factor structure by Wood et al., (2014), the development of the TRAQ 5.0 was endorsed by the authors (Appendices A & G). Participant responses to the twenty questions on the TRAQ 5.0 included answers organized into a 5-point ordinal response scale correlating to the Stages of Change Model by Prochaska and DiClemente (1986). Choice options for perceived stage of change include “No, I do not know how” [to perform this skill level important for transition to adult health care], “No, but I want to learn”, “No, I am learning to do this”, “Yes, I started doing this” and “Yes, I always do this when I need to.” An example question is “do you know what to do if you are having a bad reaction to your medications?” (Wood et al., 2014; Appendix A).

### Stages of Change Model

As previously noted few studies align transition to adult health care with a specific theoretical framework (Tuchman, Schwartz, Sawicki, & Britto, 2010; Wong et al., 2010). One

exception is the Stages of Change Model, otherwise known as the Transtheoretical Model of Change Behavior (Prochaska & DiClemente, 1986). The model, originally based on smoking cessation behaviors, eventually included other health behaviors.

The Stages of Change Model focuses on the stage of decision-making of the individual and is a model of intentional change (Prochaska & DiClemente, 1983). The Stages of Change Model was developed to unite principles and processes of change from existing theories of psychotherapy and behavioral change (Prochaska, 2008). There are two major aspects to the model. The first aspect is the Stages of Change followed by the second major aspect, the Process of Change. A focal assumption of the model is that the application of the processes is better interpreted in the context of the stages of change (Prochaska & DiClemente, 1986).

The change model evolved through studies examining how people who smoked were able to stop smoking on their own without the need for medical treatment (Prochaska & DiClemente, 1983; Prochaska & DiClemente, 1982). Further use of the model has been demonstrated in behavioral changes required in physical activity and exercise (Marshall & Biddle, 2001), mammography screening, colorectal screening, diet, stress management, depression management, partner violence, weight loss, bullying prevention, anorexia (Prochaska, 2008), and adherence with HIV and hypertension medications (Willey et al., 2000).

The validity of the Stages of Change model for medication adherence was demonstrated in a study by Willey et al. (2000), using two self-reports of the Medication Adherence Scale and the Medical Outcomes study adherence measure, along with electronic monitoring of adherence behavior in a sample of 161 HIV-positive patients and 731 patients with hypertension. The patients' self-reported Stages of Change baseline was associated with the percentage of prescribed doses taken in the following 30 days with electronic monitoring.



These applications of the model include both addictive and non-addictive behaviors. The commonality among these problems is that they all involve important long-term health mindfulness. Youth with CF require constant and unique management of life-threatening complications of a genetic disease that has no cure in order to maintain quality of life for as long as possible.

The Stages of Change Model is unique in that it proposes change as it unfolds over time in a cyclic process (Prochaska, 2008). This distinction is considered one of the model's strengths (Marshall & Biddle, 2001). The series of stages of change, known as the first major aspect of the model, are the precontemplation stage, contemplation stage, action stage, and finally maintenance stage. Later the contemplation stage was subdivided creating a preparation stage (DiClemente et al, 1991). The stages of change are often measured using a four or five-item response in which questions asked are responded to with a "yes" or "no" answer. The responses to the questions disclose whether the individual meets a particular stage criterion (Prochaska et al, 1994). These stages, distinguished by a temporal dimension distinguish when definite shifts in attitudes and behaviors occur (Prochaska, DiClemente, & Norcross, 1992). These particular stages can be used clinically to direct areas for intervention based on the patient's readiness to change. Integration between the stages of change and the second major aspect of the theory, the process of change, was one of the main findings to emerge in self-change research (DiClemente et al., 1991). Assumptions driving the Stages of Change Model include that no single theory can account for all behavior change, and that behavior change progresses through a sequence of stages over time. Stages can be stable and changeable and without planned interventions people can remain fixed at an early stage, and if change is to occur, they require stage-matched interventions in order to progress to the next stage (Prochaska and Velicer, 1997).

## Stages of Change

### Precontemplation Stage

Precontemplation is the stage when the individual has no intention to take action in the near future (Prochaska and DiClemente, 1986). The individual may be uninformed or under informed about the need for change, and is often characterized as resistant or unmotivated. Youth may not be exposed to the need to take any responsibility for self-care management of CF. Caregivers may have assumed the role of full responsibility for their youths' health care needs; consequently, youth are not ready to transition to adult health care. This stage correlates with the TRAQ skill level of “no, I do not know how” [to perform this skill level important for transition to adult health care] (Wood et al., 2014).

### Contemplation Stage

In the move from precontemplation to contemplation, the individual must become aware of the situation, intentionally wish to change, and be ready to take ownership of it. This progress from precontemplation to contemplation may at times rely on internal developmental changes or external environmental changes that propel the individual into a new stage in life. At this stage, ambivalence exists as the individual weighs the pros and cons of change. In the contemplation stage, the caregiver or professional health care provider may have suggested that the youth consider adoption of self-care activities, which may signal awareness to the youth of the need to assume a greater role in self-care. Increasing age and youth internal development may be a factor in advancing interest in becoming self-sufficient. Interest alone does not signify transition readiness. This stage correlates with the TRAQ skill level of “no, but I want to learn” [to perform this skill level important for transition to adult health care] (Wood et al., 2014).

### Determination Stage (or Preparation Stage)

When reaching the determination (or preparation) stage, the pros in favor of attempting to change the behavior outweigh the cons. During the preparation stage, the individual often has a plan of action that may include consulting with a counselor, talking with a physician, or using a self-change approach. Youth at this stage may seek information from their caregiver or professional health care provider to become actively involved in the transition process of assuming self-responsibility for their care. Once again, this stage does not denote that the youth is ready to transition to adult health care. This stage correlates with the TRAQ skill level of “no, but I am learning to do this” [skill important for transition to adult health care] (Wood et al., 2014).

### Action Stage

The action stage is determined if the individual has recently modified their behavior and has made overt changes in his/her life-style. The individual needs to have a sense of self-efficacy and believe that he/she has autonomy in order to change. Skill acquisition distinguishes this stage. Behavior is not yet stabilized and may be particularly stressful if failure is experienced. Having reached the action stage, the youth has started to assume self-care management of CF and responsibility gradually transfers from caregiver to self. During the action stage, youth are ready to transition to adult health care but may still require considerable guidance and support from their caregivers. This stage correlates with the TRAQ skill level of “yes, I have started doing this” [skill important for transition to adult healthcare] (Wood et al., 2014).

## Maintenance Stage

The final stage is concluded when individuals have stabilized their behavior and are working to prevent relapse to earlier stages. At the maintenance stage, youth have successfully attained self-care management of CF and no longer rely on caregivers. This stage correlates with the TRAQ skill level “yes, I always do this when I need to” (Wood et al., 2014)

## Regression

Regression can occur at any stage and individuals may revert to an earlier stage. If regression does occur, interventions in the process of change should mirror that stage. In this study, I will not address regression. Regression may be evident in subsequent assessments of readiness to transition investigated during six monthly follow-up visits.

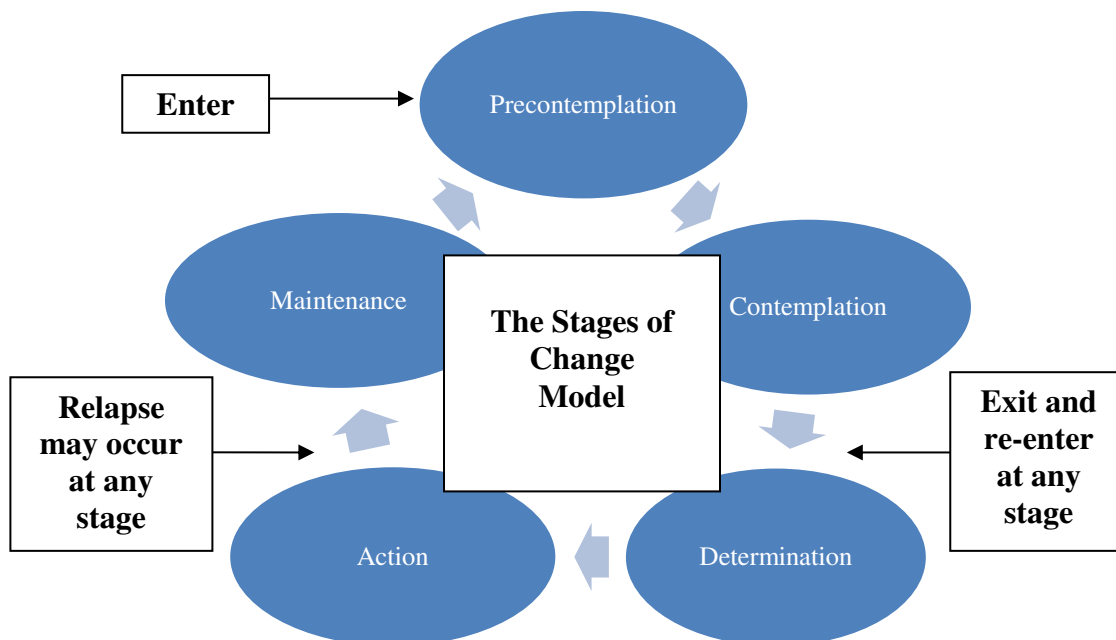


Figure 2. The Stages of Change Model

Transition for youth involves a change in behavior with the need for taking on a new lifestyle understood. Youth must independently self-manage the role of managing medication, appointment keeping, tracking health issues, talking with providers, and managing daily activities previously assumed by their caregivers. Previous researchers have found that medication adherence might be improved by applying the Stages of Change model of behavior change (Breux-Shropshire, Brown, Pryor, & Maples, 2012; Genberg, B. L., Lee, Y., Rogers, W. H., Willey, C., & Wilson, I. B., 2013; Willey et al., 2000).

The stages of change begin with the precontemplation stage when the youth has not considered adopting self-management skills and advances through contemplation or awareness of change required, followed by the determination stage when learning to adopt the change occurs. The action stage designates that the youth has acquired self-care management and the final stage of maintenance concludes stabilization of self-care management acquisition.

Use of the Stages of Change Model ties together the concepts of self-care management in youth with CF and can show in which stage of change youth report greater transition readiness. These stages of readiness can further be analyzed and linked according to age. Furthermore, caregiver perception of youth transition readiness may validate youth perception of readiness as well as validate the model.

### Processes of Change

The five stages of change provide a description of the actual shift in time when the behavior occurs, whereas the second major aspect of the Stages of Change Model is the process of change that assists in explaining how these shifts occur. The processes of change include five experiential processes (cognitive, affective, and evaluative processes) used in the early stages

which include consciousness raising, environmental reevaluation, dramatic relief, social liberation, and self-reevaluation. Experiential processes are important in the early stages where people change thoughts, feelings, and attitudes related to their behavior. Behavioral-type processes such as conditioning, commitments, and social support are more prominent during the action and maintenance stages. These processes include self-liberation (self-efficacy), helping relationships, counterconditioning, reinforcement management, and stimulus control. Many theories may be integrated during the processes of change, which may effectively move the participant into the next stage of change. Individuals weigh the pros and cons of changing behavior with the cons outweighing the pros during the precontemplation stage. This balance changes as the individual contemplates change. The construct of self-efficacy adapted from Bandura's self-efficacy theory (Bandura, 1977), beginning at the preparation stage and progressing through the maintenance stage, represents the increasing belief people have that they can cope with high-risk situations without relapsing. In this study, I will not examine the process of change but will determine the stage of change in which youth perceive themselves to be. This study will set the groundwork for process of change interventions. Once it is clear what stage of change the youth is in, nurses would know which processes to apply in order to help youth move to the next stage of change towards self-care management maintenance.

### Gaps in Clinical Practice

As previously identified in the review of literature, frequent transition discussion and planning is a key element in youth preparation for transition to adult health care, yet discussion and planning for transition is low in clinical practice (Knapp et al., 2013). Furthermore, few researchers have examined youth perceptions of self-management skills necessary for transition

to adult health care, with only a couple investigating youth/caregiver congruence using validated measures.

Policies developed to guide health care transition, using age as criteria, have been based on expert opinion and general agreement with no indication of scientific merit, and lack theoretical frameworks (AAP et al., 2011). The TRAQ based on the Stages of Change theory is a validated 20-item scale measuring self-care management skills required in health care transition. Data obtained from this scale can be further analyzed according to age and caregiver perceptions of youth stages of self-care management. Although the TRAQ was developed using youth with CF, many youth with other chronic diagnoses were included and therefore the instrument is not illness specific. While studies examining individuals with other diagnoses provide useful information, they may be limited in their generalization to individuals with the specific diagnosis of CF.

I am seeking through this study to determine what level of transition readiness youth with CF report using the TRAQ, based on The Stages of Change Model. Further investigation will determine whether transition readiness in youth differs related to age, and how caregivers perceive youth readiness to transition using an adapted TRAQ questionnaire, the TRAQ-C. With the permission of the original instrument developers, I developed the TRAQ-C. This will allow me to determine youth and caregiver congruence on stage of skill level in self-care management. I will also investigate whether discussions regarding transition to adult care took place, and if so, the age of youth when first discussed, and how often discussed during clinic visits.

## CHAPTER THREE: RESEARCH METHODS

In this chapter, I present the methods used in this study to include setting, sample, study measures, data collection procedures, data analysis, and ethical considerations. The study is a descriptive, correlational, cross-sectional design. Youth were recruited from four freestanding pediatric hospital CF clinics in Florida, associated with the Cystic Fibrosis Foundation (CFF). The purpose of this study was to determine how youth with CF perceive their self-care management skills required for transition to adult health care, the relationship between age and skill acquisition, youth and caregiver congruence on perceived transition readiness, and frequency of transition discussion with provider.

### Setting

All clinics are part of the nationwide CFF clinics where clinicians evaluate, diagnose, treat, and provide long-term management for infants, children, and youth in a pediatric-friendly environment. Patients are seen in the four CF clinics regardless of whether insurance is obtained through Medicaid, CMS Medicaid, or privately. As part of the standard of routine care, a multi-disciplinary approach to maintaining optimal health occurs at all CF clinics. Monitoring the health of youth with CF includes routine chest x-rays, bacterial studies of sputum, pulmonary function tests and pulmonary therapy treatments performed by respiratory therapists. Education is a key component and provided by the entire team. Nutritional support includes performing blood tests to determine nutritional status. A CF-registered dietician individualizes medical nutrition therapy plans and tracks growth and weight over time. Social workers counsel, offer support with transitioning into adult health care, and help with supplies, equipment and insurance coverage, while nurses oversee care coordination. Youth and their caregivers spend several



hours on their day scheduled at the CF clinic for quarterly health assessments.

### Sample

The study population included a purposeful total sample size of 58 youth recruited over a period of twenty-six weeks beginning May 2015. Fifty-two of the 58 youth also participated with a caregiver. The definition of youth in the literature is broad; for example, the United Nations defines youth as encompassing ages 15-24, determined merely for statistical consistency across regions (United Nations Youth, 2008). For the purpose of this study, youth entailed the ages of 14 and older, with the upper limit determined by whether health care was received in a pediatric setting. The selection of a minimum age of 14 was based on the AAP position statement that calls for a written health-care transition plan with youth beginning at this age (AAP, 2002). Furthermore, the US Department of Health and Human Services' Maternal and Child Health Bureau (2011) called for a standardized transition readiness assessment tool utilized at age 14. Approximately 70 youth who fit the age criterion receive care annually in these clinics.

### Inclusion Criteria

All youth with CF age 14 and older, receiving care from a pediatric pulmonologist during their scheduled quarterly clinic visit at the four clinics were eligible for this study. Primary caregivers accompanying youth were eligible for addressing two of the research questions.

### Exclusion Criteria

Youth seeking emergent care or experiencing severe illness as determined by the pulmonologist were excluded from the study.

## Measures

### Demographics

A Youth Demographic Form requested age, gender, grade in school or year in college, and number of hours worked if applicable (Appendix I). A Caregiver Demographic Form requested gender, level of education, age, and marital status (Appendix J). A further question asked whether the caregiver was the primary caregiver who took care of their child's medical needs. Both youth and caregiver demographic forms included the following three questions. Did they engage in a conversation with the CF team regarding transition to adult health care? At what age was the youth when this conversation occurred (never, 12 and younger, 13, 14, 15, 16, 17, 18, older than 18)? How often did the conversation occur (never, one, two, three, or four times a year)?

### Transition Readiness Assessment Questionnaire (TRAQ)

In this study, the *Transition Readiness Assessment Questionnaire 5.0* (TRAQ; Wood, Sawicki, Reiss, Livingood & Kraemer, 2014) (Appendix A) was used for youth with CF to rate their skill ability in five domains of self-management, including self-care activity in managing medications, appointment keeping, tracking health issues, talking with providers, and managing daily activities. The TRAQ 5.0 is a later version of the original TRAQ 4.1 (Sawicki et al., 2011). The TRAQ 4.1 was found to be the best-validated transition-readiness tool in a systematic review ( $n = 10$ ) of the psychometric properties of transition readiness assessment tools in youth with chronic disease (Zhang, Ho & Kennedy, 2014).

Following ongoing use of the TRAQ 4.1, by Wood and colleagues (2014), the authors identified concerns with the content and structure of the 29-item scale, which consisted of two

subscales, self-management and self-advocacy. Although the original response options were based on the five Stages of Change model, a sixth response option of “not needed for my care” was included. This response option, intended to allow youth to indicate that a particular skill was not required for their care, was misinterpreted by some youth. Item reduction occurred in the following ways. Four items related to medical equipment that did not apply to all youth with chronic illness were removed, with the decision that the questionnaire would be better understood by youth. A further question “do you ask questions of the doctor, nurse, or clinic staff?” received 28% missing values, and was removed. The remaining 24 questions had no item with more than 3.6% missing values. Following removal of these five items, the remaining 24 questions were administered to 526 youth in two separate samples ranging in age from 14-26 years at three academic clinics.

The first sample comprised 305 participants in 2011 with paper and pencil (147) and on-line (158) survey format, collected during clinical care from youth with CF and other diagnoses. The number of items were reduced using nonresponse and exploratory factor analysis (EFA). Successive rounds of EFA using maximum likelihood estimation and both orthogonal orthomax and oblique parsimax rotations were conducted on 269 complete responses. Three questions not loading in the initial EFA on at least one factor at 0.45 were eliminated, and the factor analysis rerun. In the second EFA one item, “do you pay or arrange payments for your medications” did not load on any factor at 0.45 and was removed, reducing the number of items on the questionnaire from 29 to 20. No differences were found in the structures after examining the pattern matrix. The five largest eigenvalues for the final EFA were 21.36, 2.59, 1.24, 1.07, and 0.92. The scree plot justified the five domains of managing medications, appointment keeping, tracking health issues, talking with providers, and managing daily activities.

Using data collected from paper and pencil surveys from a second sample of 221 youth, Confirmatory factor analysis (CFA) was conducted. Forty-three respondents had one or more missing values and their surveys were eliminated, leaving a sample size of 178. Initial steps included a structural equation model with the TRAQ 20-items and the hypothesized five factors. The  $p$ -value for goodness of fit was .15; the root mean square error approximation (95% confidence interval) was 0.0268 (0, 0.0463), with a probability of close fit  $p$ -value of .098; goodness-of-fit index was 0.92; and Bentler comparative fit index was 0.992 (Wood et al., 2014).

Reliability testing was conducted on the pooled two samples for the responses ( $n = 447$ ) on the revised 20-item TRAQ. Items were removed sequentially and Cronbach's alpha was recalculated. Following each item deletion the Cronbach's alpha decreased, thereby indicating that the item contributed to internal consistency. Four of the five subscales had good reliability exceeding 0.70. The only subscale with internal validity below 0.70 was managing daily activities at 0.67. The authors are in the process of testing additional items to determine whether they could be added to the scale. The subscale talking with providers consisted of only two items. Although a minimum of three items is usually accepted for a factor to be included in a scale, the two items had the highest loading factors across all items on the EFA, with no other item loading on this factor in either the EFA or the CFA. The authors felt that these items had high face validity and that conversations with the health care team were crucial to adult health independence, and therefore included this subscale. The overall Cronbach's reliability for the pooled sample of 447 from EFA and CFA analyses was determined to be .94 (Wood et al., 2014). Following reliability testing the authors endorsed this current version of the TRAQ 5.0 (Wood et al., 2014; Appendices A & G).

Criterion validity was tested for significant relationships between overall TRAQ scores by age, race, sex, and insurance categories using Wilcoxon rank sum test individually and Kruskal-Wallis multivariable analysis of variance. As hypothesized, all five subscale scores were significantly higher for youth who were 18 and older, when compared to youth younger than 18. Females scored significantly higher than males. There was no difference by race and insurance type.

*Table 1.* Cronbach’s Alpha for TRAQ 5.0 Subscales

Subscale	Cronbach’s Alpha	Number of Items
Managing medications	.86	4
Appointment keeping	.90	7
Tracking health issues	.77	4
Talking with providers	.80	2
Managing daily activities	.67	3

With permission from the authors who originally developed the measure, the researcher adapted the youth version of the TRAQ to elicit caregiver perceptions of each of the 20 items (TRAQ-C, Appendix B). For example, a youth question, “Do you know what to do if you are having a bad reaction to your medications?” was adapted for caregivers to read, “Does your child know what to do if having a bad reaction to their medications?” Both youth and caregiver versions of the TRAQ were scored similarly. Cronbach’s alpha was calculated for the overall scale for youth (.92) and caregivers (.91) for the adapted TRAQ-C results in this study. Although the overall scale internal reliability is high for both the youth TRAQ and the caregiver TRAQ-C, caution in interpreting these results is advised given the small sample size.

### Data Collection Procedures

The PI met with the physician and/or director of each clinic, and established training for specific study coordinators at two of the sites, which included CITI training. The PI was the sole data collector for 83% of respondents, with the study coordinators responsible for the remaining 17%. Flyers advertising the study were posted in the four pulmonologist's CF clinic waiting rooms (Appendices K & L). The phone number of the PI was listed on the flyer.

Data collection occurred during youth CF clinic appointments, when youth and caregivers were in the individual patient waiting room between their medical tests. During one quarterly follow-up visit, the PI or designated study coordinator in the clinic approached youth and their caregivers for participation in the study. The health care team disclosed minimum age for criteria.

Assent, parental permission, and consent were obtained during the same clinic visit. Youth and caregivers individually completed a brief demographic form (Appendices I & J) and separately completed quantitative measures (Appendices A & B). Youth completed the measure *Transition Readiness Assessment Questionnaire* (TRAQ) and their caregivers completed an adapted version for caregivers asking their perception of their child's transition skill readiness (TRAQ-C). During completion of the questionnaire, either the PI or the research coordinator was present in the room. No collaboration of responses occurred between youth and caregiver during completion of the instruments. Time to complete the questionnaires took between ten to fifteen minutes. Following data collection each were offered a \$5 gift certificate as compensation for their time.

## Data Analysis

Data were analyzed using SPSS 21.0. Descriptive statistics summarized the gender distribution and mean age of the sample, with bar graphs to depict youth and caregiver perception of youth skill attainment. Missing data were examined to determine potential impact on statistical tests. Analysis of the entire measure of the TRAQ (20 items) as well as the five individual subscales determined which stage of transition readiness the youth perceived him or herself. Mean responses to the 20 individual questions were tabulated to demonstrate level attainment of skill from lowest scoring to highest scoring for youth and caregiver perception. Specific statistical tests used to answer the research questions are listed below.

1. *What stage of change in transition readiness related to self-care activities of managing medications, appointment keeping, tracking health issues, talking with providers, and managing daily activities do youth with cystic fibrosis report?*

This question was answered using descriptive statistics. Bar graphs depicted the stage of change of the youth's current focus: pre-contemplation for change, contemplation for change, determination to start change, is actively changing or has reached the maintenance stage for each of the five subscales on the TRAQ.

2. *Is level of transition readiness in youth with cystic fibrosis related to age for each of the various self-care activities (managing medications, appointment keeping, tracking health issues, talking with providers, and managing daily activities)?*

Descriptive statistics summarized how youth self-management skill level changes by age, with ages divided into three groupings (14-15, 16-17 and 18-22), to depict how stage of readiness changes with age. Five simple linear regressions were calculated predicting youth

perception of the five TRAQ self-care activities (managing medications, appointment keeping, tracking health issues, talking with providers, and managing daily activities) by age. Simple linear regression offers the ability to calculate the increase in age required for youth to attain the next stage of skill acquisition. The independent variable was age and the dependent variable was the mean ratings of subscales.

3. *How congruent are youth with cystic fibrosis and caregivers in reporting perceptions of level of transition readiness related to managing medications, appointment keeping, tracking health issues, talking with providers, and managing daily activities?*

Comparison of the total TRAQ scores reported by youth and total TRAQ-C scores reported by caregivers was performed using a paired t-test. The independent variables were whether the respondent was the youth or caregiver, while the dependent variables were the youth and caregiver mean ratings of the TRAQ and TRAQ-C. An independent-samples t-test compared the means of the youth and caregiver for the five subscales of the TRAQ and TRAQ-C, which determined which subscales rated more consistently or differently.

4. *How congruent are youth with cystic fibrosis and caregivers in reporting transition discussions with provider? 4a. At what ages do youth with cystic fibrosis and caregivers report discussions with provider? 4b. How often do youth with cystic fibrosis and caregivers report discussions with provider?*

Descriptive statistics summarized percentage of youth and caregiver in agreement that a discussion had occurred, median age when discussion first occurred, and frequency of discussion. Associations between youth/caregiver agreement that a transition discussion had taken place, and how often transition was discussion were analyzed with a Fisher's exact test.



### Protection of Human Participants

The PI completed all requirements for conducting research, including CITI training. Human research protocol was submitted to the Institutional Review Board at the University of Central Florida and at each of the four CF clinics used in this study (IRB consents Appendices C, D, E, & F). The study met the criteria for expedited review in which written consent was waived, as the research did not involve greater than minimal risk as classified by federal regulations (45CFR46.404). Caregiver verbal permission was obtained from the caregiver for their child to participate if the participant was a minor (less than 18 years of age), and verbal assent was obtained from all minors wishing to participate. For participants 18 years of age or older, verbal consent was obtained directly. Caregiver verbal consent was also obtained. Participants were assured that they were free to decline participation. Responses to the questionnaire were held confidential. The questionnaires and participant demographics are stored in a locked cabinet in a locked private office and will be retained for five years or until all presentations, publications, and ongoing research are completed.

## CHAPTER FOUR: RESULTS

A summary of the data collected and the results of statistical analysis will be discussed in this chapter in order to answer the research questions. The goal of this study was to determine how youth with CF perceive their self-care management skills required for transition to adult health care, the relationship between age and skill acquisition, youth and caregiver congruence on perceived transition readiness, and frequency of transition discussion with provider.

### Sample Size, Response Rate, and Missing Data

One caregiver declined to participate for self and youth, and one caregiver declined to participate for self. However, their child wished to participate and the caregiver gave permission for their participation. Five youth participating in the study attended CF clinic with no caregiver, were over the age of eighteen, and consequently able to consent for themselves. This resulted in a response rate of 97.35%.

Missing data were negligible (0.5%) and randomly dispersed. One youth responded to one question as not applicable, four caregivers responded to four different questions as not applicable, and seven caregivers did not respond to seven different questions. Missing data for the TRAQ and TRAQ-C responses were handled by computing and substituting mean item scores.

### Demographics

The mean age of the youth responding was 16.5 years (range 14-22). Fifty percent of youth were female. Eight youth attended college, 44 attended high school, and three attended middle school. One youth was dually enrolled in college and high school. Another youth, who

was dually enrolled in high school and college was also working. Eleven worked, with five working < 20 hours per week and six working between 21-39 hours per week. Three youth neither worked nor attended any form of school.

The majority of caregivers were female (80.8%) and married (80.77%). Three (5.77%) caregivers reported less than high school education, 10 (19.23%) reported graduating from high school, nine (17.31%) reported they had received some college education, while 30 (57.69%) had attained an associate degree or higher. The average age of the caregiver was 41-50 years. Seventy-five percent considered they were the primary caregiver for their child's medical needs with 25% reporting shared responsibility. Table 2 describes demographic characteristics of youth and Table 3 describes demographic characteristics of their caregivers.

Table 2. Demographic Characteristics of Youth Participants

Characteristic	Number	Percent
<b>Age</b>		
14	4	6.9
15	15	25.9
16	13	22.4
17	11	19
18	9	15.5
19	3	5.2
20	2	3.4
22	1	1.7
Total	58	100
<b>Gender</b>		
Female	29	50
Male	29	50
Total	58	100
<b>Grade Middle/High School</b>		
7	1	1.7
8	2	3.4
9	8	13.8
10	13	22.4
11	12	20.7
12	11	19
Total in Middle/High School	47	81
<b>Year in College</b>		
1	5	8.6
2	2	3.4
4	1	1.7
Total in College	8	13.8
Total no High School/College Or Work	3	5.2
<b>Number of hours worked per week</b>		
Less than 21	5	8.6
21-39	6	10.3
Total that Work	11	18.9
<b>Dual Enrollment</b>		
Dual enrollment high school/college	1	1.7
Dual enrollment high school/college and work	1	1.7

*Table 3. Demographic Characteristics of Caregiver Participants*

Characteristic	Number	Percent
<b>Age</b>		
Under 30	1	1.9
31-40	12	23.1
41-50	33	63.5
51-60	4	7.7
61-70	2	3.8
Total	52	100
<b>Gender</b>		
Female	42	80.8
Male	8	15.4
Missing data	2	3.8
Total	52	100
<b>Education</b>		
Less than high school	3	5.8
High school graduate	10	19.2
Some college	9	17.3
Associate degree or higher	30	57.7
<b>Marital Status</b>		
Married	42	80.8
Single	9	17.3
Widow	1	1.9
<b>Primary Caregiver (takes care of medical needs)</b>		
Yes	39	75
Shared responsibility	13	25

Mean Scores for TRAQ and TRAQ-C

The following table compares the mean scores from youth on the TRAQ with those of their caregiver on the TRAQ-C (Table 4). The questions are listed from the lowest to the highest youth perceived ability to perform the task. Youth reported higher ability to perform every task than caregivers did.

*Table 4. Comparison of Youth (TRAQ) and Caregiver (TRAQ-C) Mean Scores*

Transition Readiness Assessment Questionnaire 5.0	Youth	Caregiver
Do you apply for health insurance if you lose your current coverage?	1.84	1.15
Do you get financial help with school/work?	2.19	1.46
Do you know what your health insurance covers?	2.38	1.42
Do you manage your money & budget household expenses?	2.38	2.08
Do you make a list of questions before the doctor's visit?	2.45	1.94
Do you call the doctor's office to make an appointment?	2.52	1.58
Do you fill a prescription if you need to?	2.52	1.80
Do you follow-up on any referral for tests or check-ups or labs?	2.74	1.67
Do you reorder medications before they run out?	2.81	1.90
Do you call the doctor about unusual changes in your health?	2.95	1.65
Do you fill out the medical history form, including a list of your allergies?	3.17	2.23
Do you arrange for your ride to medical appointments?	3.26	1.79
Do you keep a calendar or list of medical and other appointments?	3.34	2.04
Do you know what to do if you are having a bad reaction to your medications?	3.98	3.12
Do you help plan or prepare meals/foods?	4.14	3.52
Do you keep home/room clean or clean-up after meals?	4.38	3.81
Do you use neighborhood stores and services?	4.40	3.40
Do you take medications correctly and on your own?	4.55	4.12
Do you tell the doctor or nurse what you are feeling?	4.67	4.27
Do you answer questions that are asked by the doctor, nurse, or clinic staff?	4.69	4.46

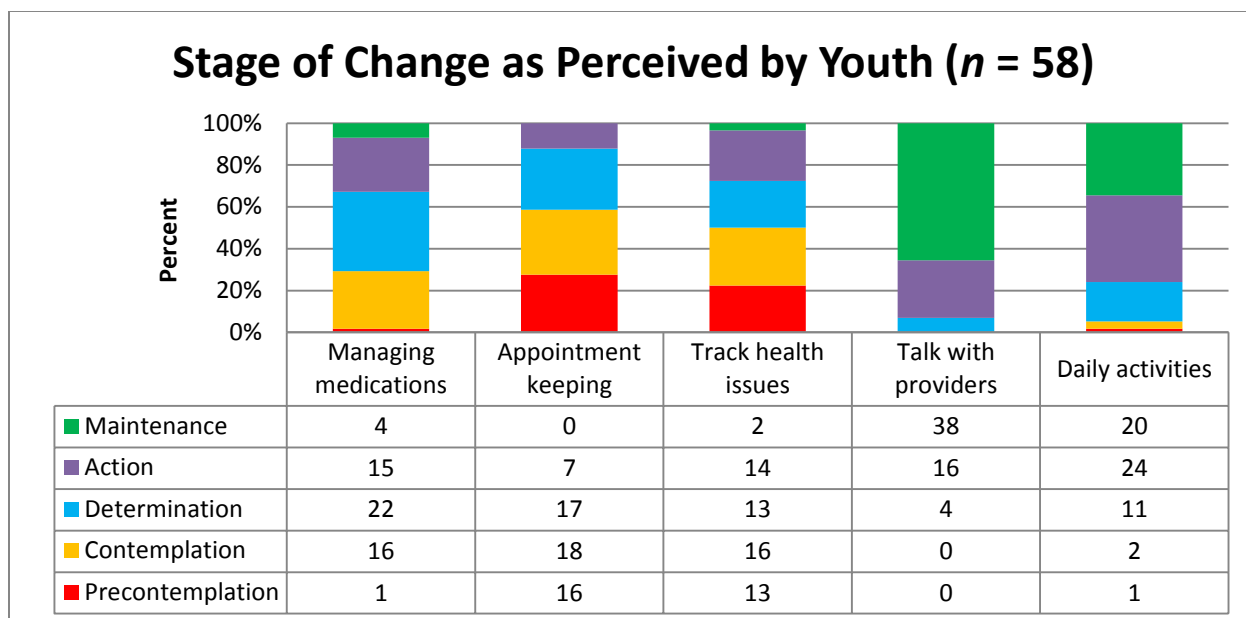
Options for scoring: 1=No, I do not know how; 2=No, but I want to learn; 3=No, but I am learning to do this; 4=Yes, I started doing this; 5=Yes, I always do this when I need to

## Statistical Analysis

### Research Question 1

- 1. What stage of change in transition readiness related to self-care activities of managing medications, appointment keeping, tracking health issues, talking with providers, and managing daily activities do youth with cystic fibrosis report?*

The following figure (3) depicts all youth ( $n = 58$ ) responses to stage of change of the five subscales in managing medication, appointment keeping, tracking health issues, talking with providers, and daily activities). Bar graphs represent the stage of change in transition readiness of the youth's current focus: pre-contemplation, contemplation for change, determination to start change, is actively changing or has reached the maintenance stage. Each stage represents respectively, a range of youth perception of not knowing how to complete the task, to wanting to learn how to complete the task, through preparing to learn, starting to complete the task and finally completion of the task and no longer reliant on caregiver. The majority of youth, ages 14-22, had not started to learn how to complete the tasks involved for managing medications (67%), appointment keeping (88%), and tracking health issues (72%). Only seven percent perceived that they managed their medications by self. When managing daily activities, 76% of youth perceived they had started to complete the task or completed it independent of caregiver. Ninety-three percent of youth perceived that they had attained the learning stages or independent stage when talking with health care providers, with only seven percent at the preparation stage of learning. No youth perceived that they did not talk or were contemplating talking with their health care providers.



Maintenance = *Yes*, I always do this when I need to; Action = *Yes*, I started doing this; Determination = *No*, but I am learning to do this; Contemplation = *No*, but I want to learn; Precontemplation = *No*, I do not know how

Figure 3. All Youth ( $n = 58$ ) Participants Rated Stage of Change for Each Subscale

#### Research Question 2

2. *Is level of transition readiness in youth with cystic fibrosis related to age for each of the various self-care activities (managing medications, appointment keeping, tracking health issues, talking with providers, and managing daily activities)?*

Youth ages were first grouped into three age categories: 14-15 years ( $n = 19$ ), 16-17 years ( $n = 24$ ), and 18 and older ( $n = 15$ ), and graphed to represent how stage of change varies across the separate skills in the five subscales (Figures 4, 5, and 6). Skill level increased with age in all five subscales. While only one youth (5.26%) in the 14-15 year-old age group perceived self as actively managing medications, six youth (25%) in the 16-17 year-old group perceived the same and 12 (80%) youth age 18-22 reported either starting to complete the task or completing the task every time they needed to.

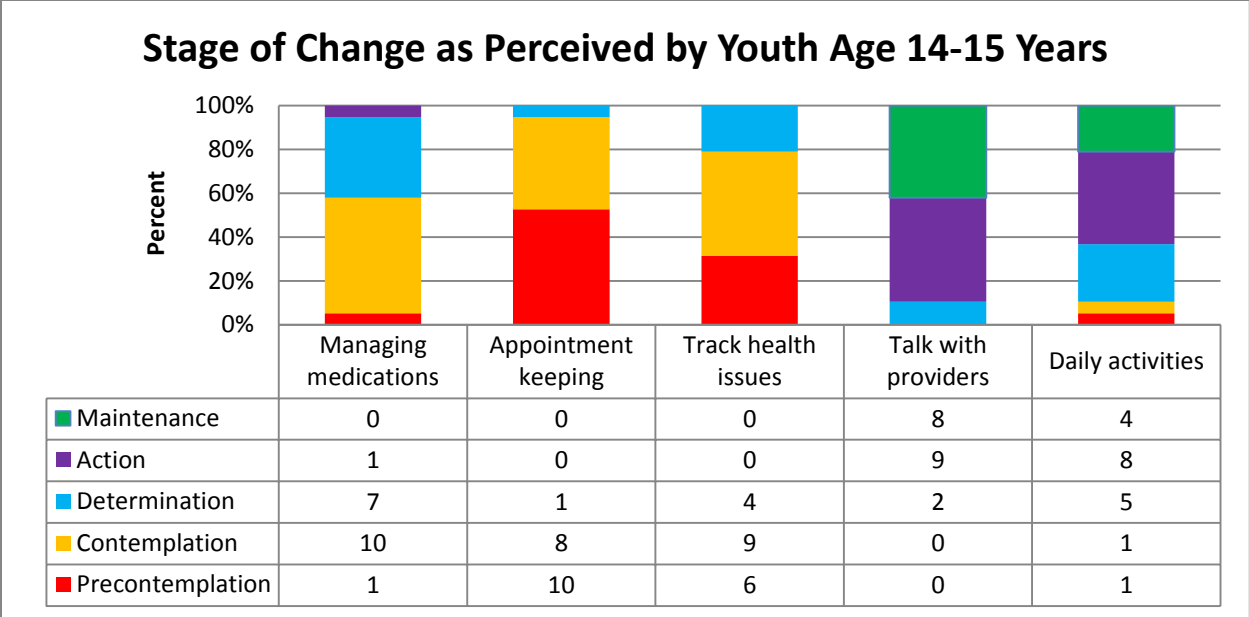


No youth age 14-15 perceived that they knew how to keep appointments, with only one youth (4.17%) age 16-17 starting to complete the task. Sixty percent of youth age 18-22 were still not completing this task, while the remaining 40% in this age group were starting to complete the task.

Likewise, no youth age 14-15 perceived that they knew how to track health issues, while five (20.83%) of 16-17 year-olds knew how to perform this task. Seventy-three percent of 18-22 year-olds were able to perform this task.

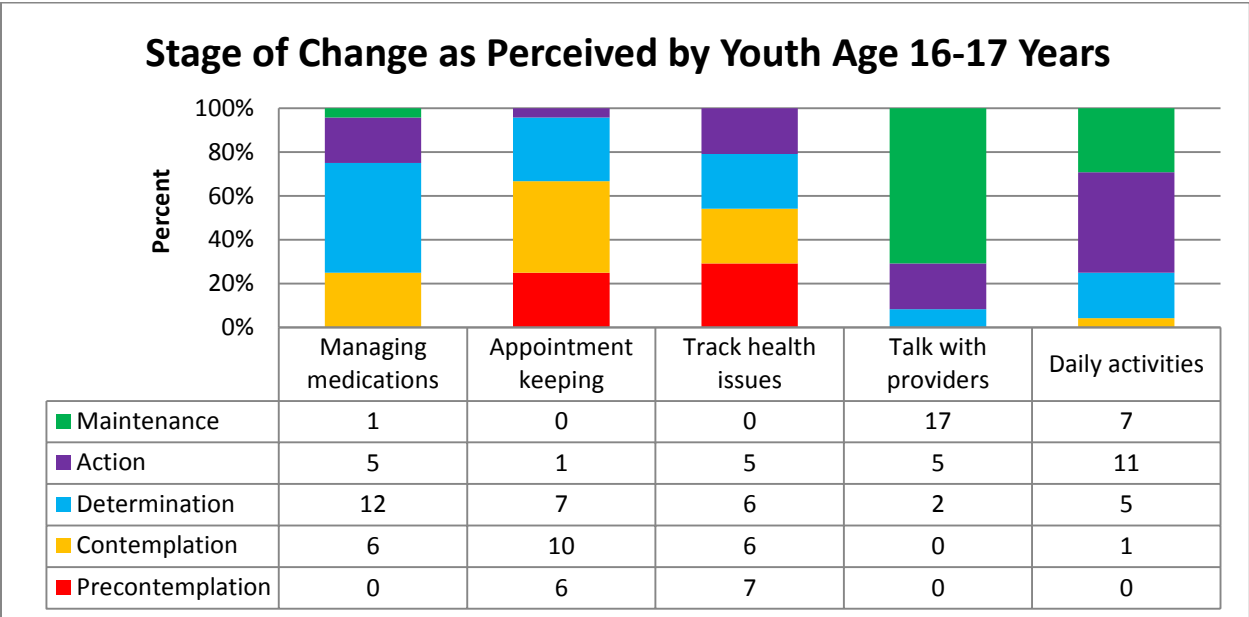
When talking with health care providers, 17 youth (89.47%) in the 14-15 year age group and 14 youth (93.33%) in the 16-17 year age group knew how to perform this task, while 100% of 18-22 year-olds perceived they completed this task. In both the 14-15 and 16-17 year age groups, only two youth were preparing to learn how to talk with providers.

When managing daily activities, 12 youth (63.16%) age 14-15, 18 youth (75%) age 16-17, and 14 youth (93.33%) age 18-22 perceived they had started to complete this task or were completing it all the time. Throughout all age groups, only one youth had not thought about performing daily activities, with two youth contemplating the task and eleven youth preparing to learn.



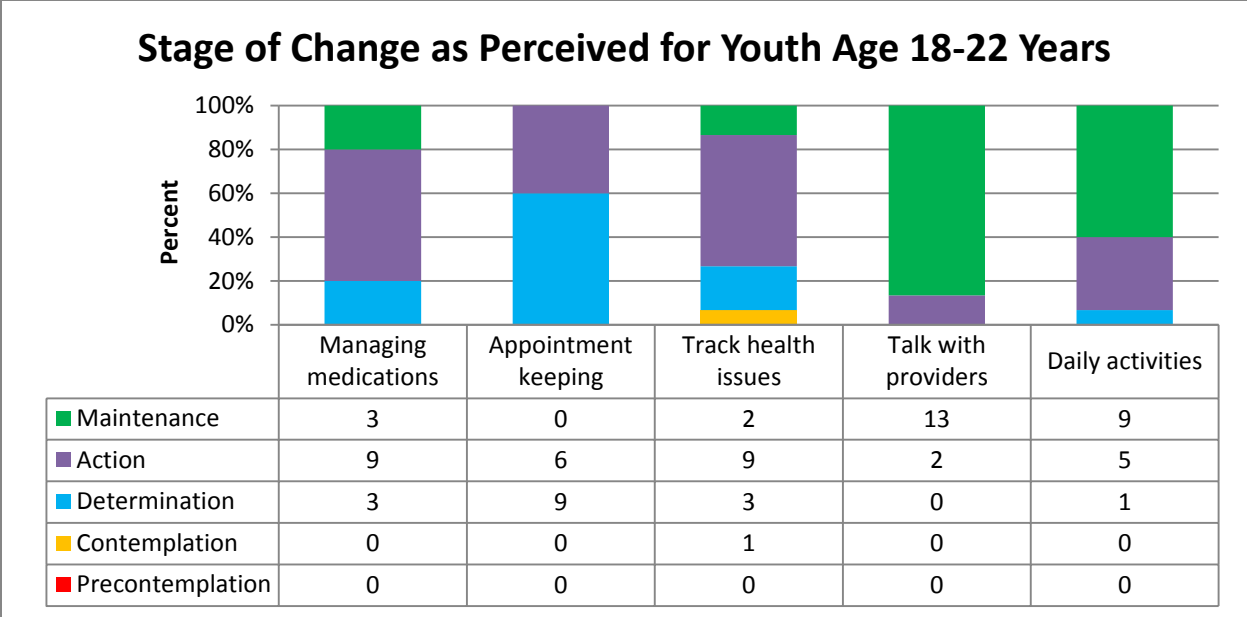
Maintenance = *Yes*, I always do this when I need to; Action = *Yes*, I started doing this; Determination = *No*, but I am learning to do this; Contemplation = *No*, but I want to learn; Precontemplation = *No*, I do not know how

Figure 4. Youth Age 14-15 Years ( $n = 19$ ) Rated Perceived Stage of Change



Maintenance = *Yes*, I always do this when I need to; Action = *Yes*, I started doing this; Determination = *No*, but I am learning to do this; Contemplation = *No*, but I want to learn; Precontemplation = *No*, I do not know how

Figure 5. Youth Age 16-17 Years ( $n = 24$ ) Rated Perceived Stage of Change



Maintenance = *Yes*, I always do this when I need to; Action = *Yes*, I started doing this; Determination = *No*, but I am learning to do this; Contemplation = *No*, but I want to learn; Precontemplation = *No*, I do not know how

Figure 6. Youth Age 18-22 Years (n = 15) Rated Perceived Stage of Change

Five simple linear regressions were utilized to predict youth perception of the five self-care activities based on age (Table 5). The simple regression model used is Transition Readiness Scale =  $\beta_0 + \beta_1$  age on the *Transition Readiness Assessment Questionnaire* (TRAQ). There are five *Transition Readiness Assessment* scores and each was modeled using the above regression model.

For *managing medications*, the regression slope estimation of  $\beta_1$  is 0.319 and is significant ( $p < .001$ ). The  $R^2$  for the regression model is .351. Youth predicted score on managing medications is equal to  $-1.792 + .319(\text{age})$ , when age is measured in years. This implies that youth managing medications score is increased on average by .319 for each yearly increase in age.

For *appointment keeping*, the regression slope estimation of  $\beta_1$  is 0.459 and is significant ( $p < .001$ ). The  $R^2$  for the regression model is .501. Youth predicted score on appointment keeping is equal to  $-4.990 + .459(\text{age})$ , when age is measured in years. This implies that youth appointment keeping score is increased on average by .459 for each yearly increase in age.

For *tracking health issues*, the regression slope estimation of  $\beta_1$  is 0.453 and is significant ( $p < .001$ ). The  $R^2$  for the regression model is .404. Youth predicted score on tracking health issues is equal to  $-4.617 + .453(\text{age})$ , when age is measured in years. This implies that youth tracking health issues score is increased on average by .453 for each yearly increase in age.

Likewise, when *talking with providers*, the regression slope estimation of  $\beta_1$  is 0.115 and is significant ( $p = .008$ ). The  $R^2$  for the regression model is .119. Youth predicted score on talking with providers is equal to  $2.764 + .115(\text{age})$ , when age is measured in years. This implies that youth talking with providers score is increased on average by .115 for each yearly increase in age.

Lastly, when *managing daily activities*, the regression slope estimation of  $\beta_1$  is 0.162 and is significant ( $p = .009$ ). The  $R^2$  for the regression model is .162. Youth predicted score on managing daily activities is equal to  $1.602 + .162(\text{age})$ , when age is measured in years. This implies that youth managing daily activities is increased on average by .162 for each yearly increase in age.

Table 5. Effects of Age on Stage for Specific Skills

TRAQ Subscale	Estimation of $\beta$ (SE)	Regression Intercept	R <sup>2</sup>	p-value
Managing medications	0.319 (0.728)	-1.792	.351	<.001
Appointment keeping	0.459 (0.770)	-4.990	.501	<.001
Tracking health issues	0.453 (0.927)	-4.617	.404	<.001
Talking with providers	0.115 (0.528)	2.764	.119	.008
Daily activities	0.162 (0.746)	1.602	.117	.009

Results from all five simple regression equations suggest that age predicts youth perceptions of the ability to complete the skills assessed in each of the five TRAQ subscales. As youth grow older, they perceive greatest increase in their ability in appointment keeping, 0.459(*sd* = 1.081),  $p < .001$ , followed by tracking health issues, 0.453(*sd* = 1.190),  $p < .001$ , medication management, 0.319(*sd* = 0.896),  $p < .001$ , daily activities, 0.162(*sd* = 0.787),  $p = .009$ . As youth grow older, they perceive the least increase in their ability in talking with providers, 0.115(*sd* = 0.557),  $p = 0.008$ .

### Research Question 3

3. *How congruent are youth with cystic fibrosis and caregivers in reporting perceptions of level of transition readiness related to managing medications, appointment keeping, tracking health issues, talking with providers, and managing daily activities?*

A paired t-test was used to compare the overall mean TRAQ scores between youth group and caregiver dyad group ( $n = 52$ ). Youth scored significantly higher ( $m = 3.187$ ,  $sd = .769$ ) than their caregivers ( $m = 2.490$ ,  $sd = .788$ ;  $t = 7.408$ ,  $df = 51$ ,  $p < .001$ ) when assessing readiness for transition to adult care. Table 6 below depicts the significant result of the total TRAQ paired t-test.

Table 6. TRAQ 2-tailed Paired t-Test

TRAQ (20 questions)	Youth	Caregiver	Mean Difference (SD)	95% Confidence Interval of the difference	<i>p</i> -value
	3.187 (0.769)	2.490 (0.788)	0.697 (0.019)	0.508, 0.886	< .001

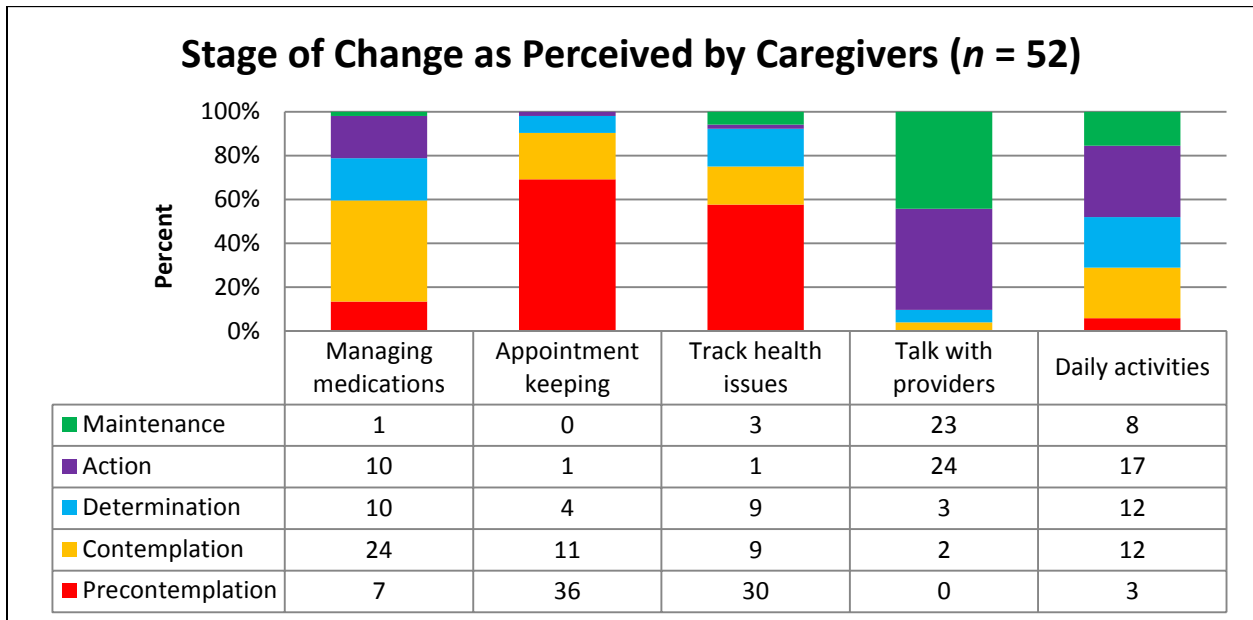
An independent two-samples t-test comparing the mean scores of the youth ( $n = 58$ ) and caregivers ( $n = 52$ ) found significant differences between the mean scores of the two groups for all domains (i.e. managing medications, appointment keeping, tracking health issues, talking with providers, and managing daily activities). Youth scored significantly higher than their caregivers when comparing means on their perception of managing medications, appointment keeping, tracking health issues, and managing daily activities ( $p < .001$ ). Talking with providers demonstrated the least discrepancy between youth and caregivers ( $p = .039$ ). The largest discrepancy between youth and caregiver perception of skill attainment occurred in appointment keeping, followed by tracking health issues, managing daily activities, and managing medications. Table 7 depicts the significant results of the independent-samples t-test for the five subscales of the TRAQ.

Table 7. TRAQ Subscales 2-tailed Independent t-Test

TRAQ Subscales	Youth	Caregiver	Mean Difference (SD)	95% Confidence Intervals of the Difference	p-value
Managing Medications	3.466 (.896)	2.764 (.986)	0.702 (0.09)	-1.057, -.345	< .001
Appointment Keeping	2.582 (1.081)	1.647 (.833)	0.935 (0.248)	-1.298, -.572	< .001
Tracking Health Issues	2.862 (1.190)	1.934 (1.135)	0.928 (0.055)	-1.368, -.487	< .001
Talking with Providers	4.664 (.557)	4.414 (.698)	0.25 (0.141)	-.488, -.013	.039
Daily Activities	4.270 (.787)	3.557 (1.086)	0.713 (0.299)	-1.075, -.349	< .001

The following figure (7) demonstrates caregiver perceived stage of change for youth. Comparison of youth and caregiver total scores for precontemplation (i.e., the youth has not considered learning the task), contemplation (i.e., the youth desires to learn), and determination (i.e., the youth is preparing to learn) revealed that caregivers and youth differ considerably in their perception of task acquisition. For managing medications, 79% of the caregivers perceive that their child was not yet ready to complete the tasks, whereas 67% of the youth believe they were unable to do so. Almost all caregivers (98%) perceive that their child was unable to keep appointments, whereas 88% of the youth believe they were unable to do so. When tracking health issues, 92% of the caregivers perceive that their child was unable to complete the tasks, whereas 72% of the youth believe they were unable to do so. Similar perceptions were found in

talking with providers, with only 10% of caregivers determining that their child did not complete this task, with 7% of youth believing they were unable to do so. Finally, when managing daily activities, 52% of caregivers perceive that their child was unable to complete the tasks, whereas 24% of youth believe they are unable to do so.



Maintenance = *Yes*, my child always does this when they need to; Action = *Yes*, my child started doing this; Determination = *No*, but my child is learning to do this; Contemplation = *No*, but my child wants to learn; Precontemplation = *No*, my child does not know how

*Figure 7. All Caregivers Rated Perceived Youth Stage of Change for Each Subscale*

Although there were marked differences in caregiver and youth perception, the general trend for each task was similar. However, when looking at individual dyad responses, the degree of congruence ranged considerably by dyad across all age groups. Across all age groups, the mean scores for the entire measure ranged from 1.9-4.8 for youth, and 1.35-4.89 for caregivers.



#### Research Question 4

4. *How congruent are youth with cystic fibrosis and caregivers in reporting transition discussion with provider? (4a). At what age do youth with cystic fibrosis and caregiver report discussions with provider? (4b). How often do youth with cystic fibrosis and caregiver report discussions with provider?*

A Fisher's exact test was used to determine the association between whether a transition of care discussion had taken place between youth and provider and caregiver and provider. A statistically significant association between youth and caregiver was found ( $p < .003$ ). Of the 52 dyads, 13 (25%) agreed that a conversation had never occurred, while 24 (46.15%) agreed that a conversation had occurred. More female youth (72.41%) reported transition discussion than male youth (41.38%).

(4a). The median age recalled by youth for transition discussion with health care provider was 16 years ( $m = 15.78$  years, range 13-18 years). Caregivers also recalled a median age of 16 years ( $m = 15.48$  years, range 13-18 years) for transition discussion with provider. Table 8 describes age of first transition discussion as recalled by youth and caregiver. Nine (17.31%) youth and caregivers were in agreement on age of youth when a discussion about transition to adult health care was first mentioned with 12 (23.53%) in agreement that a discussion had never occurred. Fifteen (28.85%) dyads disagreed about whether the conversation had ever happened.

Table 8. Age of First Transition Discussion

Youth	Caregiver									Total
Age (year)	Never Discussed	≤12y	13y	14y	15y	16y	17y	18y	>18y	
Never Discussed	12	2	3	1	1	4				23
13y			2							2
14y		1			2	1	1	1		6
15y	1			1		1	1			4
16y	3					4	1			8
17y					2	3	1			6
18y								1		1
>18y									1	1
Total	16	3	5	2	5	13	4	2	1	51*

\*One caregiver missing data point

(4b). Table 9 describes the frequency of transition discussion with health care provider. Frequency of transition discussion varied considerably between youth ( $n = 51$ ) and caregiver ( $n = 51$ ). For example, 21 (41.18%) youth and caregivers agreed on frequency of discussion, of which 12 agreed (23.52%) that a discussion never occurred. Six (11.76%) youth who thought a discussion had never occurred had a caregiver who thought transition was discussed at every visit. The average frequency for discussion perceived by caregivers was 1.67 discussions per year, while the average frequency perceived by youth was 0.98 discussions per year. Frequencies were obtained by totaling the number of all visits per year and dividing that number by all participants.

Table 9. Frequency of Transition Discussion with Provider/Year

		Caregiver					Total
		Never	One	Two	Three	Every (4)	
Youth	Never	12	4	1	2	6	25
	One	5	5	2	1	1	14
	Two	0	1	1	1	3	6
	Every (4) <sup>1</sup>	0	3	0	0	3	6
	Total	17	13	4	4	13	51

<sup>1</sup> Every (4) = Every visit in a year, which equals 4 times a year

The Fisher's exact test was performed to examine congruence of frequency of discussions for the following categories: never, one, two, three, and every visit (4 times a year), in a four-row by four-column contingency table. There was no association between perception of frequency of transition discussions between youth and caregiver ( $p > .059$ ).

## CHAPTER FIVE: DISCUSSION AND CONCLUSION

There is a paucity of literature exploring how youth with CF perceive their readiness to transition to adult health care. Presently, only one published study using the TRAQ attempted to determine caregiver perception of youth readiness. The study sample was 32 dyads and included youth with various chronic medical conditions (Sawicki et al, 2014). Consequently, this study conducted only with youth with CF aimed to better understand and target transition readiness in this specific population. This was also the first time that TRAQ has been used exclusively in youth with CF to investigate how self-care management skills in five domains (i.e., managing medications, appointment keeping, tracking health issues, talking with providers, and daily activities) are related to age; youth and caregiver congruence on perceived transition readiness; and frequency of transition discussion with provider.

Findings from this study show statistically significant increases in self-management skills with increasing age in four of the five domains (managing medications, appointment keeping, tracking health issues, and managing daily activities). Ceiling effects in the talking with provider domain likely obscured age effects. However, results from this study reveal that although youth acquisition of self-care management skills increases with age, many skills are still lacking in the older age group. This age group is at an age when transfer to adult health care and independence from parental supervision are expected. Furthermore, findings reveal discrepancies in youth and caregiver perception of transition discussion with providers. In addition, caregivers acknowledged deficits in transferring essential knowledge for independent self-care management. The following sections will summarize the findings, recommendations for future practice, research and policy changes.

### Study Findings Extending the Literature

The *first* research question sought to determine what stage of change in transition readiness related to self-care activities of managing medications, appointment keeping, tracking health issues, talking with providers, and managing daily activities, youth with CF reported. Youth determined their skill level by selecting a response on a scale ranging from 1-5 corresponding with the Stages of Change theory. Skills in each domain may be accomplished at differing stages of youth maturity. Therefore, it is important to report on each of the five subscales to determine which skills may be attained at a younger age, and which require lengthy acquisition.

Domains with the lowest scores pertained to appointment keeping and tracking health issues. Most of the skills within these two domains the caregiver performed for the younger youth. Youth may assume that these skills are not their responsibility, may show little interest in learning, and give little thought to a time in the future when independent from caregiver. For example, a couple of younger youth had no concept of the process required in reordering medications, explaining they had no need to learn this skill because “my meds come in the mail.” Knowledge of filling a prescription and reordering medications before they run out are of utmost importance for youth with CF given the vast amount of medications required for daily maintenance. Another example of knowledge deficit occurred when one youth selected that he knew what his health insurance covered. When asked by his caregiver what health care coverage entailed, his response “to see my doctor and get my medications” revealed a very basic understanding of coverage. These skills become more critical as youth move towards transitioning out of the pediatric arena. Furthermore, given that the mean age of the sample was

16.5 years, and that the majority had not started the process to learn how to complete these skills is concerning and warrants further investigation.

Youth perceived that they were beginning to learn skills within the subscale managing medications. Youth may see these skills as more relevant to their responsibility, and therefore rate capabilities higher. The majority of youth identified they could manage daily activities; skills that youth may perceive as integral to their daily regimen. Youth scored highest in stage of change in the autonomous skills of talking with providers. Youth visit their CF clinic frequently and may have seen the same health care providers since early childhood. This may explain their comfort level and consequent high ranking of skill when discussing health with clinicians.

The *second* research question sought to determine if level of transition readiness in youth with CF is related to age for each of the various self-care activities (managing medications, appointment keeping, tracking health issues, talking with providers, and managing daily activities).

Consistent with other studies, increasing age was found to predict perception of advanced self-care skills (Wood et al., 2014). In contrast to the study by Wood and colleagues, in which skill perception in youth younger than 18 were compared with youth 18 and older, this study categorized ages into three groupings (14-15, 16-17, and 18 and above). This afforded the opportunity to discern level of self-care ability during the earlier formative years.

Skills lacking across all age groups included those required in the subscales of appointment keeping and tracking health issues. Results from this study found that it would take just over two years to attain the next stage of readiness. Although as might be expected the younger age groups had not begun to demonstrate these skills, 60% of older youth age 18-22 did not make appointments and 27% did not track health issues.

Previous researchers found that inability to perform both skill-sets of appointment keeping and tracking health issues have resulted in adverse outcomes following transfer to adult health care (Bryant et al., 2011; van Staa et al., 2011a). Furthermore, appointment keeping and arranging following-up appointments was associated with successful transition to adult health care in youth with congenital heart disease (Reid et al., 2004).

Similarly, poor adherence in managing medications for youth with CF may result in poor transition outcomes (Eakin et al., 2011). In addition, other authors have considered medication knowledge the most important transition skill (Fredericks et al., 2011). Results from this study show that managing medications would require approximately three years for youth to approach a full point difference in stage of readiness. Given these findings, previous studies in which transition preparation began at age 17, with transfer to adult health care occurring at age 19, is too late (McLaughlin et al., 2008). Allocating two years in which to acquire skills necessary for transition is too short a period for development of many of these skills in self-care and does not provide adequate time to prepare youth. Furthermore, some CF clinics are now transitioning youth prior to their eighteenth birthday, and consequently transition preparation requires an earlier start.

The *third* research question included caregiver perception and asked how congruent youth with CF and caregivers are in reporting perceptions of level of transition readiness related to managing medications, appointment keeping, tracking health issues, talking with providers, and managing daily activities.

Although the mean scores attained by youth in this study rated their ability higher than did their caregiver in every aspect, overall means of every subscale showed a similar trend for stage of skill attainment, which argues for the validity of the scores. Youth and caregiver

reported similar responses in taking medications correctly and knowledge of what to do if experiencing a bad reaction to medication. These skills may be considered of greater importance to the immediate daily health care needs of youth with CF and may be easier for caregivers to observe more accurately. Perhaps caregivers determine that medication management is of the utmost importance, believing that maintaining CF treatment will result in prevention of complications, and therefore devote their time educating only in this area. Other tasks in skill acquisition are therefore not learned. Some skills, based on this study may not be learned until youth is independent.

The greatest disparity between youth and caregiver perception of readiness to transition to adult health care in this study lies in appointment keeping and tracking health issues. The mean scores for both subscales were low for both youth and caregivers. Although many of the skills listed in these subscales may not seem important in the day-to-day medication regimen of younger youth with CF, the majority of youth age 18-22 were not performing the skills of appointment keeping (including follow-up for referrals, and knowledge of coverage and application for health insurance). Furthermore, more than a quarter were not yet tracking health issues such as completing their medical history form to include a list of their allergies. Caregivers may be consumed with the day-to-day medication and chest PT regimen, and not thinking ahead to transferring responsibility of other important skills acquisitions such as ordering medication, refilling medication and appointment keeping, etc. (McPherson et al., 2009).

Both youth and caregiver rated the three questions pertaining to health insurance and finances lowest (table 4). Previous authors have discussed delays in unmet needs for care due to financial reasons (Scal, Davern, Ireland, & Park, 2008; Callahan & Cooper 2004). These authors



noted that youth ages 19-24 years old had the lowest rates of health care coverage in the United States. Perhaps, given the ever-changing health insurance laws, caregivers, too, struggle to understand coverage and therefore may not discuss with youth. Youth need to know the components of care their insurance will cover when they are of age and responsible for their own medical bills. This study revealed that many youth between the ages of 18-22 are still not performing these skills.

Youth and caregiver were the most congruent in their ratings about talking with providers, and both rated these skills the highest. Similarly, all questions on the daily activities scored high. However, just over half of caregivers thought youth unable to complete daily activities, in contrast to almost a quarter of youth perceiving the same.

While the mean scores by youth and caregivers generally showed that attainment of self-care management skills increases with age, some youth and their caregivers scored significantly differently regardless of age. A couple of youth scored their skills lower than their caregiver, while some caregivers rated youth two full stages below the youths' self-assessment. This highlights the need for individualized transition planning, to include caregiver assessment of youth skills followed by open discussion on attainment of skill perception.

Differences in youth and caregiver mean scores may be explained by several factors. Youth may overestimate their ability to complete self-care activities, while caregivers may underestimate their youth's ability. Furthermore, the modified TRAQ-C directed caregivers to select youth behaviors that include the two categories of knowing that youth are contemplating the task and *desire* to learn a skill, and that they are *starting to learn* a skill. Both may be difficult to ascertain if the dyad have not discussed this prior to completion of the questionnaires. Some caregivers may not closely monitor their youth's behavior, which may lead them to

underestimate youth skill and readiness. Furthermore, some caregivers may recall the significance of youth missing the occasional treatment or medication and overreact by determining that they complete the task less than they actually do.

Only one published study to date has examined congruence in self-care management skills between youth and caregiver readiness to transition to adult health care (Sawicki et al., 2014). The study used TRAQ, with a sample of 32 dyads with differing medical diagnoses, which included CF. Despite the older age ( $m = 19.8$ ) in the study by Sawicki compared to this study ( $m = 16.5$ ), findings consistent with the Sawicki study include similarities in individual mean scores of the 20 questions on the TRAQ. Youth and caregivers in both studies reported answering questions posed by the health care team as the highest, followed by taking their medications correctly and on their own (Table 4). Furthermore, the questions scoring the lowest for youth included obtaining financial help with school or work. Both youth and caregivers considered that applying for health insurance if coverage was lost was the skill scoring lowest in competence.

The total average score on the TRAQ and TRAQ-C in this study revealed that youth reported greater transition readiness than their caregiver (3.189 vs 2.490). This differs considerably with findings by the authors of the TRAQ measure (Sawicki et al, 2014) who found that both youth and caregivers (32 dyads) reported the same score (3.3). However, as previously discussed, the Sawicki (2014) study included older youth. Possible age differences in cognition and self-reflection as well as sharing adult views about how much effort and sophistication is required for self-management skills may explain the difference in scoring. Furthermore, the inclusion of varying diagnoses may not entail the burden of care youth with CF sustain. Youth with CF take multiple medications throughout the day, often perform CPT for several hours a

day, and may incur diabetes management; all of which may require a longer period to assimilate. In addition, the data collection procedure was not apparent from the study description, and youth and caregiver may have collaborated when responding.

Participation in this study elicited appreciation, increased self-reflection, and raised awareness of skills necessary for independent care. One youth commented, “I like that you are asking *me* this . . . that you want to know what *I* think”. Youth may feel they have little input during the clinical encounter where clinic time usually focuses on the completion of tasks, with procedures done *to* them rather than communication *with* them. Caregivers’ comments included, “This enlightens me *so* much!”, “How *much* we have to teach her!”, “We have a *long* way to go”. Many caregivers commented that they were very grateful to see all the skills required for self-care on one sheet, which had “opened their eyes” to further prepare and support their youth. Similar non-verbal responses came from other caregivers who during completion of the questionnaire paused, looked off to the side, raised their eyebrows, sighed, and then continued with their responses.

Following completion of the questionnaires, many dyads chose to exchange questionnaires, discuss the questionnaires with each other, and engage in important related dialogue. After discussion between one mother and daughter centering on medication adherence, upon reflection, one mother turned to the PI and said, “I lay them out for her and she takes them”. She then hesitated and slowly admitted, “I guess . . . I should have *her* lay them out . . . and then check for accuracy?”

The aforementioned anecdotal comments indicate that purposeful conversation between dyad and providers should enhance transition readiness. Discussions pertaining to dyad congruence of skill assessment may indicate areas in which to resolve discrepancies.

Congruency between youth and caregivers in reporting transition discussions with provider, at what age, and how often are addressed in the *last* research question. Among the total sample, 43.1% of youth and 67.3% of caregivers recalled discussing transition to adult health care with their providers. However, congruence between youth and caregiver dyad differed significantly in recall of transition discussion with provider. There was an association between whether a transition discussion had taken place between youth and caregiver (46.15%), and the relationship between youth and caregivers was significant ( $p = .003$ ). However, 25% agreed that a conversation never took place. The majority of dyads (53.85%) either disagreed or never discussed transition to adult health care. This finding demonstrates the need for new approaches to transition conversation.

Discordance between youth and caregiver about the number of transition conversations suggests that apparent efforts to discuss transition are *not* being heard by youth. Perhaps the completion of invasive procedures during clinic time takes precedence over hearing discussions regarding distant transition plans. Discussion alone may not engage youth. Involvement in eliciting their ideas within the format of a questionnaire may make them feel more connected and therefore engage youth better.

For youth and caregivers who both reported that a transition discussion had occurred, the median youth age when the discussion first took place was sixteen years, but range varied from age 12 or younger ( $n = 3$ ) to older than eighteen ( $n = 1$ ). This age range suggests that there is variation in standard of practice across providers and clinics.

Youth and caregivers did not differ significantly ( $p > .059$ ) about the frequency of provider transition discussion. However, there was considerable variation in dyadic congruence. For example, six youth who thought a discussion had never occurred had a caregiver who

thought it was discussed every visit. Once again, youth may not be hearing the transition discussion or may not perceive that pertinent discussions are related to transition.

These findings suggest that the AAP (2011) recommendation to introduce transition discussion by the age of 12 is not being followed. In a previous study, McLaughlin and colleagues (2008) also found late age for initial discussion of transition. Researchers in other recent studies have reported a similar discrepancy between youth and caregiver recall of transition discussions (Sawicki et al., 2014; Knapp et al., 2013). It may be difficult to recall transition conversations and place them within the appropriate time, especially since the recall period for older youth and caregivers spanned five to seven years (Brener, Billy, & Grady, 2003). These findings reinforce the need for a written transition plan with yearly evaluation as suggested by The American Academy of Pediatrics (2002).

Participation in this study increased anxiety in a couple of youth and caregivers. When introduced to the study a 19-year-old girl anxiously exclaimed, “Please don’t tell me you’re going to transition me today!” A mother of a 21-year-old girl revealed “mixed feelings” about the impending transfer, expressed fears over complications stemming from poor compliance when her child was responsible for self-care, and questioned whether the adult health care team would understand the disease and her child. Following completion of the TRAQ-C for her 17-year-old son, another mother abruptly claimed, “He can’t do *any* of this. When he turns eighteen, he is on his own. The responsibility will be *all* his!” Caregiver fears of relinquishing control of their youth’s care may impede youth ownership in assuming autonomous care (Giarelli, Bernhardt, & Pyeritz, 2008; Jones & Hamilton, 2008; Lubkin & Larson, 1998).

Findings from this study revealed that two to three years are required to attain the next level in skill acquisition transition for the domains of appointment keeping and tracking health

issues. Transition discussion at an early age, framed through completion of the TRAQ and TRAQ-C, should prevent much of the anxiety reflected by youth and caregivers. Although increasing age was found to predict perception of self-care management, a few youth, regardless of age, were not completing several self-care skills; highlighting the need, that transition requires a flexible process adapted to individual needs. Completion of a transition skills assessment questionnaire at 6-monthly intervals should engage youth in a gradual shift to self-management and eventual transfer to the adult setting. Youth who feel involved in their transition plan are more likely to engage in the process (Karlsson, et al., 2008; Kirk, 2008; Soanes & Timmons, 2004; van Staa et al., 2011b).

#### Recommendations for Future Practice

Given that results from this study revealed a discrepancy between youth and caregiver assessment of self-management skill attainment, it is an important factor to consider when designing transition programs to include caregiver perception of readiness. The majority of caregivers welcomed the opportunity to participate in this study. Following completion of the questionnaire, they expressed gratitude at viewing all the self-care management skills required for transition to adult health care, listed on one piece of paper. The experience reinforced many areas in which their youth needed support in the process of attaining self-management skills. This indicates that caregivers may benefit from guidance in transferring these responsibilities to their youth.

Caregivers may have difficulty recognizing youth skill attainment and desire to learn specific skills required for self-care as identified in this study. Without prior discussion regarding the skills required for self-management, caregivers may not know if their child has

contemplated learning a specific skill. Youth often selected the response choice for transition readiness “no, but I want to know” [how to complete this skill necessary for transition to adult health care]. Caregivers seldom selected this option to correspond with their child’s answer. This may indicate that caregivers and youth require more discussions about the youths’ wishes. With identification of gaps in perception of readiness between youth and caregiver identified, counseling and education with the health care team can begin to explore how to move transition readiness forward.

Likewise, youth may benefit from intervention goal setting. Use of the TRAQ helps set the stage establishing level of youth current self-management, in order to prepare them for the next stage of change. Guidance and support of adolescent autonomy by the health care team would probably be beneficial in movement to self-management (Dashiff et al., 2013; Modi et al, 2008). Following initial baseline data obtained from the mean scores on the TRAQ and TRAQ-C, repeated assessments at six-monthly intervals would determine if youth and caregiver report similar perceptions of skill ability.

The experiential process involved in completing the TRAQ and TRAQ-C at six-monthly intervals raises consciousness and awareness with self-evaluation of skills. These external and internal influences may signal readiness to assume a greater role in self-management as described by the Stages of Change theory. Likewise, caregivers may reflect on self-care skills appropriate to transfer to their child. In addition, administering these questionnaires on a bi-annual basis to determine areas requiring improvement would guide clinicians in development of individualized interventions to support youth in transition. Adoption of bi-annual assessments using the TRAQ and TRAQ-C highlight the need for all stakeholders that skill acquisition is a crucial first step in recognition that the move to adult health care is a natural developmental

milestone. In addition, routinely discussing acquisition of skills necessary for youth to assume self-care at an early age should alleviate many of the feelings of anxiety associated with transition to adult health care.

A consensus statement written by the AAP (2002) recommended that by age 14, completion of a written transition readiness assessment, which is updated yearly, is warranted for successful transition. Completion of readiness assessment questionnaires, such as the TRAQ and TRAQ-C during ongoing preparations for transition during pediatric care can accompany youth after transfer to adult care, and utilized by health care teams in guiding discussions and completion of deficits, thereby ensuring continuity of care.

Guided by youth perception of the stage of skill acquisition portrayed by the TRAQ, along with caregiver perception of readiness to transition, nurses are able to effectively and efficiently educate and promote health, while social workers can mediate any misunderstandings and differences of opinion between youth and caregiver. Knowing what stage of preparation the youth with CF perceives him or herself in order to assume self-care management responsibility, provides the health care team with opportunity to tailor interventions through the processes of change. For example, the majority of youth in this study possessed a cell phone, and could therefore be encouraged to access their calendar to assume responsibility for appointment reminders and dates for medication refills.

Furthermore, nurses and social workers should be able to identify potential vulnerable and critical points during transitions, intervene to prevent negative consequences, and encourage self-management necessary for successful timely transfer to adult health care. At present little time is devoted to discussion of transition readiness and self-management skills during routine quarterly clinic visits (Modi et al., 2008).



Given that the majority of youth across all ages report high levels of autonomy when talking with providers, time set aside for private consultation with the health care team about transition and acquisition of transition skills should be part of the routine clinical visit. All clinical staff at the four CF clinics in this study acknowledged that although considered optimal care, in reality, time alone with youth consistently falls short in practice. During this time alone, completion of the questionnaires would ensure non-collaboration of responses and opportunities to explore differences of opinion.

#### Recommendations for Future Research

Additional research to establish the predictive validity of the TRAQ is needed to guide the health care team in optimal timing for transition to adult health care. Longitudinal studies are required to determine whether interventions during youth equate to a more successful transition. Skills related to the acquisition of appointment keeping and tracking health issues even in older youth were considerably lacking. If future research demonstrates that the regression slopes obtained in self-care management skills are generalizable, studying the processes related to skill acquisition and covariance with age is suggested. Furthermore, initial baseline data obtained from the mean scores on the TRAQ and TRAQ-C should be correlated with a six-monthly follow-up to determine if youth and caregiver report similar perceptions of skill ability. In addition, there is scant evidence to link transition preparation to improved outcomes (Bloom et al., 2012; Sawicki, 2014). Longitudinal studies demonstrating successful acquisition of self-management skills by youth may determine whether successful transition correlates with better outcomes post transition, such as decreased utilization of the emergency department, stable

measures of pulmonary function and body mass index, and a decrease in hospitalization for CF exacerbation.

Adaptation of the TRAQ to include a question asking the stage of change for the skill acquisition of chest physical therapy (CPT) may be required for this specific population. Because the TRAQ was developed with all chronic illnesses in mind, there are no specific questions pertaining to performing CPT. Chest PT may be one of the greatest burdens for youth with CF, requiring the most time to complete every day.

Further development of the TRAQ-C, which was modified from the validated TRAQ by the researcher, is necessary. Although the internal reliability of the entire scale was found to be high for the caregiver TRAQ-C (.91), caution in interpreting these findings is advised given the small sample size. A few caregivers requested another category included on the TRAQ-C. Only two overall options were available to them. These included selecting if their child either *did* or *did not* know how to perform a skill. There was no option to select asking if their child knew how to perform a skill, but *chose* not to. By including this option, the health care team could further explore reticence to accomplish the skill. Furthermore, the lively discussion between youth and caregivers following the data collection, lends support for further studies incorporating mixed methods or qualitative approaches to deepen understanding of how caregivers transfer self-care management skills and how youth acquire this knowledge.

### Policy

Policy implications specific to patients with CF include petitioning support from the CF Foundation to include bi-annual self-care assessments of skill management. Eighty-five percent of individuals in the United States with CF receive care in Cystic Fibrosis Care Centers

(McLaughlin et al., 2008). The CF Foundation's Patient Registry collects health information on youth with CF who receive care at CF Foundation-accredited care centers. Yearly reports contain detailed center-specific data in which to compare health outcomes across centers. This information provides data to guide clinicians in identifying health trends, treatments, and in developing clinical care practice guidelines. Therefore, this is the ideal avenue in which to encourage individual clinic adherence to completion of an assessment measure, which is administered to youth and caregivers at 6-monthly intervals. Results from these assessments would then accompany youth as a hand-off report to health care providers in the adult CF Foundation-accredited care centers and other adult clinics. The deficits found in this study in self-care management skills in the domains of appointment keeping and tracking health issues could be remedied with education.

#### Limitations of Study

While this study contributes to the literature on transition readiness in youth with CF, it remains subject to several limitations. As with all studies involving completion of a questionnaire, accuracy of responses rely on self-report and are subject to recall bias. Furthermore, the small sample size may limit generalizability.

#### Self-report

Threats to validity are inherent in self-report, especially when health-risk behaviors are questioned which may portray youth in a less desirable way (Brenner et al., 2003). In this study, self-report bias may manifest as youth wishing to appear more autonomous in their self-care. Furthermore, caregivers may feel that youth skill attainment is a reflection of parenting skills. In order to portray their parenting skills in a more favorable light they may rate youth ability as

higher than in reality. Self-report may also be compromised because some of the questions posed may be difficult to recall.

The capability to recall includes the ability to place events in the appropriate time (Brener et al, 2003). Both youth and caregiver were asked to recall if they had discussed transition with the health care team, and if so, age this occurred and frequency of discussion. There was great variability in these responses, which may indicate inability to recall over a long period of many years.

### Sample Size

A further possible limitation to this study encompassed the small sample size of youth with CF. Other researchers also face this limitation because transition discussion is appropriate only to youth prior to their transfer to adult health care, and excludes younger age children. This eligible age span is small. Furthermore, other researchers have collected data from only one clinical site (Williams et al, 2011; Capelli et al., 1989). In order to complete a more robust investigation, this study included four clinical sites to achieve a larger sample size. This added strength to the study.

### Conclusion

Findings from this study indicate that although increasing age predicts perception of self-care management, the majority of youth age 18-22 were still contemplating skills required in the domain of appointment keeping, and were starting to learn skills in the domain of tracking health issues, and were therefore still dependent on their caregiver in these areas. Results from the regression analysis revealed that for some skills, youth do not report competence until they are nearing adulthood. Further results indicate that at age 14 youth are contemplating, or beginning

to learn self-care management skills in three of the five domains, with the majority actively talking to providers and managing daily activities. This indicates that age 14 is appropriate to begin transition skill evaluation. Many self-management skills take years to attain, while some are possible to learn at an earlier age.

It is beneficial to include caregiver perceptions of readiness in transition programs. Participation by the caregiver in the skills assessment and perception of readiness to complete tasks required for autonomous care of their child, encourages discussion in preparation for youth to assume self-care. Recommendations include individualized education and exploration of issues in transition in order to unite youth and caregiver in skill acquisition, utilizing an individualized process negotiated between dyad and provider in order to engage youth in a gradual shift to self-management. Utilization of instruments such as the TRAQ and TRAQ-C on which to base individualized flexibility is integral to transition readiness. Youth involvement with completion of the instrument should strengthen existing efforts in which transition discussion is *not* being heard by youth, and frame guidance for caregivers in teaching opportunities. Furthermore, frequent transition discussion beginning at an early age should alleviate much of the anxiety surrounding transition, and diminish variance in standard of practice across clinics.

The majority of prior transition research has centered on caregiver and health care provider perception of readiness. It is time to *view youth as the driver in the process* as suggested by AAP (2011), incorporate their perceptions, correct misunderstandings, educate, and support their journey in transition to adult health care, utilizing measures such as the TRAQ, and TRAQ-C as guidance.

**APPENDIX A: TRANSITION READINESS ASSESSMENT QUESTIONNAIRE (TRAQ)**

## Transition Readiness Assessment Questionnaire 5.0

*Directions:* Please check the box that best describes your skill level in the following areas that are important for transition to adult healthcare. There is no right or wrong answer and your answers will remain confidential and private.

	No, I do not know how	No, but I want to learn	No, but I am learning to do this	Yes, I started doing this	Yes, I always do this when I need to
<i>Managing Medications</i>	1	2	3	4	5
1. Do you fill a prescription if you need to?					
2. Do you know what to do if you are having a bad reaction to your medications?					
3. Do you take medications correctly and on your own?					
4. Do you reorder medications before they run out?					
<i>Appointment Keeping</i>	1	2	3	4	5
5. Do you call the doctor's office to make an appointment?					
6. Do you follow-up on any referral for tests or check-ups or labs?					
7. Do you arrange for your ride to medical appointments?					
8. Do you call the doctor about unusual changes in your health (For example: Allergic reactions)?					
9. Do you apply for health insurance if you lose your current coverage?					
10. Do you know what your health insurance covers?					

	No, I do not know how	No, but I want to learn	No, but I am learning to do this	Yes, I started doing this	Yes, I always do this when I need to
11. Do you manage your money & budget household expenses (For example: use checking/debit card)?					
<i>Tracking Health Issues</i>	1	2	3	4	5
12. Do you fill out the medical history form, including a list of your allergies?					
13. Do you keep a calendar or list of medical and other appointments?					
14. Do you make a list of questions before the doctor's visit?					
15. Do you get financial help with school or work?					
<i>Talking with Providers</i>	1	2	3	4	5
16. Do you tell the doctor or nurse what you are feeling?					
17. Do you answer questions that are asked by the doctor, nurse, or clinic staff?					
<i>Managing Daily Activities</i>	1	2	3	4	5
18. Do you help plan or prepare meals/foods?					
19. Do you keep home/room clean or clean-up after meals?					
20. Do you use neighborhood stores and services (For example: Grocery stores and pharmacy stores)?					

© Wood, Sawicki, Reiss, Livingood & Kraemer 2014



**APPENDIX B: TRANSITION READINESS ASSESSMENT QUESTIONNAIRE-  
CAREGIVER (TRAQ-C)**

## Transition Readiness Assessment Questionnaire - Caregiver

*Directions:* Please check the box that best describes your child’s skill level in the following areas that are important for transition to adult healthcare. There is no right or wrong answer and your answers will remain confidential and private.

	No, my child does not know how	No, but my child wants to learn	No, but my child is learning to do this	Yes, my child started doing this	Yes, my child always does this when they need to
<i>Managing Medications</i>	1	2	3	4	5
1. Does your child fill a prescription if they need to?					
2. Does your child know what to do if they are having a bad reaction to their medications?					
3. Do they take medications correctly and on their own?					
4. Do they reorder medications before they run out?					
<i>Appointment Keeping</i>	1	2	3	4	5
5. Does your child call the doctor’s office to make an appointment?					
6. Does your child follow-up on any referral for tests or check-ups or labs?					
7. Does your child arrange for their ride to medical appointments?					
8. Does your child call the doctor about unusual changes in their health (For example: Allergic reactions)?					
9. Does your child apply for health insurance if they lose their current coverage?					

	No, my child does not know how	No, but my child wants to learn	No, but my child is learning to do this	Yes, my child started doing this	Yes, my child always does this when they need to
10. Do they know what their health insurance covers?					
11. Do they manage their money & budget household expenses (For example: use checking/debit card)?					
<i>Tracking Health Issues</i>	1	2	3	4	5
12. Does your child fill out the medical history form, including a list of their allergies?					
13. Does your child keep a calendar or list of medical and other appointments?					
14. Does your child make a list of questions before the doctor's visit?					
15. Do they get financial help with school or work?					
<i>Talking with Providers</i>	1	2	3	4	5
16. Do they tell the doctor or nurse what they are feeling?					
17. Does your child answer questions that are asked by the doctor, nurse, or clinic staff?					
<i>Managing Daily Activities</i>	1	2	3	4	5
18. Does your child help plan or prepare meals/foods?					
19. Does your child keep home/room clean or clean-up after meals?					
20. Does your child use neighborhood stores and services (For example: Grocery stores and pharmacy stores)?					

© Wood, Sawicki, Reiss, Livingood & Kraemer 2014 (Adapted by Valerie Lapp with author permission)

**APPENDIX C: ARNOLD PALMER HOSPITAL FOR CHILDREN IRB APPROVAL  
LETTER**



1414 Kuhl Ave.  
Orlando, FL 32806  
321.843.7000  
orlandohealth.com

FWA # 00000384

DATE: June 10, 2015

TO: Valerie Lapp, MSN, RN  
FROM: Arnold Palmer Medical Center (APMC) IRB

PROJECT TITLE: [736239-2] Perceived readiness to transition to adult healthcare for youth with cystic fibrosis and congruence with their caregivers' views  
REFERENCE #: 15.032.03  
SUBMISSION TYPE: Amendment/Modification

ACTION: APPROVED  
APPROVAL DATE: June 9, 2015  
STUDY EXPIRATION DATE: April 15, 2016  
REVIEW TYPE: Expedited Review

Thank you for your submission of Amendment/Modification materials for this project. The following items were received:

- Amendment/Modification - Amendment or Revision Approval Request (UPDATED: 05/22/2015)
- Protocol - Protocol Amended dated 5/22/2015 Tracked Changes Version (UPDATED: 06/9/2015)
- Protocol - Protocol Amendment dated 5/22/2015 Clean Version (UPDATED: 06/9/2015)

The Arnold Palmer Medical Center (APMC) IRB has APPROVED your submission. This approval is based on an appropriate risk/benefit ratio and a project design wherein the risks have been minimized. All research must be conducted in accordance with this approved submission.

This submission has received Expedited Review based on the applicable federal regulation. The Arnold Palmer Medical Center (APMC) IRB is organized and operates in compliance with DHHS regulations as described in 45 CFR part 46, i.e. The Common Rule, FDA regulations as described in 21 CFR Parts 50 and 56, and guidelines resulting from the International Conference on Harmonisation (ICH) E-6 Good Clinical Practice guidelines as appropriate.

In addition, the Arnold Palmer Medical Center (APMC) IRB operates in compliance with portions of the Health Insurance of Portability Act of 1996 (HIPAA Privacy Rule) that apply to research, as described in 45 CFR Parts 160 and 164 as appropriate.

Please note that any revision to previously approved materials must be approved by this office prior to initiation. Please use the appropriate revision forms for this procedure.

If you have any questions, please contact the IRB Office at (321) 841-5895. Please include your project title and reference number in all correspondence with this committee.

Sincerely,

David Nykanen, MD - Co-Chairman of the APMC Institutional Review Board

This letter has been electronically signed in accordance with all applicable regulations, and a copy is retained within Arnold Palmer Medical Center (APMC) IRB's records.

*Orlando Health Facilities:*    - ARNOLD PALMER HOSPITAL FOR CHILDREN    - SOUTH SEMINOLE HOSPITAL  
- UF HEALTH CENTER AT ORLANDO HEALTH    - WINNIE PALMER HOSPITAL FOR WOMEN & BABIES  
- SOUTH LAKE HOSPITAL    - DR. P. PHILLIPS HOSPITAL    - ORLANDO REGIONAL MEDICAL CENTER  
- HEALTH CENTRAL HOSPITAL

**APPENDIX D: NEMOURS CHILDREN'S HOSPITAL FLORIDA IRB APPROVAL  
LETTER**



**Nemours Office of Human Subjects Protection**  
 10140 Centurion Parkway North  
 Jacksonville, FL 32256  
 Phone: 904-697-4023 Fax: 904-697-4024

**MEMORANDUM**

DATE: July 7, 2015  
 TO: Floyd Livingston, MD  
 FROM: Nemours IRB 2  
 STUDY TITLE: [738816-1] PERCEIVED READINESS TO TRANSITION TO ADULT HEALTHCARE FOR YOUTH WITH CYSTIC FIBROSIS AND CONGRUENCE WITH THEIR CAREGIVERS' VIEWS  
 IRB #: 738816  
 SUBMISSION TYPE: New Project  
 ACTION: APPROVED  
 APPROVAL DATE: July 7, 2015  
 EXPIRATION DATE: July 6, 2016

Thank you for your submission of New Project materials for this research study. Your submission received expedited review based on the applicable federal regulation and meets all DHHS criteria for approval. The above-referenced research study is approved per expedited category 7.

The IRB has determined that:

- This is "Research not involving greater than minimal risk per 45CFR46.404".
- **All approved documents can be found under "Board Documents"**. The requirement for obtaining informed consent/parental permission and assent and authorization for use and disclosure of protected health information is waived based on the applicable federal regulation.
- To continue, the research requires IRB review and approval on an annual basis. July 6, 2016 is the last day that research may be conducted. The Principal Investigator is responsible for the timely submission of the continuing review application. Please post this date on your research calendar. **Please be reminded that applications for continuing review need to be submitted at least 2 weeks ahead of the expiration date to give sufficient lead time for IRB review.**

Reviewed/approved documents in this submission:

- Advertisement - Flyer for Clinic (UPDATED: 06/22/2015)
- Application Form - Application for Initial Review of Human Subjects Research (UPDATED: 06/22/2015)
- Conflict of Interest - Declaration - Research Team Member Agreement Disclosure Statement Version June 2015.docx (UPDATED: 07/6/2015)
- Conflict of Interest - Declaration - Julia Bowser-Research Team Member Agreement and Disclosure Statement (UPDATED: 06/25/2015)
- Conflict of Interest - Declaration - Research Team Member Agreement and Disclosure Statement (UPDATED: 06/22/2015)
- Consent Waiver - Waiver of consent and HIPAA authorization (UPDATED: 06/9/2015)
- CV/Resume - Valerie Lapp CV (UPDATED: 03/27/2015)



- Letter - Marketing Approval for Fyer (UPDATED: 06/22/2015)
- Letter - Participant Letter for Study (UPDATED: 06/22/2015)
- Letter - Nemours physician letter of support for study (UPDATED: 06/15/2015)
- Letter - UCF IRB letter of approval (UPDATED: 06/9/2015)
- Letter - APH IRB letter of approval (UPDATED: 06/9/2015)
- Other - CITI Group 2. Social/Behavioral Research Investigators and Key Personnel (UPDATED: 03/27/2015)
- Other - CITI Group1. Biomedical research Investigators and Key Personnel (UPDATED: 03/27/2015)
- Other - CITI Good Clinical Practice Course (UPDATED: 03/27/2015)
- Protocol - Protocol (UPDATED: 06/22/2015)
- Training/Certification - Livingston Floyd CITI COI Jan 28 2013.pdf (UPDATED: 07/6/2015)

**Investigator Agreement:** As the PI, you have agreed to assure that this research is conducted in compliance with Nemours policy and all applicable federal regulations and [ICH standards], which also includes the following:

- All research must be conducted in accordance with this approved submission. Any revision to approved materials must be approved by the IRB prior to initiation.
- Remember that informed consent/parental permission is a process beginning with a description of the study and insurance of participant understanding followed by a signed consent form. Informed consent must continue throughout the study via a dialogue between the researcher and research participant. Federal regulations require each participant receive a copy of the signed consent document.
- All serious and unexpected adverse events and unanticipated problems affecting participants must be reported promptly to the IRB according to NOHSP policy.
- All non-compliance issues or complaints regarding this study must be reported to the Director, NOHSP.
- All research records must be retained for a minimum of three years.
- A Closure Report must be submitted to the IRB when this protocol is completed.

If you have any questions, please contact Laurie Ward at Nemours Children's Specialty Care, 807 Children's Way, Jacksonville, FL 32207 at (904) 697-3415 or [lward@nemours.org](mailto:lward@nemours.org). Please include your study title and reference number in all correspondence with this office.

**APPENDIX E: UNIVERSITY OF FLORIDA SHANDS HOSPITAL IRB APPROVAL  
LETTER**

DATE: 7/23/2015  
TO: Susan Horky  
Box 100296  
Gainesville, Florida 32610  
FROM: Peter Iafrate, Pharm.D  
Chair IRB-01  
IRB#: **IRB201500323**  
TITLE: PERCEIVED READINESS TO TRANSITION TO ADULT HEALTHCARE FOR YOUTH WITH CYSTIC FIBROSIS AND CONGRUENCE WITH THEIR CAREGIVERS' VIEWS

**Approved as Expedited**

**Expires on: 7/19/2016**

You have received IRB approval to conduct the above-listed research project. Approval of this project was granted on 7/19/2015 by IRB-01. This study is approved as expedited because it poses minimal risk and is approved under the following expedited category/categories:

7. Research on individual or group characteristics or behavior (including, but not limited to, research on perception, cognition, motivation, identity, language, communication, cultural beliefs or practices, and social behavior) or research employing survey, interview, oral history, focus group, program evaluation, human factors evaluation, or quality assurance methodologies. [ Note: Some research in this category may be exempt from the HHS regulations for the protection of human subjects. (45 CFR 46.101(b)(2) and (b)(3).) This listing refers only to research that is not exempt. ]

**Approval Includes, but is not limited to:**

Protocol Version 1

**Consent Waiver Type(s):**

Waiver of Documentation of Informed Consent The researcher will still inform the potential subject about the research and seek to obtain consent, sometimes by including an IRB approved written statement that includes the mandatory elements of consent. However, consent of the subject is not documented by having the subject sign an Informed Consent form.

**HIPAA Waiver Type(s):** to enroll subjects in the study

**Special notes to Investigator:** None

**Principal Investigator Responsibilities:**

The PI is responsible for the conduct of the study. Please review these responsibilities described at: <http://irb.ufl.edu/irb01/researcher-information/researcherresponsibilities.html>  
Important responsibilities described at the above link include:

- Using currently approved consent form to enroll subjects (if applicable)
- Renewing your study before expiration
- Obtaining approval for revisions before implementation
- Reporting Adverse Events
- Retention of Research Records

- Obtaining approval to conduct research at the VA
- Notifying other parties about this project's approval status

cc: Dawn Baker

---

*The Foundation for The Gator Nation*

An Equal Opportunity Institution

*Confidentiality Notice: This e-mail message, including any attachments, is for the sole use of the intended recipients(s), and may contain legally privileged or confidential information. Any other distribution, copying, or disclosure is strictly prohibited. If you are not the intended recipient, please notify the sender and destroy this message immediately. Unauthorized access to confidential information is subject to federal and state laws and could result in personal liability, fines, and imprisonment. Thank you.*

**APPENDIX F: UNIVERSITY OF CENTRAL FLORIDA IRB APPROVAL LETTER**



University of Central Florida Institutional Review Board  
Office of Research & Commercialization  
12201 Research Parkway, Suite 501  
Orlando, Florida 32826-3246  
Telephone: 407-823-2901, 407-882-2901 or 407-882-2276  
[www.research.ucf.edu/compliance/irb.html](http://www.research.ucf.edu/compliance/irb.html)

### Notice that UCF will Rely Upon Other IRB for Review and Approval

From : UCF Institutional Review Board  
FWA00000351, IRB00001138

To : Valerie Lapp

Date : May 07, 2015

IRB Number: SBE-15-11288

Study Title: **Perceived readiness to transition to adult healthcare for youth with cystic fibrosis and congruence with their caregivers' views**

Dear Researcher:

The research protocol noted above was reviewed by the University of Central Florida IRB Designated Reviewer on May 07, 2015. The UCF IRB accepts the Orlando Health's Institutional Review Board review and approval of this study for the protection of human subjects in research. The expiration date will be the date assigned by the Orlando Health Institutional Review Board and the consent process will be the process approved by that IRB.

This project may move forward as described in the protocol. It is understood that the Orlando Health's IRB is the IRB of Record for this study, but local issues involving the UCF population should be brought to the attention of the UCF IRB as well for local oversight, if needed.

All data, including signed consent forms if applicable, must be retained and secured per protocol for a minimum of five years (six if HIPAA applies) past the completion of this research. Any links to the identification of participants should be maintained and secured per protocol. Additional requirements may be imposed by your funding agency, your department, or other entities. Access to data is limited to authorized individuals listed as key study personnel.

Failure to provide a continuing review report for renewal of the study to the Orlando Health IRB could lead to study suspension, a loss of funding and/or publication possibilities, or a report of noncompliance to sponsors or funding agencies. If this study is funded by any branch of the Department of Health and Human Services (DHHS), an Office for Human Research Protections (OHRP) IRB Authorization form must be signed by the signatory officials of both institutions and a copy of the form must be kept on file at the IRB office of both institutions.

On behalf of Sophia Dziegielewski, Ph.D., L.C.S.W., UCF IRB Chair, this letter is signed by:

A handwritten signature in black ink, appearing to read "Patria Davis".

Signature applied by Patria Davis on 05/07/2015 03:27:35 PM EDT

IRB Coordinator

**APPENDIX G: LETTER OF APPROVAL TO USE TRAQ**

**To:** Linda Gibson-Young  
**Subject:** RE: TRAQ measure request

Dear Linda – these are both good questions.

In our initial studies, older age and female gender were associated with higher TRAQ scores in CF adolescents.

I have looked at some markers of disease severity (lung function) and have not seen as much in terms of an association, but that may be due to a smaller sample size. I think fielding the questionnaire to more youth would be very helpful. I would recommend the use of the shortened 20 item instrument.

Greg Sawicki

---

**From:** Linda Gibson-Young [<mailto:Linda.Gibson-Young@ucf.edu>]

**Sent:** Friday, December 20, 2013 10:26 AM

**To:** Sawicki, Gregory

**Subject:** TRAQ measure request

Good day Dr. Sawicki,

I have a PhD candidate interested in using the TRAQ to assess readiness in the transition to adult healthcare with cystic fibrosis. We could use version 4.1 or 5.0.

Specific research questions:

- 1) Does age or gender predict perceived readiness to transition to adult healthcare in adolescents and young adults with cystic fibrosis?
- 2) What is the relationship between disease severity on readiness to transition to adult healthcare in adolescents and young adults with cystic fibrosis?

She aims to assess 90 adolescents and young adults beginning February 2014. Thank you for considering use of this measure.

Linda Gibson-Young, PhD, ARNP, FNP-BC

Assistant Professor  
College of Nursing  
University of Central Florida  
12201 Research Parkway, Suite 489  
Orlando, FL 32826  
407-823-1055  
[Linda.gibson-young@ucf.edu](mailto:Linda.gibson-young@ucf.edu)



**APPENDIX H: LETTER OF APPROVAL TO ADAPT TRAQ FOR CAREGIVER USE**

From: "Sawicki, Gregory" <[Gregory.Sawicki@childrens.harvard.edu](mailto:Gregory.Sawicki@childrens.harvard.edu)>  
Date: December 15, 2014 at 10:23:36 PM EST  
To: Linda Gibson-Young <[Linda.Gibson-Young@ucf.edu](mailto:Linda.Gibson-Young@ucf.edu)>  
Subject: RE: TRAQ measure request

Linda - thanks for your email. I think it would be very interesting to adapt the scales for caregivers. I have tried to do so in a small pilot study, but this never went further. The paper describing this data is linked below:

[Clin Pediatr \(Phila\)](#). 2014 Oct;53(11):1062-8. doi: [10.1177/0009922814541169](https://doi.org/10.1177/0009922814541169). Epub 2014 Jul 7.

**Ready, set, stop: mismatch between self-care beliefs, transition readiness skills, and transition planning among adolescents, young adults, and parents.**

[Sawicki GS](#)<sup>1</sup>, [Kelemen S](#)<sup>2</sup>, [Weitzman ER](#)<sup>3</sup>.

**Author information**

**Abstract**

Health care transition (HCT) from pediatric to adult-focused systems is a key milestone for youth. Developing self-care skills and HCT planning are key elements. In a survey at 4 pediatric specialty clinics to 79 youth aged 16 to 25 years and 52 parents, skill-based HCT readiness was assessed using the Transition Readiness Assessment Questionnaire (TRAQ). Multivariable logistic regression evaluated the association between TRAQ scores and self-care beliefs. In all, 70% of youth and 67% of parents believed that they/their child could manage their care. Only 38% of youth and 53% of parents reported thinking about HCT; only 18% of youth and 27% of parents reported having a HCT plan. Youth with higher TRAQ scores were more likely to believe they could manage their care, controlling for age and gender (adjusted odds ratio = 4.0, 95% confidence interval = 1.7-9.5). Transition readiness

<https://pod51038.outlook.com/owa/>

12/16/2014

skills are associated with self-care beliefs. However, a mismatch exists between high reported self-care beliefs and low levels of transition planning.

---

**From:** Linda Gibson-Young [[Linda.Gibson-Young@ucf.edu](mailto:Linda.Gibson-Young@ucf.edu)]

**Sent:** Friday, December 12, 2014 9:29 AM

**To:** Sawicki, Gregory

**Subject:** RE: TRAQ measure request

Dr. Sawicki,

As per our previous discussion, University of Central Florida PhD (Nursing) student Valerie Lapp is proposing a study titled: HOW DO YOUTH WITH CYSTIC FIBROSIS (CF) PERCEIVE THEIR READINESS TO TRANSITION TO ADULT HEALTH CARE?

Valerie has designed this study to use the Transition Readiness scales as related to age with CF youth. One recent idea was to examine youth and caregiver perception. Could we adapt this scale to examine caregiver perception with transition readiness?

Thanks for your time,

Linda

Linda Gibson-Young, PhD, ARNP, FNP-BC, CNE

Assistant Professor  
Clinical Nurse Practitioner MSN and DNP Program Director  
College of Nursing  
University of Central Florida  
12201 Research Parkway, Suite 489  
Orlando, FL 32826  
Office: 407-823-1055  
Cell: 205-515-6491  
[Linda.gibson-young@ucf.edu](mailto:Linda.gibson-young@ucf.edu)

**APPENDIX I: ADOLESCENT DEMOGRAPHIC COLLECTION FORM**

Please circle your response

Age	14	15	16	17	18	19	20	21	22	23	24	25	
Gender	Male						Female						
Grade in School	N/A	6 <sup>th</sup>	7 <sup>th</sup>	8 <sup>th</sup>	9 <sup>th</sup>	10 <sup>th</sup>	11 <sup>th</sup>	12 <sup>th</sup>					
Year in college	N/A	1	2	3	4								
Number of hours you work	N/A	Less than 21 hours a week						21-39 hours/week			40 hours/week		
Have you had conversations with the cystic fibrosis healthcare team about transitioning to an adult setting?	Yes						No						
If yes, at what age were you when you first had a conversation with the cystic fibrosis health care team about transitioning to an adult setting?	Never	12 and younger				13	14	older than 18					
How often do you discuss transition to adult healthcare with the cystic fibrosis team?	Never	Once a year			Two times a year			Three times a year					
					Every visit								

Thank you for completing this form.

**APPENDIX J: PARENT/CAREGIVER DEMOGRAPHIC COLLECTION FORM**

Please circle your response

Gender	Female	Male			
Education	Less than High School Some College	HS Graduate Associate degree or higher			
Age	Under 30 51-60	31-40 60-70	41-50 over 71		
Marital Status	Married	Single	Domestic Partner		
Are you the primary caregiver (do you take care of your child's medical needs?)	Yes	No	Shared Responsibility		
Have you had conversations with the cystic fibrosis healthcare team about transitioning to an adult setting?	Yes	No			
If yes, at what age was your child when you first had a conversation with the cystic fibrosis health care team about transitioning to an adult setting?	Never 15	12 and younger 16	13 17	14 18	older than 18
How often do you discuss transition to adult healthcare with the cystic fibrosis team?	Never	Once a year Three times a year	Two times a year Every visit		

Thank you for completing this form.

**APPENDIX K: FLYER TO ADVERTISE STUDY ARNOLD PALMER HOSPITAL,  
ORLANDO AND SHANDS, GAINESVILLE**



## **We want to hear from you**

### **All teenagers and young adults 14 years and older**

We are studying your ability to care for yourself as you grow in age and we need your input. During your visit to the clinic, we will ask you and your parent to complete a questionnaire about your own care activities related to cystic fibrosis. If you are interested, please talk with your doctor, nurse, social worker or call Valerie Lapp, doctoral student at UCF 407.928.2438 for more information.



**APPENDIX L: FLYER TO ADVERTISE STUDY NEMOURS, ORLANDO AND  
PENSACOLA**



## All Teenagers and Young Adults 14 Years and Older

- We are inviting you to participate in a research study.
- We want to study your ability to care for yourself as you grow in age and we need your input.
- During your visit to the clinic, we will ask you and your parent to complete a questionnaire about your own care activities related to cystic fibrosis (this will take about 10 minutes to complete).
- If you are interested, please talk with Dr. Floyd Livingston (407) 650.240 at 1717 South Orange Avenue, #100, FL 32806 or call sub-investigator, Valerie Lapp, doctoral student nurse at the University of Central Florida (407) 928.2438 for more information.

If you are unable to reach the researchers listed above and have general questions, or have concerns or complaints about the research, or questions about your rights as a research subject, please contact the Nemours IRB at [NOHSP@Nemours.org](mailto:NOHSP@Nemours.org) or call (904) 697.4022

The logo for Nemours Children's Hospital, featuring the word "Nemours" in a blue serif font, followed by "Children's Hospital" in a smaller blue sans-serif font. A red curved line is positioned below the word "Nemours".

## LIST OF REFERENCES

- American Academy of Pediatrics, American Academy of Family Physicians, and American College of Physicians, Transitions Clinical Report Authoring Group (2011). Supporting the health care transition from adolescence to adulthood in the medical home. *Pediatrics*, *128*, 182-200. doi: 10.1542/peds. 2011-0969
- American Academy of Pediatrics (2002). A Consensus Statement on Health Care Transitions for Young Adults With Special Health Care Needs. *Pediatrics*, *110*(6), 1304-1306.
- American Academy of Pediatrics (1988). Council on Child and Adolescent Health. Age limits of pediatrics. *Pediatrics*, *8*(5), 736.
- American Lung Association (2010). *Cystic Fibrosis*. State of lung disease in diverse communities, 41-44. Retrieved September 2013, from <http://www.lung.org/finding-cures/our-research/solddc-index.html>
- Anthony, S. J., Kaufman, M., Drabble, A., Seifert-Hansen, M., Dipchand, A. I., & Martin, K. (2009). Perceptions of transitional care needs and experiences in pediatric heart transplant recipients. *American Journal of Transplantation*, *9*, 614-619.
- Arnett, J. J. (2000). Emerging adulthood. A theory of development from the late teens through the twenties. *American Psychology*, *55*(5), 460-480.
- Badlan, K. (2006). Young people living with cystic fibrosis: An insight into their subjective experience. *Health and Social Care in the Community*, *14*(3), 262-270.
- Bandura, A. (1977). Self-efficacy: Toward a unifying theory of behavior change. *Psychological Review*, *84*, 191-215.
- Berk, L. E. (2010). *Development through the lifespan*. (5<sup>th</sup> Ed.). Boston: Allyn & Bacon.

- Binks, J. A., Barden, W. S., Burke, T. A., & Young, N. L. (2007). What do we really know about the transition to adult-centered health care? A focus on cerebral palsy and spina bifida. *Archives of Physical Medicine and Rehabilitation*, 88, 1064-1073.
- Bloom, S. R., Kuhlthau, K., van Cleave, J., Knapp, A.A., Newacheck, P., & Perrin, J. M. Health Care transition for youth with special health care needs. *Journal of Adolescent Health*, 51, 213-219.
- Blum, R. W. (1995). Transition to adult health care: Setting the stage. *Journal of Adolescent Health*, 17, 3-5.
- Breaux-Shropshire, T. L., Brown, K. C., Pryor, E.R., & Maples, E. H. (2012). Relationship of blood pressure self-monitoring, medication adherence, self-efficacy, stage of change, and blood pressure control among municipal workers with hypertension. *Workplace Health & Safety*, 60(7), 303-311.
- Bregnballe, V., Schiotz, P. O., & Lomborg, K. (2011). Parenting adolescents with cystic fibrosis: The adolescents' and young adults' perspectives. *Patient Preference and Adherence*, 5, 563-570.
- Brener, N. D., Billy, J. O. G., & Grady, W. R. (2003). Assessment of factors affecting the validity of self-reported health-risk behavior among adolescents: Evidence from the scientific literature. *Journal of Adolescent Health*, 33,436-457.
- Brunfield, K., & Lansbury, G. (2004). Experiences of adolescents with cystic fibrosis during their transition from paediatric to adult health care: A qualitative study of young Australian adults. *Disability and Rehabilitation*, 26(4), 223-234.

- Bryant, R., Young, A., Cesario, S., & Binder, B. (2011). Transition of chronically ill youth to adult health care: Experience of youth with hemoglobinopathy. *Journal of Pediatric Health Care, 25*(5), 275-283.
- Callahan, S. T., & Cooper, W. O. (2004). Uninsurance and health care access among young adults in the United States. *Pediatrics, 116*, 88-95.
- Cappelli, M., MacDonald, N. E., & McGrath, P. J. (1989). Assessment of readiness to transfer to Adult care for adolescents with cystic fibrosis. *Children's Health Care, 18*(4), 218-224.
- Christian, B. J., & D'Auria, J. P. (1997). The child's eye: Memories of growing up with cystic fibrosis. *Journal of Pediatric Nursing, 12*(1), 3-12.
- Cystic Fibrosis Foundation. (Updated 3/19/2014) *Care Center Network*. Retrieved April 2014 from <http://www.cff.org/treatments/carecenternetwork/>
- Dashiff, C., Suzuki-Crumly, J., Kracke, B., Britton, L., & Moreland, E. (2013). Cystic fibrosis-related diabetes in older adolescents: Parental support and self-management. *Journal for Specialists in Pediatric Nursing, 18*, 42-53.
- DiClemente, C. C., Prochaska, J. O., Fairhurst, S. K., Velicer, W. F., Velazquez, M. M., & Rossi, J. S. (1991). The process of smoking cessation: An analysis of precontemplation, contemplation, and preparation stages of change. *Journal of Consulting and Clinical Psychology, 59*(2), 295-304.
- Dobson, J. V., Bryce, L., Glaeser, P. W., & Losek, J. D. (2007). Age limits and transition of health care in pediatric emergency medicine. *Pediatric Emergency Care, 23*(5), 294-297.
- Eakin, M. N., Bilderback, A., Boyle, M. P., Mogayzel, P. J., & Riekert, K. A. (2011). Longitudinal association between medication adherence and lung health in people with cystic fibrosis. *Journal of Cystic Fibrosis, 10*, 258-264.

- Eakin, M. N., & Riekert, K. A. (2013). The impact of medication adherence on lung health outcomes in cystic fibrosis. *Current Opinion in Pulmonary Medicine*, 19(6), 687-691.
- Flume, P. A., Anderson, D. L., Hardy, K. K., & Gray, S. (2001). Transition programs in cystic fibrosis centers: Perceptions of pediatric and adult program directors. *Pediatric Pulmonology*, 31, 443-450.
- Fredericks, E. M., Dore-Stites, D., Lopez, M. J., Well, A., Shieck, V., Freed, G. L. Eder S. J., & Magee, J. C. (2011). Transition of pediatric liver transplant recipients to adult care: Patient and parent perspectives. *Pediatric Transplantation*, 15, 414-424.
- Genberg, B. L., Lee, Y., Rogers, W. H., Willey, C., & Wilson, I. B. (2013). Stages of change for adherence to antiretroviral medications. *AIDS Patient Care & STDs*, 27(10), 567-572.
- Giarelli, E., Bernhardt, B. A., & Pyeritz, R. E. (2008). Attitudes antecedent to transition to self-management of a chronic genetic disorder. *Clinical Genetics*, 74, 325-337.
- Gjengedal, E., Rustøen, T., Wahl, A. K., & Hanestad, B. R. (2003). Growing up and living with cystic fibrosis. *Advances in Nursing Science*, 26(2), 149-159.
- Healthy People 2020. Retrieved September 2013 from <http://www.healthpeople.gov/2020/topics/objectives/2020/pdfs/HP2020objectives.pdf>
- Huang, J. S., Gottschalk, M., Pian, M., Dillon, L., Barajas, D., & Bartholomew, L. K. (2011). Transition to adult care: Systematic assessment of adolescents with chronic illness and their medical teams. *The Journal of Pediatrics*, 159(6), 994-998.
- Jedeloo, S., van Staa, A., Latour, J., & van Exel, J. (2010). Preferences for health care and self-management among Dutch adolescents with chronic conditions: A Q-methodological investigation. *International Journal of Nursing Studies*, 47, 593-603.

- Jones, S. E & Hamilton, S. (2008). The missing link: Paediatric to adult transition in diabetes services. *British Journal of Nursing*, 17(13), 842-847.
- Karlsson, A., Arman, M., & Wikblad, K. (2008). Teenagers with type 1 diabetes: A phenomenological study of the transition towards autonomy in self-management. *International Journal of Nursing Studies*, 45, 562-570.
- Kennedy, A., & Sawyer, S. (2008). Transition from pediatric to adult services: Are we getting it right? *Current Opinion in Pediatrics*, 20, 403-409.
- Kirk, S. (2008). Transitions in the lives of young people with complex healthcare needs. *Child: Care, Health and Development*, 43(5), 567-575.
- Knafl, K. A., & Deatrick, J. A. (1986). How families manage chronic conditions: An analysis of the concept of normalization. *Research in Nursing & Health*, 9(3), 215-222.
- Knapp, C., Huang, I., Hinojosa, M., Baker, K., & Sloyer, P. (2013). Assessing the congruence preparedness as reported by parents and their adolescents with special healthcare needs. *Journal of Maternal Child Health*, 17, 352-358.
- Knauth, A., Verstappeln, A., Reiss, J., & Webb, G. D. (2006). Transition and transfer from pediatric to adult care of the young adult with complex congenital heart disease. *Cardiology Clinical*, 24(4), 619-629
- Lindsay, S., Kingnorth, S., & Hamdani, Y. (2011). Barriers and facilitators of chronic illness self-management among adolescents: A review and future directions. *Journal of Nursing and Healthcare of Chronic Illness*. doi:10.1111/j.1752-9824.2011.01090.x
- Lotstein, D. S., McPherson, M., Strickland, B., & Newacheck, P. W. (2005). Transition planning for youth with special health care needs: Results from the National Survey of Children with Special Health Care Needs. *Pediatrics*, 115(6), 1562-1568.



- Lubkin, I. M., & Larson, P. D. (1998). *Chronic illness: Impact and interventions* (4<sup>th</sup> ed.). Sudbury, Massachusetts: Jones and Bartlett.
- Marshall, S. J., & Biddle, S. J. H. (2001). The Transtheoretical Model of behavior change: A meta-analysis of applications to physical activity and exercise. *Annals of Behavioral Medicine*, 23(4), 229-246.
- McCurdy, C., DiCenso, A., Boblin, S., Ludwin, D., Bryant-Lukosius, D., & Bosompra, K. (2006). There to here: Young adult patients' perceptions of the process of transition from pediatric to adult transplant care. *Progress in Transplantation*, 16(4), 309-316.
- McLaughlin, S. E., Diener-West, M., Indurkha, A., Rubin, H., Heckmann, R., & Boyle, M. P. (2008). Improving transition from pediatric to adult cystic fibrosis care: Lessons from a national survey of current practices. *Pediatrics*, 121, e1160-e1167.
- McPherson, M., Thaniel, L., & Minniti, C. (2009). Transition of patients with sickle cell disease from pediatric to adult care: Assessing patient readiness. *Pediatric Blood Cancer*, 52, 838-841.
- Michaud, P. A., Suris, J. C, Viner, R. (2007). The adolescent with a chronic condition: Epidemiology, developmental issues and health care provision. *World Health Organization*, 1-43.
- Modi, A. C., Marciel, K. K., Slater, S. K., Drotar, D., & Quittner, A. L. (2008). The influence of parental supervision on medical adherence in adolescents with cystic fibrosis: Developmental shifts from pre to late adolescence. *Children's Health Care*, 37, 78-92.
- Peter, N. G., Forke, C. M., Ginsberg, K. R., & Schwarz, D. F. (2009). Transition from pediatric to adult care: Internists' perspectives. *Pediatrics*, 123, 417-423.

- Prochaska, J. O. (2008). Decision making in the Transtheoretical Model of behavior change. *Medical Decision Making*, Nov-Dec., 845-849. doi: 10.1177/0272989X08327068.  
Retrieved December 2013, from <http://mdm.sagepub.com/content/28/6/845>
- Prochaska J. O., & DiClemente C. C. (1982). Transtheoretical therapy: Toward a more integrative model of change. *Psychotherapy*, 19, 276-288.
- Prochaska J. O., & DiClemente C. C. (1983). Stages and processes of self change of smoking: Toward an integrative model of change. *Journal of Clinical Psychology*, 51, 390-395.
- Prochaska J. O., & DiClemente C. C. (1986). The Transtheoretical approach. In J. C. Norcross, *Handbook of eclectic psychotherapy* (pp.163-200). New York: Brunner/Mazel.
- Prochaska, J. O., DiClemente, C. C., & Norcross, J. C. (1992). In search of how people change: Applications to addictive behaviors. *American Psychologist*, 47(9), 1102-1114.
- Prochaska, J. O., & Velicer, W. F. (1997). The Transtheoretical Model of health behavior change. *American Journal of Health Promotion*, 12(1), 38-48.
- Prochaska J. O., Velicer, W. F., Rossi, J. S., Goldstein, M. G., Mascus, B. H., Rakowski, W., Fiore, C., Harlow, L. L., Redding, C. A., Rosenbloom, D., & Rossi, S. R. (1994). Stages of change and decisional balance for 12 problem behaviors. *Health Psychology*, 13(1), 39-46.
- Reed-Knight, B., Blount, R. L., & Gilleland, J. (2014). The transition of health care responsibility from parents to youth diagnosed with chronic illness: A developmental systems perspective. *Families, Systems, & Health*, 32(2), 219-234.
- Reid, G. J., Irvine, M. J., McCrindle, B. W., Sananes, R., Ritvo, P. G., Siu, S. C., & Webb, G. (2004). Prevalence and correlates of successful transfer from pediatric to adult health

- care among a cohort of young adults with complex congenital heart defects. *Pediatrics*, *113*(3), 197-205.
- Reiss, J., & Gibson, R. (2002). Health care transitions: Destinations unknown. *Pediatrics*, *110*(6), 1307-1314.
- Reiss, J. G., Gibson, R. W., & Walker, L. R. (2005). Health care transition: Youth, family, and provider perspectives. *Pediatrics*, *115*(1), 112-120.
- Ryan, R. M. & Deci, E. L. (2000). Self-determination theory and the facilitation of intrinsic motivation, social development, and well-being. *American Psychology*, *55*(1), 68-78.
- Sawicki, G. S., Kelemen, S., & Weitzman, E. R. (2014). Ready, set, stop: Mismatch between self-care beliefs, transition readiness skills, and transition planning among adolescents, young adults, and parent. *Clinical Pediatrics*, *53*(11), 1062-1068.
- Sawicki, G. S., Lukens-Bull, K., Yin, X., Demars, N., Huang, I., Livingood, W., Reiss, J., & Wood, D. (2011). Measuring the transition readiness of youth with special healthcare needs: Validation of the TRAQ-Transition Readiness Assessment Questionnaire. *Journal of Pediatric Psychology*, *36*(2), 160-171.
- Scal, P., Davern, M., Ireland, M., & Park, K. (2008). Transition to adulthood: Delays and unmet needs among adolescents and young adults with asthma. *Journal of Pediatrics*, *152*, 471-475.
- Soanes, C., & Timmons, S. (2004). Improving transition: A qualitative study examining the attitudes of young people with chronic illness transferring to adult care. *Journal of Child Health Care*, *8*(2), 102-112.
- Tuchman, L. K., Schwartz, L. A., Sawicki, G. S., & Britto, M. (2010). Cystic fibrosis and transition to adult medical care. *Pediatrics*, *125*, 566-573.

- Tuchman, L. K., Slap, G. B., & Britto, M. T. (2008). Transition to adult care: Experiences and expectations of adolescents with a chronic illness. *Child: Care, Health and Development, 34*(5), 557-563.
- United Nations Youth. (2008). Learning to live together: What do you mean by “youth”? Retrieved December 2014 from <http://www.unesco.org/new/en/social-and-human-sciences/themes/youth/youth-definition>
- US Department of Health and Human Services’ Maternal and Child Health Bureau (2011). Special health issues: Transition. Retrieved April 2014 from [www.hscsn-net.org/.../Transition %20Special%20Health%20Issues 508...](http://www.hscsn-net.org/.../Transition%20Special%20Health%20Issues%20508...)
- van Staa, A. L., Jedeloo, S., van Meeteren, J. & Latour, J. M. (2011a). Crossing the transition chasm: Experiences and recommendations for improving transitional care of young adults, parents and providers. *Child: Care, Health and Development, 37*(6), 821-832.
- van Staa, A., van der Stege, H. A., Jedeloo, S., Moll, H.A., & Hilberink, S. R. (2011b). Readiness to transfer to adult care of adolescents with chronic conditions: Exploration of associated factors. *Journal of Adolescent Health, 48*, 295-302.
- Viner, R. (2001). Barriers and good practice in transition from paediatric to adult care. *Journal of the Royal Society of Medicine, 40*(94), 2-4.
- Wadsworth, B. J. (2004). *Piaget’s theory of cognitive and affective development*. (5<sup>th</sup> ed.). Boston: Pearson.
- Watson, A. R. (2005). Problems and pitfalls of transition from paediatric to adult renal care. *Pediatric Nephrology, 20*, 113-117.

- Wiener, L., Battles, H., Ryder, C., & Zobel, M. (2007). Transition from a pediatric HIV intramural clinical research program to adolescent and adult community-based care services: Assessing transition readiness. *Social Work in Health Care, 46*(1), 1-19.
- Willey, C., Redding, C., Stafford, J., Garfield, F., Geletko, S., Flanigan, T., Melbourne, K., Mitty, J., & Caro, J. J. (2000). Stages of adherence with medication regimens for chronic disease: Development and validation of a measure. *Clinical Therapeutics, 22*(7), 858-871.
- Williams, T. S., Sherman, E., Dunseith, C., Mah, J. K., Blackman, M., Latter, J., Mohamed, I., Slick, D., & Thornton, N. (2011). Measurement of medical self-management and transition readiness among Canadian adolescents with special health care needs. *International Journal of Child and Adolescent Health, 3*(4), 527-535.
- Wood, D. L., Sawicki, G. S., Miller, M. D., Smotherman, C., Lukens-Bull, K., Livingood, W. C., Ferris, M., & Kraemer, D. F. (2014). The Transition Readiness Assessment Questionnaire (TRAQ): Its structure, reliability, and validity. *Academic Pediatrics, 14*(4), 415-422.
- Wong, L. H. L., Chan, F. W. K., Wong, F. Y. Y., Wong, E. L. Y., Fun Huen, K., Yeoh, E., & Fok, T. (2010). Transition care for adolescents and families with chronic illnesses. *Journal of Adolescent Health, 47*, 540-546.
- Zack, J., Jacobs, C. P., Keenan, P. M., Harney, K., Woods, E. R., Colin, A. A., & Emans, S. J. (2003). Perspectives of patients with cystic fibrosis on preventive counseling and transition to adult care. *Pediatric Pulmonology, 36*, 376-383.

Zhang, L. F., Ho, J. S. W., & Kennedy, S. E. (2014). A systematic review of the psychometric properties of transition readiness assessment tools in adolescents with chronic disease. *BMC Pediatrics*, *14*(4). Retrieved April 2014 from <http://link.springer.com/article/10.1186%2F1471-2431-14-4>

Zindani, G. N., Streetman, D. D., Streetman, D. S., & Nasr, S. Z. (2006). Adherence to treatment in children and adolescent patients with cystic fibrosis. *Journal of Adolescent Health*, *38*, 13-17.