

SELF-CARE INDEPENDENCE AND READINESS TO TRANSFER  
FROM PEDIATRIC TO ADULT HEALTH CARE IN CYSTIC FIBROSIS

By

KRISTEN K. MARCIEL

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To adolescents with cystic fibrosis and to my mother for her support

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By

Kristen K. Marciel  
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As patients with cystic fibrosis (CF) are living longer, transferring from pediatric to adult health care is becoming an increasingly prominent issue. Despite the availability of an adult provider, approximately 25% of adults with CF receive care from a pediatrician. Across studies, no standard practices as to when and how to transfer patients from pediatric to adult health care were found. The current study seeks to adapt a patient self-report measure of self-care independence, and to measure potential correlates of self-care independence in patients with CF. In addition, this study seeks to assess the relationship between proposed psychosocial variables, self-care independence, and readiness to transfer.

Participants were recruited from four CF centers across the Eastern United States. Pediatric ( $n = 50$ ) and adult ( $n = 10$ ) patients with CF participated in this study. Pediatric patients completed self-report measures of self-care independence, executive functions, and CF knowledge. Parents of pediatric patients completed psychosocial measures, including a demographic questionnaire, family functioning questionnaire, parental distress measure, and self-care independence scale. Patients, parents, physicians, nurses, and social workers rated the readiness of their patient to transfer to adult care.

Psychometric properties of the adapted self-care independence scale ranged: strong internal consistency, adequate test-retest reliability, and weak concurrent validity with CF knowledge. The self-care independence scale failed to discriminate between pediatric and adult patients. The measure showed good agreement between parents and pediatric patients. The psychosocial variables were not related to self-care independence, contrary to the hypothesis. Age and health status were statistically significant correlates of the physician's rating of readiness to transfer, with the model accounting for 60% of the variance. Self-care independence did not contribute to the physician's rating of readiness. Results were similar for the ratings by nurses and social workers. Exploratory analyses suggested that family functioning and CF knowledge accounted for variance in nurse ratings of readiness, above and beyond age and health status.

Overall, mixed results regarding the psychometric properties of the self-report of self-care independence scale were found. Older age and better health was related to greater readiness to transfer by the medical team. In addition, worse family functioning and more CF knowledge were related to nurse ratings of readiness. Small sample size limits the options for statistical analyses and the cross-sectional design prevents evaluation of causality. Future longitudinal studies should investigate the role of age, health status, knowledge, and interventions in predicting successful transition to adult care. In other research, successful transition has been operationalized as a single visit to the adult clinic. Other issues, like satisfaction, make be incorporated into defining successful transition. To the author's knowledge, this is the first study to empirically examine correlates of the CF team's ratings of a patient's readiness to transfer to adult care. Future research should explore variables which are important to patient and parent ratings of readiness.

## CHAPTER 1 INTRODUCTION

### **Pediatric Chronic Illness**

Pediatric chronic illness affects more than one million children in the United States (Wallander, Thompson, & Alriksson-Schmidt, 2003). Newacheck & Taylor (1992) estimate up to 31% of children have a chronic illness, with 34% of children with a chronic illness experiencing moderate to severe disease and impairment. These children experience a number of functional limitations that effect their self-care behaviors, education, and social interactions on a daily basis. Children with chronic health conditions and their families are also at increased risk for a number of psychosocial problems including poor adjustment, increased internalizing and externalizing disorders, low self-esteem, and less than optimal family functioning (Cadman, Boyle, Szatmari, & Offord, 1987; Cadman, Rosenbaum, Boyle, & Offord, 1991; Gortmaker, Walker, Weitzman, & Sobol, 1990; Williams et al., 1999). Some studies report improvements in adjustment over the lifespan, while other studies suggested poor adjustment to chronic disease (e.g., Northam, Anderson, Adler, Werther, & Warne, 1996; Noll et al., 1997). Most significant and troubling is that children with chronic health conditions have a reduced life expectancy, which varies based on the specific health condition.

Historically, a number of pediatric chronic health conditions were associated with reduced life expectancy. Fortunately, medical advances have improved life expectancy, with 90% of children with a chronic health condition surviving into adulthood (Hagood, Lenker, & Thrasher, 2005; Wallander et al., 2003). Along with this positive epidemiological change, unique challenges of an extended lifespan arise for patients with a chronic health condition. A paramount goal for these individuals “is to develop into autonomous, healthy, and well-functioning adults” (Wallander et al., 2003, p. 143). This is a new realm of health care for

providers and clinical researchers working with these conditions, who previously were not routinely faced with the task of helping these children and adolescents make a transition to adult care and subsequently manage their illness through the unique challenges of young adulthood. Not surprisingly, there are a number of questions being raised as to how to best care for and prepare adolescents for life as a young adult with a severe chronic illness. This is no more evident and challenging than in the area of cystic fibrosis.

### **Cystic Fibrosis**

Cystic fibrosis (CF), the most common fatal recessive genetic illness impacting predominantly Caucasians, occurs in one of 3,200 live births each year in the United States and currently affects approximately 30,000 people (Cystic Fibrosis Foundation (CFF), 2005). CF progressively impacts the functioning of multiple systems in the body, with over 90% of the morbidity and mortality attributed to degeneration in the lungs. Lung function, as measured by forced expired volume (FEV<sub>1</sub> % predicted), slowly declines over age at a rate of approximately two percent each year from age 6 to 24, and declines more gradually thereafter (CFF, 2003).

CF results from a single genetic defect, with over 1,000 variations and the most common defect being deleterious 508 gene (I need to clarify this a little) (Welsh & Smith, 1995). In 1989, this defect was identified on chromosome 7 (Riordan et al., 1989), and holds the code for the cystic fibrosis transmembrane conductance regulator (CFTR). The CFTR gene produces a protein which transports chloride and sodium across cells, particularly in submucosal glands. This abnormal electrolyte transport results in the production of thick, sticky mucus, affecting the pulmonary, gastrointestinal, pancreatic, and reproductive systems (Welsh & Smith, 1995). Due to reduced mucus clearance from the lungs, infections develop and result in fibrotic tissue and chronic inflammation (CFF, 2003). Some 85-90% of patients with CF experience pancreatic insufficiency, resulting in difficulty absorbing fats and proteins which leads to malnutrition. Some patients

develop insulin deficiency, called CF-related diabetes, and liver damage. Regarding reproduction, most men (98%) have problems with fertility, often due to the absence, malformation, or blockage of the vas deferens. Women have better reproductive capabilities, though conception is often difficult due to an excess of cervical mucus.

Diagnostic criteria for CF consist of both clinical features and laboratory results. The “gold standard” for diagnosis of over 40 years is the sweat test, which can be used with patients as young as 48 hours (CFF, 2003). Diagnosis is determined by the quantity of chloride in the sweat sample. Approximately 50% of children are diagnosed by six months of age (Stark, Mackner, Patton, & Acton, 2003), and 80% are diagnosed by age 3 years (CFF, 2005). Carrier tests accurately detect approximately 90% of people with one defective gene (Caskey et al., 1990). Neonatal screening is limited and subject to false positives, but has been associated with better nutritional status in early childhood (Farrell et al., 1997).

Given the multiple systems affected by CF, the medical regimen is complex and time-consuming and typically includes antibiotic treatments, enzyme replacement, chest physiotherapy, nebulized bronchodilators, nebulized mucolytic agents, and additional calorie intake (Eiser, Zoritch, Hiller, Havermans, & Billig, 1995; Orenstein, 1997). The order and technique of the treatment requires proper training and attention. For example, inhaled mucolytic agents are often prescribed prior to chest physiotherapy, which consists of a caregiver clapping on various chest sites (Stark et al., 2003). This daily medical regimen can be difficult to fit into a family’s schedule because it can take up to two hours per day (Eiser et al., 1995).

As in other chronic illness populations, children with CF and their families are at increased risk for negative adjustment. In a study using a diagnostic interview, 58% of children with CF received a psychiatric diagnosis, compared to 23% of non-referred children and 77% of children

referred for psychological concerns (Thompson, Hodges, & Hamlett, 1990). In terms of specific symptoms, children with CF reported worry and negative self-image. Parents struggle with the additional burden of caring for a child with CF. Primary caregivers report higher stress than normative data, specifically tasks related to CF rather than other everyday tasks (Slater, Quittner, Thompson, & Stack, 2003). Mothers spent more time with the child with CF than their healthy sibling, and had less time for recreational activities compared with control families (Quittner & Opiari, 1994). The challenges of the treatment regimen for CF may negatively impact family interactions and functioning. For example, family functioning during mealtime was poorer in families of a child with CF than in families of children without a chronic illness, particularly in communication, affect management, interpersonal involvement, and behavioral control (Janicke et al., 2005).

The extensive medical regimen requires adequate adherence to maintain positive long-term health outcomes across the lifespan (Patterson, Budd, Goetz, & Warwick, 1993). Young children tend to exhibit better adherence than adolescents (DiGirolamo, Quittner, Ackerman, & Stevens, 1997), likely due to supervision from parents. In fact, Drotar and Ievers (1994) found that adolescents took responsibility for their treatment regimen more than younger children, but required assistance from their parents 37% of the time. These studies lack longitudinal or cross-sectional data of young adults. One cross-sectional study of adherence found that older adolescents were less adherent and less supervised by parents when it came to their medical treatments (Modi et al., in press). Adolescents seek independence during this time and may not want as much assistance from their parents. Decreased parental supervision and adherence was associated with worse medical outcomes in adolescents with diabetes (Anderson et al., 1997).

Thus, adolescence represents an important period to address adherence issues, particularly given the lack of research regarding adherence from adolescence to adulthood (Stark et al., 2003).

### **The Changing Epidemiology of Cystic Fibrosis**

As children with CF develop through and beyond adolescence, they face even more challenges associated with managing their illness within the context of increasing independence as an autonomously functioning young adult. This is a growing issue as the epidemiology of CF continues to change (FitzSimmons, 1993). In 1955, few children with CF survived to school age (CFF, 2003; 2005). Due in part to improvements in medical treatments, the life expectancy doubled from 14 years in 1969 to 28 years in 1990 (FitzSimmons, 1993). Currently, the life expectancy of a person with CF is approximately mid-30's (CFF, 2005). Thus, significant developmental changes have occurred in the CF population. In fact, 40% of people with CF registered with the CF Foundation are adults. Adults with CF are now involved in many of typical aspects of life that were previously rare for this population, including completing high school (64.2%), obtaining full-time jobs (35.8%), and marrying (58.3%; CFF, 2005).

Negotiating the transition from adolescence to young adulthood and beyond for individuals with CF is complex balancing act between the new demands of young adulthood and the tasks, behaviors, and restrictions required to manage their illness. As noted previously, adolescents seek increased independence and parents decrease their supervision of treatments (Modi et al., in press). A young adult must balance spending time with work, friends and completing airway clearance treatments. As individuals with CF age, plans for the future increase in importance. Higher education and employment present new challenges for young adults with CF. If adolescent moves away from home, where manual chest physiotherapy was conducted, a jacket with a compressor to create high-frequency chest wall oscillation could be used independently in a dormitory or apartment. A young adult with CF must learn to cook and plan meals that

incorporate treatment recommendations for increased calories. Enzyme replacement may cause embarrassment in social situations, possibly resulting in hesitation to maintain adherence. Risky behaviors, such as smoking, may have additional negative implications for a young adult with CF compared to healthy peers. These self-care behaviors are critical both to normative development and to growing up with CF. Moreover, young adults with CF may also become more interested in romantic relationships and starting families; thus concerns about birth control, pregnancy, and child birth need to be addressed.

Given these unique challenges that adolescents and young adults with CF must face, the question arises as to how health care providers can best assist these individuals in their quest to develop into independent and well-adapted adults within the context of living with and managing CF. For most of their life, these adolescents and young adults with CF have been treated by pediatric pulmonologists that specialize in the care of CF. However, as adolescents begin to encounter new challenges associated with growing independence and young adulthood, they experience issues that may be more appropriately addressed by an adult care provider. Transferring health care responsibility to an adult CF care provider may be a critical piece in helping adolescents and emerging young adults assume greater self-care responsibility and manage the challenges of life associated with young adulthood (Blum, 1995). Adult care may provide patients with developmentally appropriate care by addressing issues, such as fertility, birth control, drug and alcohol use, and transplantation (Webb et al., 2001). Despite the call by the American Academy of Pediatrics and other organizations for developmentally appropriate care (Patterson and Lanier, 1999), much is still unknown about this important period of care and transition. Prior to expanding upon this issue, the concepts of transfer and transition in general, and within the context of CF, will be explained.

## Transfer and Transition in Health Care

As children grow and age, they transition from one stage to another, such as the transitions from home to kindergarten (Nelson, 2004), grade school to high school, and school to work environments (Hanley-Maxwell, Szymanski, & Owens-Johnson, 1998). Developmental tasks involved in transitioning from childhood to adolescence include education, behavior, and friendships (Roisman, Masten, Coatsworth, & Tellegen, 2004). The successful navigation through the social and academic developmental tasks predicts success in romantic relationships and occupations in young adulthood (Roisman et al., 2004).

Developmental transitions occur at various times and rates, depending on the individual. Some adolescents may linger in the period of emerging adulthood, while others may move quickly into independence. Researchers have attempted to determine when and how a person transitions through various life situations, and how to assist adolescents and young adults through this process, within both psychosocial and medical contexts. Transition has been included as a topic for medical students in order to emphasize patient-centered and family-centered care (Hagood, Lenker, & Thrasher, 2005).

To clarify the developing nomenclature with regards to the concepts of transfer and transition within health care, Flume and colleagues (2001) have defined *transfer* as “the actual responsibility of care of the patient being moved from a pediatric setting to an adult care setting” and *transition* as “the purposeful, planned preparation of patients, families, and caregivers for transfer of a patient from a pediatric to an adult care setting” (p.444). The transition from pediatric to adult health care was emphasized over fifteen years ago in the US Surgeon General’s conference on health care transition (Magrab & Millar, 1989). Specifically, the US Surgeon General report identified benefits of transition including: normalizing growing older, encouraging independence, increasing adherence, providing developmentally-appropriate care,

and supporting long-term goals. It is well recognized that the typical course of an illness may create difficulties in the process of transitioning from childhood to adulthood (While et al., 2004). For example, children with chronic health conditions have changing health care needs as disease progresses, as well as changes in logistical needs like insurance coverage and access to adult providers.

Barriers to transition include the patient's relationship with the pediatric team and hesitation to leave (Viner, 2001). This hesitation may also be on the part of the pediatric team. Adult providers may not show as much interest in a disease with pediatric origin compared with diseases originating in adulthood. Thus, it is becoming clearer that health care transition is a complex and dynamic process (Reiss & Gibson, 2002), which researchers and health care professionals are still struggling to define and understand.

### **Transfer and Transition in CF**

There is a lack of uniform agreement as to how to best address the process of transition for patients with CF (Webb, Jones & Dodd, 2001). Patterson and Lanier (1999) note the lack of agreement regarding the necessity to transition, such that the American Academy of Pediatrics allows occasions of continued care by a pediatrician, while the Society of Adolescent Medicine suggests that all adolescents move to adult health care. Although some cases of remaining with the pediatric provider are warranted, both organizations emphasize the importance of developmentally appropriate care. Expectations for patients in pediatric and adult clinics likely differ due to philosophical differences. Pediatric clinics emphasize advising and supporting patients, while adult clinics collaborate and assume independence from patients (Bryon & Madge, 2001).

Some 44 CF Foundation-accredited adult CF programs exist in the United States (Stark et al., 2003). Despite the availability of an adult provider, approximately 25% of adults with CF

receive care from a pediatrician (Anderson, Flume, Hardy, & Gray, 2002). Across a number of studies, no standard practices as to when and whether to transfer care from pediatric to adult health care should occur were found (Anderson et al., 2002; Boyle, Farukhi, & Nosky, 2001). Brumfield and Lansbury (2004) allude to the responsibility of the pediatric clinic to prepare adolescents for the move to adult care. Adult centers also play an active role in assisting adolescents and young adults. In light of the lack of standard practices, important developmental issues may not be adequately addressed.

Not surprisingly, a number of different programs have been developed to increase and improve the transition from pediatric to adult health (Reiss & Gibson, 2002). Some transition clinics consist of both pediatric and adult providers seeing a patient together, often in the pediatric clinic, to assist with the transition of care from one provider to the other. This type of joint program is currently being evaluated in London; interview and questionnaire data have not yet been reported (Lowton et al., 2005). Adolescent-specific clinics provide treatment for only adolescents with CF. These clinics often extend from pediatric clinics, but emphasize issues specific to this age group. Alternatively, patients may abruptly move from the pediatric to adult clinic without any discussion or preparation. This direct transfer of care may be reasonable for patients whose disease minimally impacts their life (While et al., 2004). Finally, some patients choose not to transition care at all, and remain in the pediatric clinic as an adult (Bryon & Madge, 2001).

Philosophical differences between pediatric and adult clinics emphasize different aspects of the progression of CF (Bryon & Madge, 2001). Patients may view that the emphasis of care changes from a focus on growth in pediatric care to the progression of the disease in adult care (Brumfield & Lansbury, 2004). However, distinct benefits of the adult clinic should be

considered. The process of transition provides an opportunity to evaluate and improve knowledge related to CF (Chapman & Bilton, 2004). Some important issues receive less attention in the pediatric clinic. For example, fertility, birth control, drug and alcohol use, and transplantation may be more effectively addressed in adult settings (Webb et al., 2001). Specifically, one study found that 26% of males first learned about their infertility at age 20 (Fair, Griffiths, & Osman, 2000). Nasr and colleagues (1992) found that family planning issues were more effectively addressed in the adult clinic. Social workers in adult centers assist patients in addressing the effects of CF on their ability to work and attend social functions (Stark et al., 2003). Other topics, such as insurance coverage and disability, may receive more attention in adult-oriented clinics. As the life expectancy increases for people with CF, adult-oriented clinics will likely address the charges for developmentally appropriate care, as well as provide hope for longevity (Schidlow, 2002).

Despite the existence of various transition programs, there is a dearth of objective, data-based outcome studies to address the success of transition programs. This lack of outcome studies has been corroborated by a number of researchers (e.g., Scal & Ireland, 2005; Bryon & Madge, 2001). Most studies of transition continue to focus on qualitative aspects, particularly on the opinions of various people (While et al., 2004). Moreover, there is limited agreement as to the best markers of positive outcome of transfer. Though transition programs may result in positive responses from patient and families, the long-term psychosocial and health outcomes associated with transition programs is unknown. Answering these questions will require longitudinal studies across multiple sites to delineate the best transfer interventions.

### **Barriers to Transition**

In addition to the lack of standardized transition programs, other barriers may hinder this process. Schidlow and Fiel (1990) have categorized obstacles to transition as stemming from the

patient, the family, the pediatric caregiver, and the adult caregiver. The patient may have learned dependent behavior, hindering self-care independence. The family may be controlling and overprotective, possibly impacting social support. Finally, the pediatric and adult caregivers determine the environment where transition takes place. Additionally, a strong emotional bond with the pediatric provider has been considered a barrier to transition. Patients and parents hesitate to leave the pediatric clinic due to their comfort with the pediatric team. Alternatively, concerns specifically related to the qualifications of the adult provider have been identified as a barrier to transition (Zack et al., 2003). Pediatricians express more concern about transition than parents, and parents express more concern than patients (Flume, Anderson, Hardy, & Gray, 2001; Anderson et al. 2002). The identification of variables related to when best to transfer to adult care providers, and ultimately which variables are related to successful transfer, may alleviate some of these concerns. These factors may also contribute to the establishment of guidelines for when to transfer.

### **Guidelines for Transition in CF**

Despite the importance of transition, “there exists no clear guidelines or systematic method of judging whether an adolescent is sufficiently prepared for transfer” (Cappelli, MacDonald, & McGrath, 1989, p. 218). Though general guidelines for adolescent care (Scal, 2002) and self-care behaviors (Betz, 2000) are available, no guidelines exist regarding transition from pediatric to adult health care in CF (Schidlow, 2002; Stark et al., 2003). Boyle and colleagues (2001) note that existing transition guidelines focus on non-pulmonary disease, and therefore suggest a need to develop distinct criteria for transferring patients with CF. With the amount of variation in practice and lack of empirical evidence to guide practice, it is not surprising that the CF Foundation has not yet adopted practice guidelines for this critical phase in life. However, the

CF Foundation (1998) did state that CF centers should have identified an adult provider by the year 2000. Unfortunately, this goal has not been met.

As a result, health care professionals use a variety of factors to determine when to transfer patients from pediatric to adult health care, such as age, marital status, pregnancy, patients' preference, and perceived maturity (Anderson et al., 2002). Issues related to disease severity, such as transplantation, present additional obstacles for transfer to adult care (Taylor, Tsang, & Drabble, 2006). In a study of patients' perceptions regarding transfer to adult health care, age (median of 18 years) was identified as the most frequently used criterion, with the application of this criterion occurring in 41.2% of the sample (Anderson et al., 2002). In addition, Flume and colleagues (2001) report that physicians perceive that transfer typically occurs around age 18. However, "age may not be an adequate measure of a patient's readiness to transfer as it does not take into account their knowledge, skills, and available support that will allow them to independently manage their disease"(Patton, Graham, Varlotta, & Holsclaw, 2003, p. 123). Vega-Bricenof and colleagues (2006) suggest that transition should occur according to the individual patient's developmental level. Communication between pediatric and adult providers and self care independence has been identified as important factors related to transition (Parker, 2007). This case description of a relationship between a pediatric and an adult clinic revealed that physical proximity promoted communication between centers, particularly regarding information and planning regarding transition of patients.

### **Self-Care Independence**

Self-care independence has been called the "keystone to 'transition readiness'" (Betz, Redcay, & Tan, 2003). Self-care independence describes the autonomy of a patient in managing their treatment regimen and health care. As adolescents gain independence in all aspects of life (Russell, Reinbold, & Maltby, 1996), they begin to assume increasing responsibility for their

medical regimen from their parents. Adolescents, themselves, recognize self-care independence as important for being prepared to attend the adult clinic (Westwood, Henley, & Willcox, 1999). Thus, strategies and measures to assess disease-specific self-care independence seem are warranted (Patton et al., 2003), and may allow for the identification of particular areas of success or potential improvement.

Self-care independence has been measured using predominantly questionnaire methodologies. For example, parent report of child and adolescent self-care skills has been used in diabetes (Wysocki et al., 1996). Questionnaires regarding family responsibility for the treatment regimen also indicate whether the parent or child assumes primary responsibility for diabetes care (Anderson, Auslander, Jung, Miller, & Santiago, 1990). Unfortunately, there is a dearth of cystic fibrosis specific measures of self-care behaviors. Existing measures of CF self-care independence fail to yield practical information that can help research and patient management (Patton et al., 2003). In response, Patton and colleagues (2003) created a parent-report questionnaire regarding self-care behaviors for use in CF, called the Self-Care Independence Scale (SCIS). This measure covers the various domains of CF treatment regimens, including nutrition, enzymes, oral medications, vitamins, airway clearance, nebulized medications, and communicating with the medical team. The items are listed within domains, and asked whether the child does or is able to do a number of behaviors. For example, an item may read, “Does or can your child... Know how long to perform chest physiotherapy?” The parent answers “yes” or “no” to each item. The SCIS has demonstrated adequate psychometrics as shown by the following: internal consistency of .93, test-retest reliability of .81, construct validity with age ( $r = .67, p < .001$ ), concurrent validity with CF knowledge ( $r = .62, p < .01$ ), and concurrent validity with general dependence ( $r = -.26, p < .05$ ). This measure has been

recommended for tracking self-care independence longitudinally, developing treatment plans, screening for participation in transition programs, and creating descriptions of normative acquisition of self-care skills (Patton et al., 2003). To date, the benefits of this measure have not been utilized as an outcome in a study related self-care independence in adolescents.

As children with CF develop into adolescents and young adults, they are encouraged to assume joint, followed by independent, care of their treatment regimen and overall illness management. Thus, it is important that researchers and clinicians ascertain the adolescent's or young adult's perspective of their level of self-care independence. A self-report version of a self-care independence measure would allow for quick assessment of self-care, which would allow for development of appropriate treatment plans to improve specific behaviors related to the patient's treatment regimen. Another benefit of a self-report self-care independence measure is the ability to track progress over time. While parents may take turns taking an adolescent to a medical appointment, the adolescent would always be available as a consistent informant. A measure of self-care independence might be a useful tool to predict when a patient is ready to transfer to adult-oriented care. Even after the patient transfers to the adult clinic, monitoring self-care independence would allow the identification of areas for potential improvement. However, no patient self-report measures exist that yield specific behaviors related to the CF treatment regimen. This type of data best aids both research and patient disease management.

### **Correlates of Self-Care Independence and Readiness to Transfer**

As previously noted, there are a number of other criteria that have been considered by health care providers for determining whether a patient with CF is ready to transfer from pediatric to adult-oriented care. Identifying correlates of readiness to transfer to adult-oriented health care is necessary in order to develop interventions that target specific variables. Everyday cognitive abilities, family functioning, and parental distress all may impact the adolescent's

ability to care for themselves, which may ultimately impact their long-term readiness to transfer and overall successful transition. However, to the author's knowledge, no study has examined the impact of these variables on self-care independence and readiness to transfer.

### **Executive Functions**

Executive functions describe behaviors of considering information, making decisions, and expressing those decisions (Gallagher, 2007). These cognitive processes may be important when people with a chronic illness understand their disease management, decide to take their medication, plan to do so, and complete the task. In older adults, memory and executive functions predicted their adherence to oral medications, as measured by electronic monitor pill bottle covers (Insel, Morrow, Brewer, & Fiqueredo, 2006). Lower adherence was also associated with worse executive function in a sample of HIV positive adults (Hinkin et al., 2004). In a study of adolescents with type 1 diabetes mellitus, lower executive functions was associated worse metabolic control (Detzer, Whitaker, Isquith, Christiano, & Casella, 2004). Bagner and colleagues (2007) found that parent report of better executive functioning was related to better adherence in children with type 1 diabetes, while age was unrelated to these variables. This suggests that parents may believe that children who are better able to plan and organize are also applying these skills to their health care regimen. Although executive function has been studied in relation to estimates of adherence and health status, it has not been compared with self-care independence. The ability of the adolescent to organize medications and plan treatments likely relate to the amount of responsibility they assume for their own care.

### **Family Factors**

Compared to the lack of research on executive functions and adherence in CF, some research between family factors and adherence in CF exists. Family factors have been identified as associated with CF treatment adherence in a number of studies (e.g., Abbott, Dodd, Gee, &

Webb, 2001). In study of patients with CF and their families, observed positive family relationship quality predicted better treatment adherence to airway clearance and nebulized medications (DeLambo, Ievers-Landis, Drotar, & Quittner, 2004). Specifically, family relationship quality accounted for 9.6% of the variance in mothers' reports and 14.9% of the variance in fathers' reports of adherence, above and beyond demographic variables and disease severity. Less recreation and more emotional expressiveness in families was related to greater compliance (Patterson, 1985). More organization also correlated with compliance (Patterson et al., 1993). Given the association between family factors and adherence, better family functioning likely relates to more self-care independence. Families with positive interactions, good communication, and sufficient support provide an environment that may foster the development of self-care skills.

### **Parental Distress**

A number of studies have examined the adjustment of parents of children with CF. For example, Slater and colleagues (2003) found increased stress and depression in parents of children with CF, compared with normative data. Increased parenting stress is associated with parent ratings of decreased adherence with nutritional recommendations (Eddy et al., 1998). In terms of diagnostic criteria, depression is related to decreased motivation to complete tasks and impairments in daily functioning (American Psychiatric Association, 1994). Thus, assisting a child with complex medical treatments may be hindered by depression. As adolescents assume greater responsibility for their medical treatments, it may be challenging for parents to intervene to make certain that treatments are completed (Foster et al., 2001). For a distressed parent, this may be particularly difficult. Depressed parents may also lack motivation in teaching their children to take more responsibility for their treatments.

## Specific Aims and Hypotheses

As patients with CF are living longer, transferring from pediatric to adult health care is becoming an increasingly prominent issue. Given the theoretical relationship between self-care behaviors and successful transfer to adult care, the proposed study seeks to develop and validate a patient self-report measure of self-care independence, and measure potential correlates of self-care independence in patients with CF. The study will examine potential correlates of self-care and readiness to transfer, and determine if self-care serves as a mediator between psychosocial variables (i.e., executive functions, family functioning, and parental distress) and readiness to transfer. The specific aims and hypotheses of this study are as follows:

- 1) *To adapt a self-report version of a measure of self-care independence, modified from the existing parent-report version.*
  - a. It is predicted that the patient-report self-care measure will demonstrate adequate test-retest reliability over a four-week period.
  - b. It is predicted that the patient-report self-care measure will demonstrate concurrent validity with a CF knowledge questionnaire.
  - c. It is predicted that the patient-report self-care measure will demonstrate adequate internal consistency.
  - d. It is predicted that the patient-report self-care measure will demonstrate discriminative validity by yielding significantly different scores as reported by patients in the pediatric or adult clinic, with patients in the pediatric clinic scoring lower than patients in the adult clinic.
- 2) *To determine the relationship between parent and patient report of self-care independence.* It is hypothesized that patient and parent reports of self-care will be positively correlated. Moreover, it is predicted that patient will report higher levels of self-care than their parents.
- 3) *To examine the association between psychosocial variables with patient and parent reports of self-care independence.* It is hypothesized that executive functions, family functioning, and parental distress will be associated with parent report and patient report of self-care independence, such that executive functions and family functioning will be positively associated with self-care, while parental distress will be negatively correlated with self-care independence.

- 4) *To determine the relationship between reported self-care independence of pediatric patients with CF and their readiness to transfer from the pediatric to the adult clinic.*  
After controlling for age, income, and disease severity, it is expected that both parent and patient report of self-care independence will be positively associated with the physician's rating of readiness to transfer.
  
- 5) *To examine a mediator model that describes the relationship between the psychosocial variables (executive functions, family functioning, and parental distress), self-care independence, and readiness to transfer.*
  - a. It is expected that patient reports of self-care independence will mediate the relationship between the each of the psychosocial variables (executive functions, family functioning, and parental distress) and the physician's rating of readiness to transfer.
  
  - b. It is expected that parent reports of self-care independence will mediate the relationship between the each of the psychosocial variables and the physician's rating of readiness to transfer.

## CHAPTER 2 METHODS

### **Participants**

A total sample of 60 participants with CF, 50 patients from pediatric clinics and 10 patients from the adult clinic, were recruited for participation in this study. Pediatric participants were enrolled from the pediatric CF care centers at University of Florida ( $n = 11$ ), East Tennessee Children's Hospital ( $n = 15$ ), and Cincinnati Children's Hospital Medical Center ( $n = 24$ ). Institutional review boards at each site approved the project. Patients and parents provided assent and consent prior to participating. Pediatric patients ranged in age from 12 to 24 years old ( $M = 15.93$ ,  $SD = 2.89$ ). Sixty pediatric patients were invited to participate. Of those patients, nine patients declined to participate due to the following reasons: four expressed interested in participating but did not sign consent due in part to their lack of availability that day, three patients declined to participate primarily due to the burden of taking the time required to complete the measures, and two patients did not want to participate in a CF-related project. One family dropped out after feeling uncomfortable with the financial questions. All pediatric participants who participated were mailed a second self-care independence measure. Of those mailed, 54% were completed and returned ( $n = 27$ ).

Adult patients ( $n = 10$ ) were recruited from the CF care center at University of Florida ( $n = 3$ ) and from University of Miami ( $n = 7$ ). Adult patients ranged in age from 18 to 38 years old ( $M = 26.8$ ,  $SD = 5.67$ ). All adult patients who were recruited from these two clinics agreed to participate in the study.

### **Inclusion/Exclusion Criteria**

Children and adolescents with CF ages 12 years and older attending the pediatric CF clinics were invited to participate in the study. In addition, adults with CF ages 40 years and

younger attending the adult CF clinic were invited to participate in the study. Participants with CF must have carried their diagnosis for at least one year. Participants aged 17 and younger had the permission of a parent or legal guardian to participate. Exclusion criteria include participating patient or parent/legal guardian unable to read English at the 5<sup>th</sup> grade level, and patient or parent with a major psychiatric disorder.

## **Procedure**

### **Institutional Review Board Approval**

The approval of the Institutional Review Board at each participating CF center (the University of Florida Health Science Center (UF), Cincinnati Children's Hospital Medical Center (CCHMC), East Tennessee Children's Hospital (ETCH), and University of Miami(UM)) was obtained prior to implementation of recruitment and data collection protocol at that site.

### **Recruitment**

A member of each medical team mailed a letter to patients and parents of pediatric patients who have attended a clinic appointment within the past year. The letter included a description of the project, eligibility criteria, and the investigator's contact information, as well as a toll free number to allow patients to call to enroll in the study. Families and adult patients were invited to contact the research team to ask questions or enroll in the study. Alternatively, each family or adult participant could choose to mail their contact information to the Investigator in order for the research team to contact the family. As an additional method of recruitment, families were approached by a member of the medical team during clinic visits, provided with a brief description of the study, and invited to participate in the study. Patients and parents were provided the option of completing the survey during their clinic visit while they were waiting to be seen, completing the survey in the waiting room after their clinic visit, or taking the survey home to be completed and returned in an addressed and stamped envelope. Families who

expressed interest in participating received two copies of the consent form and all the measures at clinic or by mail to the family's home.

### **Survey Administration**

Participants who preferred to complete the forms during their clinic visit first signed the informed consent form and then completed the measures in the exam room or waiting room. Participants who choose to complete the measures at home signed consent forms at the clinic, and then were given the questionnaires, as well as an addressed, stamped envelope to return the measures to the primary investigator. In addition, for participants who completed measures at home, follow-up phone calls were conducted as a reminder. Each participant (the pediatric patient, parent, or adult patient) was compensated for their time with \$5 upon the completion of the assessment.

### **Adaptation and Validation of the Self-Care Independence Scale-Self Report**

#### **Adaptation of the Patient-Report Self-Care Independence Measure**

The original Self-Care Independence Scale-Parent Report (SCIS; Patton et al., 2003) was adapted to create a self-report measure for youth, identified as the Self-Care Independence Scale-Self Report (SCIS-SR). The pronouns were changed to reflect the perspective of the patient, rather than the parent. For example, an item like "Does your child know when to take enzymes?" was changed to "Do you know when to take your enzymes?" After initial changes were made, the measure was tested for readability and face validity. A pediatric pulmonologist, pediatric psychologist, and graduate students reviewed the measure and provided feedback related to clarity, as well as depth and breadth of content. The final measure consisted of 44 adapted items.

Establishment of the psychometric properties of this measure involved determining the internal consistency, test-retest reliability, concurrent validity, and discriminative validity.

### **Internal Consistency**

Internal consistency was calculated using baseline data from all participants who completed the Self-Care Independence Scale-Self Report (SCIS-SR).

### **Test-Retest Reliability**

Each participating patient from the pediatric clinic was mailed a second copy of the Self-Care Independence Scale-Self Report (SCIS-SR) seven days after completion of the SCIS-SR with the original survey packet. They were asked to complete the measure again and to return the measure by mail within two weeks. Measures that were completed and returned within 4 weeks of when the retest measure was sent were included for analysis.

### **Concurrent Validity**

Each participant with CF attending one of the pediatric CF clinics also completed the CF Knowledge questionnaire. Scores on the CF knowledge questionnaire were then compared to scores on the Self-Care Independence Scale-Self Report (SCIS-SR) to establish concurrent validity.

### **Discriminative Validity**

Patients with CF attending the adult CF clinic at Shands/UF or University of Miami were recruited to complete the Self-Care Independence Scale-Self Report (SCIS-SR). The scores of patients from the adult clinics were compared to the pediatric patients. Patients from the adult care clinic were also asked to complete a demographic measure. Scores from the patients in the adult clinic were compared to scores from participants in the pediatric clinic to provide a measure of discriminative validity.

## Measures

### Demographic Questionnaire

Demographic information was collected using a 24-item questionnaire developed for use in this study. Parents and adult patients responded to questions about themselves, such as age, gender, marital status, work status, education, race, and household income. Parents and adult patients also provided information about their participating child or adolescent, including age, grade in school, medical history, and availability of health insurance. Parents and adult patients also provided general information on others in the home, including their ages, relationships, and diagnoses.

### Behavior Rating Inventory of Executive Function

The Behavior Rating Inventory of Executive Function – Self Report Version (BRIEF-SR; Guy, Isquith, & Gioia, n.d.) was used to measure executive functions in everyday life from the self report of children, adolescents, and young adults aged 11 to 22 in the pediatric CF clinics. This 80-item measure has Likert-type ratings ranging from “never” to “often” on a 3-point scale. This measure was based on the BRIEF (Gioia, Isquith, Guy, & Kenworthy, 2000). The creators of the measure recommend at least a fifth grade reading level of the participants. The measure required approximately 10 to 15 minutes to complete, and produced the following subscales: Inhibit, Shift, Emotional Control, Monitor, Working Memory, Plan/Organize, Organization of Materials, and Task Completion. Combinations of these subscales comprised the Behavioral Regulation and Metacognition Indices, as well as the Global Executive Composite (GEC). Two validity scales, Inconsistency and Negativity, assisted with the interpretation of the scores. In previous research, the BRIEF-SR demonstrated high internal consistency for the GEC ( $\alpha = .96$ ) and adequate consistency within scales ( $\alpha = .72-.96$ ). Test-retest reliability produced a strong correlation ( $r = .89$ ) over a five week period. Correlation with the parent version ( $r = .56$ )

suggested adequate inter-rater agreement. Given that skills of planning and organizing are likely important for self-care independence behaviors, specific to managing CF, the Global Executive Composite was used in this study.

### **Family Assessment Device**

The Family Assessment Device (FAD; Epstein, Baldwin, & Bishop, 1983; Miller, Epstein, Bishop, & Keitner, 1985) was used as a measure of family functioning based on the McMaster model, based on a systems perspective (Miller, Ryan, Keitner, Bishop, & Epstein, 2000). This 60-item measure described families based on seven scales: Problem Solving, Communication, Roles, Affective Responsiveness, Affective Involvement, Behavioral Control, and Overall Family Functioning. Family members, including children, age 12 and older can complete this measure (Epstein, Baldwin, & Bishop, 2000), by rating items on a 4-point Likert-type scale ranging from “strongly agree” to “strongly disagree.” Higher scores suggested poorer family functioning. Studies revealed adequate internal consistency ( $\alpha = .71-.92$ ) and test-retest reliability ( $r = .66-.76$ ) in clinical and nonclinical samples (Miller et al., 1985; Kabacoff et al., 1990). Concurrent validity with other family functioning measures has been demonstrated in a pediatric asthma sample (Bihun et al., 2002). Based on existing literature that multiple aspects of family functioning (e.g., family communication, interaction styles, behavioral control, and emotional regulation) are related to adherence, the overall family functioning scale will be used in the current study.

### **Brief Symptom Inventory**

The Brief Symptom Inventory – 18 (BSI-18; Derogatis, 2001) assessed distress in adults by soliciting responses to 18 items using a 5-point Likert-type scale, ranging from 0 (not at all) to 4 (extremely), regarding how often they experienced certain symptoms in the past week. Answers to these items produced scores on three dimensions of depressive, anxious, and somatic

symptoms, as well as a Global Severity Index (GSI). A principal components analysis supported the use of the three subscales. This measure was derived from the Brief Symptom Inventory (Derogatis, 1993) and the Symptom Checklist-90-Revised (SCL-90-R; Derogatis, 1994). The BSI-18 demonstrated concurrent validity with the SCL-90-R, as evidenced by correlations between comparable subscales ( $r = .91-.96$ ). Internal consistency ranged from adequate to good across subscales and the GSI ( $\alpha = .74-.89$ ). The GSI was used in this study as a measure of the overall distress and psychological functioning of parents.

### **Self-Care Independence Scale**

Patton and colleagues (2003) developed a parent-report measure of a child's self-care independence (SCIS) for the CF medical regimen. Scores ranged from 0 to 44, with a mean total score of 28 in a sample of children ages 4 to 17 years (Patton et al., 2003). Items, such as "knowing when to take enzymes," were answered with a "yes" or "no" response. All 44 items requested a response of "yes" or "no." This measure has demonstrated adequate psychometrics. Specifically, high internal consistency was demonstrated by a Cronbach's coefficient alpha of .93. Test-retest reliability over a 4-week period yielded a significant correlation of .81 ( $p < .001$ ). This measure demonstrated adequate concurrent validity, as evidenced by the correlations with a CF knowledge interview ( $r = .62, p < .01$ ) and with a measure of dependent behaviors ( $r = -.26, p < .05$ ). This study will examine the total score of items endorsed as "yes", with higher scores indicating more self-care independence.

### **Self-Care Independence Scale-Self Report**

The original parent-report version of the SCIS was adapted for adolescents and young adults as a self-report measure (see Appendix A). The steps of validation of the Self-Care Independence Scale – Self Report (SCIS-SR) were presented in the Procedures section. Scores were calculated consistent with the parent-report measures, ranging from 0 to 44. The SCIS-SR

will be used in the same way as the SCIS, such that the total number of items endorsed as “yes” will be examined in this study. As with the parent-report measures, higher scores indicate more self-care independence.

### **CF Knowledge Questionnaire**

The CF Knowledge Questionnaire (CFK; Quittner & Drotar, 1997) measure consisted of 21 multiple choice questions, and assessed patients’ knowledge about CF. This shorter version of the more extensive knowledge measure (Quittner & Drotar, 1997) demonstrated adequate internal consistency ( $\alpha = .91$ ) in a study of 47 children and adolescents aged 7 to 17 (Davis, Quittner, Stack, & Yang, 2004). Overall knowledge scores were calculated as percentage correct. Raw scores of knowledge can range from 0 to 36, with higher scores indicating greater CF knowledge.

### **Rating of Readiness to Transfer**

Patients, parents, physicians, nurses, and social workers were asked to rate the participating pediatric patients on their readiness to transfer to the adult clinic. A 5-point Likert-type scale allowed each informant to rate patients from “not at all ready” to “has been ready” ready to transfer. This scale was developed for use in this study (see Appendix B). In addition to the rating, informants were asked to rank order their reason for the rating. Reasons could include items presented to the informant, such as age, health status, emotional maturity, issues related to current functioning, and developmental issues. Informants also had a choice of “other,” with which they could write in additional reasons for their rating of readiness.

### **Pulmonary Function Tests**

Forced expiratory volume in one second ( $FEV_1$  % predicted) has been used as a primary indicator of lung function in CF (Orenstein, 1997). As more obstruction accumulates in the lungs, less volume of air can be expired. Mild lung function is categorized as 70-99%, moderate

as 40-69%, and severe as less than 40% (Fiel, FitzSimmons, & Schidlow, 1994). Lung function data was extracted from the clinic chart or medical record by either a member of the medical team or the primary investigator from the day during which the initial assessment was conducted. This will serve as a measure of disease severity.

### **Power Analyses**

Based on Patton and colleagues (2003) finding of a strong correlation between test and retest scores on a parent-report self-care measure ( $r = .81, p < .001$ ), power analysis (using G\*power) suggests 17 participants are needed to find a significant positive association between the first and second assessments. Previous research regarding the positive correlation between parent report of self-care and children's scores on a CF knowledge interview ( $r = .62, p < .01$ ), power analysis recommends 29 participants to detect a similar relationship. For the regression models, a minimum of ten participants per independent variable will be recruited, as recommended by Harris (1985). Alternatively, Harris also suggests a minimum of 50 participants for a regression analysis. Thus, approximately 50 participants are needed for these analyses.

### **Statistical Analyses**

Descriptive statistics were conducted for all relevant variables. Analyses for the specific aims are as follows:

- 1) *To adapt a new patient-report version of an existing parent-report measure of self-care independence.*
  - a. Internal consistency of the SCIS-SR will be measured using Cronbach's coefficient alpha.
  - b. The short-term stability of the total scores on the SCIS-SR from time 1 and time 2 will be examined using Pearson's  $r$  correlation coefficient to determine the test-retest reliability over a four-week period in a subset of participants. The subset of participants will be defined as those participants who return the questionnaire in

the mail. The response rate will be reported as the percent of participants who returned the second SCIS-SR based on the original sample.

- c. Concurrent validity will be determined by a Pearson's  $r$  correlation coefficient between a CF knowledge questionnaire and total scores on the SCIS-SR.
  - d. Independent samples t-tests will be used to determine whether the mean scores on the SCIS-SR are significantly different between the participants in the pediatric and adult clinics at Shands/UF.
- 2) *To determine the relationship between parent and patient report of self-care independence.* Pearson's  $r$  correlation coefficient will be used to examine the relationship between parent and patient report of self-care independence. Total scores will be compared using paired samples t-tests, to determine if there is a statistically significant difference between parent and patient report of self-care independence.
  - 3) *To examine the correlation between psychosocial variables and self-care independence, as reported by patients and their parents.* Two linear regression models will be used to determine the amount of variance in self-care independence that is accounted for by executive functions, family functioning, and parental distress, while controlling for patient's age, income, and disease severity in the first block. The first regression will examine the variance in patient report of self-care, while the second regression will examine parent report of self-care independence. Beta weights will be examined to determine the individual contribution of the variables.
  - 4) *To determine the relationship between reported self-care independence and readiness to transfer to the adult clinic.* Two hierarchical regressions will be conducted.
    - a. In the first regression, age, income, and disease severity (measured by lung function) will be entered in the first block, and patient report of self-care independence will be entered in the second block as a correlate of the physician's rating of readiness to transfer.
    - b. The second regression will evaluate parent report of self-care independence as a correlate of the physician's rating of readiness to transfer, while also controlling for age, income, and disease severity.
  - 5) *To examine a mediator model that describes the relationship between the correlates of self-care, self-care independence, and readiness to transfer.*
    - a. A mediator model of self-care independence will be tested if hypotheses 3 and 4 are supported. Thus, psychosocial variables would significantly account for variance in self-care independence, and self-care independence would significantly account for variance in readiness to transfer, as recommended by Baron and Kenny (1986). In order to test the role of self-care independence as a mediator, a hierarchical regression will be conducted. The first block will control for demographic variables of age, income, and lung function. The second block will contain the psychosocial variables of executive functions, family functioning,

and parental distress. The third block will consist of self-care independence. Self-care independence will mediate the relationship between psychosocial variables and readiness to transfer, if self-care better accounts for the variance in readiness to transfer, above and beyond the contribution of demographic and psychosocial variables.

- b. The model will be tested using both the parent report and patient report of self-care independence in order to examine these relationships by each informant.

## CHAPTER 3 RESULTS

### Demographics

#### Pediatric Clinic Patients

Age ranged from 12 to 24 years ( $M = 15.89$ ,  $SD = 2.89$ ). Patients recruited from pediatric clinics were similar in age (UF-CCHMC ( $t(32) = 1.11$ ,  $p = .28$ ), UF-ETCH ( $t(23) = .43$ ,  $p = .68$ , CCHMC-ETCH ( $t(37) = -.88$ ,  $p = .39$ ); see Table 1). Gender of the pediatric patients was mostly male (64%). The average lung function, as measured by forced expiratory volume in one second (FEV<sub>1</sub>% predicted), was in the mild range ( $M = 79.42$ ,  $SD = 21.48$ ). Specifically, 70.8% of pediatric patients had mild disease severity to normal lung function, 27.1% moderate, and 2.1% severe. Lung function did not significantly differ by site (UF-CCHMC ( $t(32) = -.29$ ,  $p = .77$ ), UF-ETCH ( $t(23) = -.92$ ,  $p = .37$ , CCHMC-ETCH ( $t(35) = -.79$ ,  $p = .44$ ). Pediatric patients were identified by their parent as 95.6% Caucasian and 4.4% African American. A majority of the participating parents were married (68.2%), while a smaller percentage were divorced (15.9%) or single (15.9%). Parents' education ranged from some high school (8.9%), high school graduate (24.4%), some college (28.9%), college graduate (31.1%), to graduate/professional degree (6.7%). Median income was in the range of \$50,000 to \$59,999. Most pediatric patients had private insurance (68.9%), while fewer were receiving Medicaid (19%). See Table 2.

#### Adult Clinic Patients

Patients in the adult clinic ranged in age from 18 to 38 years old ( $M = 26.80$  years,  $SD = 5.67$ ). Lung function ranged from severe to mild (FEV<sub>1</sub>% predicted, 29 to 87,  $M = 47.00$ ,  $SD = 27.18$ ). These patients were mostly Caucasian (80%), with some patients who were Hispanic (20%). All of the adult patients reported Medicaid or Medicare as their primary insurance (see Table 3).

## Means and Descriptive Information from Questionnaire Measures

### Self-Care Independence Scale-Self-Report

Out of a total possible score of 44, SCIS-SR scores averaged 37 items endorsed as “Yes” ( $SD = 5.99$ , range from 13 to 44 items) for the patients from the pediatric clinic. The patients from the adult clinic averaged 35 items endorsed ( $SD = 7.03$ , range from 18 to 44 items, see Table 4). Age was not related to the SCIS-SR across patients in both clinic settings ( $r = .09$ ,  $p = .49$ ).

### Knowledge

Knowledge scores ranged from 58% to 94% correct ( $M = 73.95\%$ ,  $SD = 10.67$ ). Age and knowledge were moderately, positively correlated ( $r = .55$ ,  $p < .001$ ), such that older pediatric patients scored higher on their knowledge of CF management. Boys ( $M = 27.71$ ,  $SD = 3.75$ ) scored slightly higher on the knowledge questionnaire than girls ( $M = 24.65$ ,  $SD = 3.22$ ,  $t = -2.84$ ,  $p < .01$ ). Knowledge and  $FEV_1$  were not significantly related ( $r = -.28$ ,  $p = .054$ ).

Commonly missed questions included: foods that contain the most energy are fats (91.7%), digestion begins in the mouth (81.3%), inhaled antibiotics are most effective if done after airway clearance (70.8%), and antibiotics are used to control bacteria in the lungs (66.7%).

### Behavior Rating Inventory of Executive Function

The Global Executive Composite was in the normal range on average ( $M T = 48.69$ ,  $SD = 10.27$ , range 33-75). Five participants had clinically elevated problems with the Metacognition Index ( $M T = 49.56$ ,  $SD = 10.10$ , range 34-70). Five participants reported clinically significant difficulty with working memory ( $M T = 50.92$ ,  $SD = 10.19$ , range 33-72), four participants with planning ( $M T = 48.46$ ,  $SD = 9.44$ , range 31-68), four with organizing ( $M T = 49.46$ ,  $SD = 8.78$ , range 36-73), and five with completing tasks ( $M T = 49.69$ ,  $SD = 11.04$ , range 35-81).

### **Brief Symptom Inventory**

Mean parent report of global distress was within the non-clinical range ( $M = 5.71$ ,  $SD = 7.34$ ). Only 8% of parents endorsed symptoms indicate of global distress within the clinically significant range.

### **Family Assessment Device**

The mean score for general family functioning was relatively high ( $M = 6.04$ ,  $SD = 1.02$ , range 1.83 to 7.25). Only 2.6% of the parents report overall family functioning in the clinical range for general functioning compared with cut-off scores based on normative data (Miller et al., 1985).

## **Validation of the SCIS-SR**

The first aim of the study was to adapt the SCIS for patient report. After changing the wording to be appropriate for self report and reviews by experts, this measure was administered to pediatric patients. The results of analysis to examine the reliability and validity of the measure are described below.

### **Internal Consistency**

Internal consistency of the SCIS-SR was measured using Cronbach's coefficient alpha. Results indicated good internal consistency among the items ( $\alpha = .87$ ). This score was slightly lower than the original parent-report measure ( $\alpha = .93$ ; Patton et al., 2003), but was in the good range (Nunnally & Bernstein, 1994).

### **Stability**

The stability of the SCIS-SR was examined using Pearson's  $r$  correlation coefficient to determine the test-retest reliability over a four-week period in a subset of participants ( $M_{T1} = 35.70$ ,  $SD = 6.34$ , range 13-44;  $M_{T2} = 37.81$ ,  $SD = 7.78$ , range 14-44). Although all patients were mailed the second administration, only 27 participants (56%) returned the questionnaire in the

mail. Responses on the SCIS-SR at the two time points demonstrated adequate test-retest reliability ( $r = .75, p < .001$ ), which was similar to the stability of the original measure ( $r = .81, p < .001$ ).

### **Concurrent Validity**

Concurrent validity was determined by a Kendall's tau correlation coefficient, due to non-normally distributed data, between a CF knowledge questionnaire and total scores on the SCIS-SR (skewness = -1.88, kurtosis = 5.17). The correlation between knowledge scores and SCIS-SR showed a weak correlation, which was just significant ( $r = .26, p < .05$ ). Higher knowledge scores were related to higher scores of self-care independence.

### **Discriminative Validity**

An independent samples t-test was used to describe whether the mean scores on the SCIS-SR are significantly different between the participants in the pediatric ( $M = 36.73, SD = .86$ ) and adult clinics ( $M = 34.50, SD = 2.22$ ). The scores across these two clinics were not significantly different ( $t(56) = 1.04, p = .30$ ).

The first aim of the study was partially supported. Support for internal consistency and test-retest reliability (stability) were found. Concurrent validity was weak, although there was a statistically significant relationship between self-care independence and knowledge of CF management. This study failed to show discriminative validity of the self-care independence measure.

### **Relationship between Parent and Patient Report of Self-Care Independence**

The second aim of this study was to examine the relationship between parent and patient report of self-care independence. Total scores were compared using paired samples t-tests, to determine whether the difference between parent and patient reports of self-care independence were statistically significant. Parents reported slightly higher self-care independence for their

child ( $M = 37.29$ ,  $SD = 5.56$ , range 18-44) relative to child report ( $M = 35.89$ ,  $SD = 6.26$ , range 13-44) of self-care independence. However, these scores were not significantly different ( $t(37) = -1.64$ ,  $p = .11$ ). In addition, Pearson's  $r$  correlation coefficient was used to examine the relationship between parent and patient report of self-care independence. Patient and parent reports of self-care independence were moderately correlated ( $r = .61$ ,  $p < .001$ ). Thus, the second hypothesis of the study was supported, such that parents and patient agree about the patient's self-care independence.

### **Relationship between Psychosocial Variables and Self-Care Independence**

The third aim of the study was to determine the relationship between psychosocial variables and self-care independence. Specifically, it was expected that executive functions, family functioning, and parental distress would be associated with parent report and patient report of self-care independence, such that executive functions and family functioning will be positively associated with self-care, while parental distress will be negatively correlated with self-care independence. Two sets of three linear regression models were used to determine the amount of variance in self-care independence that is accounted for by executive functions, family functioning, and parental distress in the second block, while controlling for patient's age, income, and disease severity in the first block.

Prior to executing the regression analysis, a correlation matrix including the variables of interest was examined. Contrary to the hypothesis, the psychosocial variables were not correlated with self-care independence ( $r$ s ranging from  $-.09$  to  $.03$ , all  $p$ -values were non-significant), by either patient or parent report. Although a regression analysis was no longer warranted, it is presented below as it was part of the original analytic plan.

In the first of a set of three regressions, age, income, and disease severity were entered in the first block and the Global Executive Composite score was entered in the second block as

correlates of patient-reported self-care independence. The model accounted for 27% of the variance ( $F(3,38) = 4.62, p < .01$ ), with age ( $\beta = .55, p < .001$ ) as the strongest correlate of patient-reported self-care independence. The addition of executive functioning failed to contribute to the model, increasing the total variance by 2% ( $F(1,37) = .94, p = .34$ ). Similarly, after controlling for age, income, and disease severity (24%  $R^2$ ,  $F(3,32) = 3.35, p < .05$ ), General Family Functioning did not add to the model (1%  $R^2\Delta$ ,  $F(1,31) = .29, p = .59$ ). This was also true for parental distress (see Tables 5-7).

In the second set of three regressions, age, income, and disease severity were entered in the first block and the Global Executive Composite score was entered in the second block as correlates of parent-reported self-care independence. The model was non-significant after the first block of demographic variables ( $F(3,32) = 1.50, p = .23$ ). The addition of executive functioning failed to contribute to the model ( $F(1,31) = 2.17, p = .15$ ). Similarly, after controlling for age, income, and disease severity (12%  $R^2$ ,  $F(3,32) = 1.50, p = .23$ ), General Family Functioning did not add to the model (0%  $R^2\Delta$ ,  $F(1,31) = .002, p = .97$ ). Parental distress also did not contribute to the model (see Tables 8-10).

### **Relationship between Self-Care Independence and Readiness to Transfer**

The fourth aim of the study was to determine the relationship between self-care independence and readiness to transfer to the adult clinic. The ratings of readiness to transfer by the physician were selected as the outcome in these analyses because the medical team, led by the physician, is primarily responsible for the decision regarding transfer of care. Although this is often a collaborative decision with parents and patients, the physician often determines the final outcome and the time of transfer of care. On the other hand, cystic fibrosis centers are characterized by their multidisciplinary teams. Given the moderate correlations among team

members, their ratings of readiness were also averaged to be used as a dependent variable. Two hierarchical regressions were conducted, for each of the following dependent variables: medical team's average rating, physician rating, nurse rating, and social worker rating.

### **Medical Team's Average Rating**

In the first regression, age, income, and disease severity (measured by FEV<sub>1</sub> percent predicted) were entered in the first block, and patient-report of self-care independence was entered in the second block as a correlate of the average of the medical team's rating of readiness to transfer. The model accounted for 59% of the variance ( $F(3,38) = 18.17, p < .001$ ), with age ( $\beta = .81, p < .001$ ) and disease severity ( $\beta = .42, p < .001$ ) as the strongest correlates of the medical team's average rating of readiness (see Table 11). The addition of patient-reported self-care independence did not significantly add to the amount of variance explained above and beyond the variables in block one to the model ( $F(1,37) = .07, p = .80$ ). This suggests that team members rate older and healthier patients as more ready to transfer than younger or more ill patients.

The second regression evaluated parent report of self-care independence as a correlate of the average of the medical team's rating of readiness to transfer, while also controlling for age, income, and disease severity. The model accounted for 53% of the variance ( $F(3,32) = 11.78, p < .001$ ), with age ( $\beta = .79, p < .001$ ) and disease severity ( $\beta = .47, p < .001$ ) as the strongest correlate of the medical team's average rating of readiness (see Table 12). Similarly, the addition of parent-reported self-care independence did not significantly add to the amount of variance explained above and beyond the variables in block one ( $F(1,31) = .06, p = .80$ ).

## Physician Rating

In the first regression, age, income, and disease severity (measured by FEV<sub>1</sub> percent predicted) were entered in the first block, and patient-report of self-care independence was entered in the second block as a correlate of the physician's rating of readiness to transfer. The model accounted for 60% of the variance ( $F(3,34) = 16.48, p < .001$ ), with age ( $\beta = .80, p < .001$ ) and disease severity ( $\beta = .37, p < .001$ ) as the strongest correlates of the physician's rating of readiness (see Table 13). The addition of patient-reported self-care independence did not significantly add to the amount of variance explained above and beyond the variables in block one to the model ( $F(1,33) = .64, p = .43$ ). This suggests that physicians rate older and healthier patients as more ready to transfer than younger or more ill patients.

The second regression evaluated parent report of self-care independence as a correlate of the physician's rating of readiness to transfer, while also controlling for age, income, and disease severity. The model accounted for 45% of the variance ( $F(3,29) = 7.76, p < .001$ ), with age ( $\beta = .68, p < .001$ ) and disease severity ( $\beta = .43, p < .01$ ) as the strongest correlates of the physician's rating of readiness (see Table 14). Similarly, the addition of parent-reported self-care independence did not significantly add to the amount of variance explained above and beyond the variables in block one ( $F(1,28) = .38, p = .54$ ).

## Nurse Rating

In the first regression, age, income, and disease severity (measured by FEV<sub>1</sub> percent predicted) were entered in the first block, and patient-report of self-care independence was entered in the second block as a correlate of the nurse's rating of readiness to transfer. The model accounted for 46% of the variance ( $F(3,38) = 10.94, p < .001$ ), with age ( $\beta = .72, p < .001$ ) and disease severity ( $\beta = .42, p < .01$ ) as the strongest correlates of the nurse's rating of

readiness (see Table 15). The addition of patient-reported self-care independence did not significantly add to the amount of variance explained above and beyond the variables in block one to the model ( $F(1,37) = .00, p = .96$ ). This suggests that nurses rate older and healthier patients as more ready to transfer than younger or more ill patients.

The second regression evaluated parent report of self-care independence as a correlate of the nurse's rating of readiness to transfer, while also controlling for age, income, and disease severity. The model accounted for 41% of the variance ( $F(3,32) = 7.38, p < .001$ ), with age ( $\beta = .69, p < .001$ ) and disease severity ( $\beta = .48, p < .01$ ) as the strongest correlates of the nurse's rating of readiness (see Table 16). Similarly, the addition of parent-reported self-care independence did not significantly add to the amount of variance explained above and beyond the variables in block one ( $F(1,31) = .07, p = .79$ ).

### **Social Worker Rating**

In the first regression, age, income, and disease severity (measured by FEV<sub>1</sub> percent predicted) were entered in the first block, and patient-report of self-care independence was entered in the second block as a correlate of the social worker's rating of readiness to transfer. The model accounted for 49% of the variance ( $F(3,35) = 11.19, p < .001$ ), with age ( $\beta = .76, p < .001$ ) and disease severity ( $\beta = .33, p < .05$ ) as the strongest correlates of the social worker's rating of readiness (see Table 17). The addition of patient-reported self-care independence did not significantly add to the amount of variance explained above and beyond the variables in block one to the model ( $F(1,34) = .76, p = .39$ ). This suggests that social workers rate older and healthier patients as more ready to transfer than younger or more ill patients.

The second regression evaluated parent report of self-care independence as a correlate of the social worker's rating of readiness to transfer, while also controlling for age, income, and

disease severity. The model accounted for 45% of the variance ( $F(3,31) = 8.55, p < .001$ ), with age ( $\beta = .76, p < .001$ ) and disease severity ( $\beta = .34, p < .05$ ) as the strongest correlates of the social worker's rating of readiness (see Table 18). Similarly, the addition of parent-reported self-care independence did not significantly add to the amount of variance explained above and beyond the variables in block one ( $F(1,30) = 1.18, p = .29$ ).

### **Self-care Independence as a Mediator**

A mediator model of psychosocial variables predicting readiness to transfer through self-care independence was hypothesized. Psychosocial variables were not related to self-care independence, failing to meet one requirement of testing the mediator model. Similarly, self-care independence was not related to readiness to transfer. Thus, the mediator model cannot be tested.

### **Exploratory Analyses**

#### **Readiness to Transfer**

Pearson's  $r$  correlations between ratings of readiness to transfer across patients, parents and medical personnel are displayed in Table 19. Patients' and parents' ratings of readiness of the patient to transfer were moderately correlated ( $r = .58, p < .001$ ). Patients and physicians also agreed moderately ( $r = .41, p < .01$ ). The medical team also strongly agreed on their ratings (physician-nurse  $r = .66, p < .001$ ; physician-social worker  $r = .65, p < .001$ ; nurse-social worker  $r = .63, p < .001$ ). Interestingly, parents and the medical team did not agree on the patient's readiness to transfer care, with the exception of a trend of the nurse ( $r = .30, p = .07$ ). Patients reported the highest ratings of readiness to transfer in comparison to their parent ( $t(37) = 2.18, p < .05$ ), the nurse ( $t(47) = 2.74, p < .01$ ), and the social worker ( $t(44) = 2.40, p < .05$ ). Patients also rated themselves as somewhat more ready to transfer than the physician; however, this difference was not statistically significant ( $t(41) = 1.18, p = .24$ ).

Qualitatively, all informants were asked to rank the reasons for their rating of readiness to transfer. The frequency of each reason was examined and presented according to informant. Patients, parents, and team members ranked age of the patient highly as a reason influencing their ratings of the patient's readiness to transfer to adult care (see Table 20). The patient, physician, and nurse ranked health status in the top three reasons for their readiness rating. Informants were allowed to rank "other" as a reason for their rating. They were then encouraged to write a specific reason for their ranking. Both parents and team members noted in their reasons for their ratings that often times the topic of transition had not been discussed. Patients (18%) and parents (10%) noted their relationship with the pediatric team as a reason that they were less ready to transfer. Nurses (4%) and social workers (8%) also noted the family's relationship with the team as a barrier to transferring to the adult clinic. Patients (4%) and physicians (6%) identified level of disease knowledge as an influencing factor in their readiness to transfer. Parents (2%) and members of the team (physician 2%, nurse 14%, social worker 4%) noted poor adherence as an important reason for their rating.

### **Knowledge**

Knowledge was significantly correlated to ratings of readiness by each member of the medical team (physician  $r = .49, p < .001$ ; nurse  $r = .45, p < .001$ ; social worker  $r = .39, p < .01$ ). Higher knowledge scores were related to being more ready to transfer care. Knowledge scores were not related to parent or patient ratings of readiness to transfer.

### **Knowledge and Nurse Rating of Readiness to Transfer**

In an exploratory regression, age, income, and disease severity were entered in the first block, and knowledge was entered in the second block as a correlate of the nurse's rating of readiness to transfer. The model accounted for 46% of the variance ( $F(3,38) = 10.94, p < .001$ ), with age ( $\beta = .72, p < .001$ ) and disease severity ( $\beta = .42, p < .01$ ) as the strongest correlates of

the nurse's rating of readiness (see Table 21). The addition of knowledge ( $\beta = .33, p < .05$ ) significantly added to the amount of variance (5%) explained above and beyond the variables in block one to the model ( $F(1,37) = 4.19, p < .05$ ). This suggests that knowledge influences the rating by nurses, above and beyond the effects of age and health status, with more knowledge relating to more readiness to transfer.

### **Psychosocial Variables**

Pearson correlations were examined between psychosocial variables and ratings of readiness to transfer. Across all informants, psychosocial variables were only related to the nurse's rating of readiness to transfer (see Table 22). Some of the weak relationships between psychosocial variables and readiness might have been underpowered for other informants. The nurse's rating of readiness to transfer showed a weak but significant relationship with both general family functioning ( $r = .37, p < .05$ ) and parental distress ( $r = .34, p < .05$ ). More problematic family functioning and more parental distress were related to the nurse rating the patient as more ready to transfer to the adult clinic.

### **Psychosocial Variables and Nurse Rating of Readiness to Transfer**

In two exploratory regression analyses, the associations between either family functioning or parental distress and nurse ratings of readiness were examined, above and beyond the affects of age, income, and disease severity. The first model, examining family functioning, accounted for 41% of the variance ( $F(3,32) = 7.38, p < .001$ ), with age ( $\beta = .69, p < .001$ ) and disease severity ( $\beta = .48, p < .01$ ) as the strongest correlates of the nurse's rating of readiness (see Table 23). The addition of family functioning significantly added to the amount of variance (9%) explained above and beyond the variables in block one to the model ( $F(1,31) = 5.79, p < .05$ ). This suggests that nurse's rate older and healthier patients as more ready to transfer than younger

or more ill patients. They also rate patients who have worse family functioning as more readiness to transfer. This model was not significant for parental distress.

Table 1. Demographic characteristics of pediatric patients

	All Pediatric Centers ( <i>n</i> = 50)				UF ( <i>n</i> = 11)				CCHMC ( <i>n</i> = 24)				ETCH ( <i>n</i> = 15)			
	<i>M</i>	<i>SD</i>	Range	%	<i>M</i>	<i>SD</i>	Range	%	<i>M</i>	<i>SD</i>	Range	%	<i>M</i>	<i>SD</i>	Range	%
Age	15.89	2.89	12-24		16.70	4.22	12-24		15.42	2.48	12-20		16.13	2.47	12-20	
Gender																
Female				36				36.4					33.3			40
Male				64				63.6					66.7			60
FEV <sub>1</sub> % pred	79.42	21.48	29-118		76.00	17.21	40-105		78.13	21.19	41-118		84.21	25.36	29-115	
Mild				70.8				72.7					69.6			71.4
Moderate				27.1				27.3					30.4			21.4
Severe				2.1				0					0			7.1
Ethnicity																
White				95.6				75					100			100
Afr. Am.				4.4				25					0			0
Insurance																
None				2.2				0					4.3			0
Private				68.9				66.6					82.6			46.2
Medicaid				19				33.3					8.7			30.8

Table 2. Demographic characteristics of parents of pediatric patients

	Percent
Informant	
Mothers	71.1%
Fathers	4.4%
Self (if above 18 years)	22.2%
Other	2.2%
Marital status	
Married	68.2%
Divorced/Single	31.8%
Work status	
Full-time	65.2%
Part-time	34.8%
Education	
Partial high school	8.9%
High school diploma	24.4%
Partial college	28.9%
College	31.1%
Graduate/professional degree	6.7%
Ethnicity	
White	95.6%
African American	4.4%

Table 3. Demographic characteristics of adult patients ( $n = 10$ )

	<i>M</i>	<i>SD</i>	Range	Percent
Age	26.80 years	5.67	18 to 38 years	
Gender				
Female				50%
Male				50%
FEV <sub>1</sub> percent predicted	47%	27.18	29 to 87%	
Ethnicity				
White				80%
African American				0%
Hispanic				20%
Insurance				
None				0%
Private				0%
Medicaid				100%

Table 4. Means and standard deviations

	<i>M</i>	<i>SD</i>	Minimum	Maximum
<b>Self Care Independence Scale</b>				
SCIS-SR (peds)	36.73	5.99	13.00	44.00
SCIS (parents)	37.29	5.56	18.00	44.00
SCIS-SR (peds time 2)	37.81	7.78	14.00	44.00
SCIS-SR (adult)	34.50	7.03	18.00	44.00
<b>Knowledge</b>				
Total score	26.63	3.84	21.00	34.00
Percent correct	.74	.11	.58	.94
<b>Readiness to transfer</b>				
Patient	2.86	1.10	1.00	5.00
Parent	2.29	1.01	1.00	5.00
Physician	2.60	1.29	1.00	5.00
Nurse	2.22	1.07	1.00	4.00
Social Worker	2.30	.99	1.00	4.00
<b>BRIEF Global Executive Composite</b>	48.69	10.27	33.00	75.00
<b>BSI total score</b>	5.71	7.34	.00	33.00
<b>FAD general functioning</b>	6.04	1.02	1.83	7.25

Table 5. Regression of executive functions predicting patient-report of self-care independence

Variable	B	SEB	$\beta$	$R^2$	$\Delta R^2$
Step 1				.27	
Age***	1.20	.33	.55		
Income	-.21	.30	-.10		
Lung function	.02	.04	.07		
Step 2				.29	.02
Global Executive Composite	-.08	.09	-.14		

\*\*\* $p < .001$ 

Table 6. Regression of family functioning predicting patient-report of self-care independence

Variable	B	SEB	$\beta$	$R^2$	$\Delta R^2$
Step 1				.24	
Age**	1.65	.53	.56		
Income	-.33	.37	-.15		
Lung function	.04	.05	.13		
Step 2				.25	.01
General family functioning	-.53	.99	-.09		

\*\* $p < .01$

Table 7. Regression of parental distress predicting patient-report of self-care independence

Variable	B	SEB	$\beta$	$R^2$	$\Delta R^2$
Step 1				.24	
Age**	1.65	.53	.56		
Income	-.33	.37	-.15		
Lung function	.04	.05	.13		
Step 2				.25	.01
Parental distress	-.08	.14	-.09		

\*\* $p < .01$

Table 8. Regression of executive functions predicting parent-report of self-care independence

Variable	B	SEB	$\beta$	$R^2$	$\Delta R^2$
Step 1				.12	
Age	.91	.49	.35		
Income	-.50	.35	-.26		
Lung function	.00	.04	.02		
Step 2				.18	.06
Global Executive Composite	-.14	.10	-.27		

Table 9. Regression of family functioning predicting parent-report of self-care independence

Variable	B	SEB	$\beta$	$R^2$	$\Delta R^2$
Step 1				.12	
Age	.91	.49	.35		
Income	-.50	.35	-.26		
Lung function	.00	.04	.02		
Step 2				.12	.00
General family functioning	-.04	.93	-.01		

Table 10. Regression of parental distress predicting parent-report of self-care independence

Variable	B	SEB	$\beta$	$R^2$	$\Delta R^2$
Step 1				.12	
Age	.91	.49	.35		
Income	-.50	.35	-.26		
Lung function	.00	.04	.02		
Step 2				.14	.02
Parental distress	-.11	.13	-.15		

Table 11. Regression of patient-reported self-care independence predicting the team's rating

Variable	B	SEB	$\beta$	$R^2$	$\Delta R^2$
Step 1				.59	
Age***	.28	.04	.81		
Income	.02	.04	.07		
Lung function***	.02	.02	.42		
Step 2				.59	.00
Patient-reported self-care	.01	.02	.03		

\*\*\* $p < .001$

Table 12. Regression of parent-reported self-care independence predicting the team's rating

Variable	B	SEB	$\beta$	$R^2$	$\Delta R^2$
Step 1				.53	
Age***	.34	.06	.79		
Income	-.02	.04	-.06		
Lung function***	.02	.01	.47		
Step 2				.53	.00
Parent-reported self-care					

\*\*\* $p < .001$

Table 13. Regression of patient-reported self-care independence predicting physician rating

Variable	B	SEB	$\beta$	$R^2$	$\Delta R^2$
Step 1				.59	
Age***	.39	.06	.80		
Income	.03	.05	.06		
Lung function**	.02	.01	.37		
Step 2				.60	.01
Patient-reported self-care	-.02	.03	-.10		

\*\* $p < .01$ , \*\*\* $p < .001$

Table 14. Regression of parent-reported self-care independence predicting physician rating

Variable	B	SEB	$\beta$	$R^2$	$\Delta R^2$
Step 1				.45	
Age***	.36	.09	.68		
Income	.04	.06	.09		
Lung function**	.02	.01	.43		
Step 2				.45	.00
Parent-reported self-care	-.02	.03	-.09		

\*\* $p < .01$ , \*\*\* $p < .001$

Table 15. Regression of patient-reported self-care independence predicting nurse rating

Variable	B	SEB	$\beta$	R <sup>2</sup>	$\Delta R^2$
Step 1				.46	
Age***	.27	.05	.72		
Income	-.02	.04	-.04		
Lung function**	.02	.01	.42		
Step 2				.46	.00
Patient-reported self-care	-.00	.02	-.01		

\*\* $p < .01$ , \*\*\* $p < .001$

Table 16. Regression of parent-reported self-care independence predicting nurse rating

Variable	B	SEB	$\beta$	R <sup>2</sup>	$\Delta R^2$
Step 1				.41	
Age***	.32	.07	.69		
Income	-.04	.05	-.12		
Lung function**	.02	.01	.48		
Step 2				.41	.00
Parent-reported self-care	-.01	.03	-.04		

\*\* $p < .01$ , \*\*\* $p < .001$

Table 17. Regression of patient-reported self-care independence predicting social worker rating

Variable	B	SEB	$\beta$	R <sup>2</sup>	$\Delta R^2$
Step 1				.49	
Age***	.29	.05	.76		
Income	-.00	.04	-.01		
Lung function**	.01	.01	.33		
Step 2				.50	.01
Patient-reported self-care	.02	.02	.12		

\*\* $p < .01$ , \*\*\* $p < .001$

Table 18. Regression of parent-reported self-care independence predicting social worker rating

Variable	B	SEB	$\beta$	R <sup>2</sup>	$\Delta R^2$
Step 1				.45	
Age***	.33	.07	.76		
Income	-.03	.05	-.09		
Lung function*	.01	.01	.34		
Step 2				.47	.02
Parent-reported self-care	.03	.03	.16		

\* $p < .05$ , \*\*\* $p < .001$

Table 19. Pearson's *r* correlation matrix of ratings of readiness to transfer

Informant	1.	2.	3.	4.	5.
1. Patient	---				
2. Parent	.58***	---			
3. Physician	.41**	.18	---		
4. Nurse	.18	.30 <sup>+</sup>	.66***	---	
5. Social Worker	.18	.03	.65***	.63***	---

<sup>+</sup>*p* = .07, \*\* *p* < .01, \*\*\* *p* < .001

Table 20. Top ranked reasons for ratings of readiness to transfer

	Patient	Parent	Physician	Nurse	Social Worker
1 <sup>st</sup> reason	Age (81%)	Age (70%)	Emotional maturity (77%)	Age (66%)	Age (78%)
2 <sup>nd</sup> reason	Other (67%)	Emotional maturity (52%)	Age (59%)	Health status (53%)	Other (73%)
3 <sup>rd</sup> reason	Health status (60%)	Other (50%)	Health status (46%)	Other (47%)	Emotional maturity (47%)

Table 21. Regression of knowledge predicting nurse rating

Variable	B	SEB	β	R <sup>2</sup>	ΔR <sup>2</sup>
Step 1				.46	
Age***	.27	.05	.72		
Income	-.02	.04	-.04		
Lung function**	.02	.01	.42		
Step 2				.51	.05
Knowledge*	.10	.05	.33		

\* *p* < .05, \*\* *p* < .01, \*\*\* *p* < .001

Table 22. Pearson correlations between psychosocial variables and ratings

	Family functioning	Parental distress	Executive functions
Patient rating	.28	-.12	-.21
Parent rating	.27	-.15	.13
Physician rating	.31	.07	.11
Nurse rating	.37*	.34*	.09
Social worker rating	.30	.29	.17

\* *p* < .05

Table 23. Regression of family functioning predicting nurse rating

Variable	B	SEB	$\beta$	$R^2$	$\Delta R^2$
Step 1				.41	
Age***	.33	.07	.69		
Income	-.04	.05	-.12		
Lung function**	.02	.01	.48		
Step 2				.50	.09
General family functioning*	.31	.13	.32		

\*  $p < .05$ , \*\*  $p < .01$ , \*\*\*  $p < .001$

## CHAPTER 4 DISCUSSION

Readiness to transfer is an important topic for children with chronic illnesses, particularly those with CF. The topic of transfer to adult clinic has been examined in a number of survey studies (e.g., Anderson et al., 2002; Flume et al., 2001). To the author's knowledge, this is the first study to quantitatively examine variables related to readiness to transfer, specifically demographic variables, psychosocial variables, and self-care independence. Self-care independence has been called the "keystone to 'transition readiness'" (Betz, Redcay, & Tan, 2003). In order to test this theory, this study first required the adaptation of an existing measure of self-care independence.

### **Psychometric Properties of SCIS-SR**

This study set out to adapt a measure of self-care independence for use with patients with cystic fibrosis. The measure was adapted from an existing parent-report measure of patient's self-care independence. This study found mixed psychometric properties of the SCIS-SR. This measure demonstrated good internal consistency, as well as good test-retest reliability in patients in pediatric clinics over a period of four weeks. These results were similar to the adequate psychometric properties of the original measure. However, the patient report of self-care independence demonstrated only a weak (but still significant) relationship with their knowledge of managing their disease. This finding was in contrast to the properties of the original parent-report version, that the SCIS was moderately related to parents' knowledge about CF (Patton et al., 2003). The discriminative validity of the SCIS was not supported by the comparison of the 50 pediatric patients to ten patients from adult clinics.

The weak relationship between the SCIS-SR and knowledge about CF management may be due in part to differences between the methods of measuring of knowledge in this study

compared with the original validation of the SCIS. Specifically, this study used a multiple-choice measure of knowledge which asks general questions about treatments for CF. The original study of the SCIS used a structured interview to elicit information about the child's knowledge of their own regimen. While a multiple-choice knowledge questionnaire may be useful in quantifying a patient's knowledge, a structured interview most likely allowed for more personalized information. Patient's knowledge of their own treatment regimen may be more strongly related to their current self-care behaviors, compared with knowledge about how to interpret symptoms and uses of different treatments.

With regard to the lack of discriminative validity, reporting biases may partially account for the lack of differences between the pediatric and adult clinics. Anecdotally, patients in the pediatric clinic were quick to assume credit for aspects of their treatment regimen, whether they regularly completed for a treatment independently or they were beginning to take responsibility for that treatment. Patients also endorsed taking responsibility for treatments which they reported were not part of their current regimen. Unfortunately, this study did not collect data regarding physician's prescriptions; thus, patients' endorsements of responsibility for particular treatments could not be compared to their actual regimen. In contrast to patients in the pediatric clinic, patients in the adult clinic were more likely to report that they skip a treatment, about which they also endorsed informing their doctor. Thus, patients in the pediatric clinic may have inflated scores, while patients in the adult clinic may have deflated scores. This would make it less likely to find differences between clinics.

These reporting differences have clinical implications for addressing self-care independence with families. For the adolescents who may be report doing more treatments than they are prescribed, it may be particularly important to evaluate their understanding of their

prescribed regimen. Patient-provider miscommunication may contribute to their report of doing treatments which are not part of their current treatment regimen. Patients must report all treatments they are taking to their physician. It is important for the provider to clarify prescriptions with the patient and to allow even a young patient to be part of the process, through use of visual aids and encouraging turn-taking during the conversation (Butz, Walker, Pulsifer, & Winkelstein, 2007).

Not only were there differences in the reporting styles between patients in pediatric and adult clinics, there were also methodological challenges which hindered support for discriminative validity for the self-care independence measure. Specifically, the small number of patients in each clinic setting and uneven groups could contribute to the null findings. The patients were also collected at four sites, two of which included adult clinics. This recruitment of a sample of convenience results in site being a potentially confounding variable. Future studies should compare self-care independence scores of patients in pediatric and adult clinics at the same site. This would decrease the confounding effect of site.

Age of the patient was also examined for additional construct validity of the self-care independence scale. Age was not related to self-care independence in this study, which contrasts previous results using the parent-report version of the SCIS. This may have been due in part to restriction of range of age due to the target sample of pre-adolescents and adolescents. This age range was intentionally selected because another important aspect of this study was to examine variables related to readiness to transfer to adult clinic. Specifically, this study recruited patients from pediatric clinics ages 12 through 24, whereas Patton and colleagues (2003) focused on children ages four through 17. Thus, it appears that once a child or adolescents gets to certain age, there may be a ceiling effect using this measure. This age may have been younger than the

age of the participants of this study, as even the youngest participants in this sample were reporting high levels of self-care independence. Patton and colleagues (2005) surveyed CF team members about the age at which 50% of children could perform the tasks on the SCIS. They found a range of responses from five to 13 years; however, these estimates demonstrated poor concordance overall. Thus, the age at which these behaviors emerge is not well understood.

The self-report version of the self-care independence measure was adapted for use in this study based on an existing parent-report version. Thus, there are some limitations to using a measure with pre-adolescents and adolescents which was originally developed for parents of children with CF across nearly all developmental stages. In order to enhance this new measure for use with adolescents with cystic fibrosis, focus groups could be used to determine the self-care behaviors and activities that are important to adolescents. However, given the infection control issues with patients with CF, alternatives to typical focus groups would be preferable. For example, adolescents could participate in online focus groups or discuss their ideas during individual semi-structured cognitive interviews. It would be particularly important to interview adolescents in order to better understand how self-care independence may or may not occur in the context of being more independent across multiple domains of their lives.

Another limitation of measuring self-care independence was the lack of comparison to the individual patient's prescribed treatment plan. As noted previously, patient's prescriptions or treatment regimens were not measured or accounted for in this study. Thus, the self-care independence measure fails to take into account the individual differences in treatments. Some patients and parents noted that certain items on the measure did not apply to them. For example, a patient may be pancreatic sufficient and not require enzyme supplements. In addition, multiple forms of airway clearance are mentioned on the measure. Many patients now use the Vest,

rather than the Flutter or Acapella. In addition, if a patient has been regularly prescribed the Vest, the patient may be unfamiliar with use of the Flutter. In addition some patients alternate chest physiotherapy with a therapist with using the Vest alone. These individual differences in prescription as compared to the questions on the self-care independence measure results in patient's self-care independence score being penalized unduly.

One way to address this limitation would be to score only the items that represent questions related to each patient's prescribed treatments. By dividing the number of treatments conducted independently by the total number of treatments, a percent independent score could be obtained. This percent independent score could be useful in examining self-care independence across a number of patients who have different treatment regimens. It would also be interesting to have a way of observing how many treatments were being endorsed when these treatments were not prescribed. These observations could be used as a measure of "faking good" or miscommunication about their treatment plan.

A limitation of both the study and the measure is that the self-care independence measure describes only the patient and parent's perception of the patient's self-care independence. This study may have benefited from a measure of adherence or daily recall method to compare the self-report self-care independence measure with other measures of activities during the day. Specifically, the Daily Phone Diary (DPD) is a 24-hour recall method which includes other activities and companions for every activity the adolescent does through out the day (Quittner & Opiari, 1994). Although the DPD is also based on self-report, the unobtrusive nature of the measure might allow for more accurate reporting. The DPD would allow for comparison treatments conducted by the patient alone with treatments conducted in the presence of the parent.

In terms of future research using the self-care independence measure, the authors of the original parent-report version noted that the SCIS may be useful in longitudinal studies to measure increasing responsibility and self-care independence over time (Patton et al., 2003). This would be an interesting application of the measure, which could help researchers understand the natural progression of self-care independence, as well as lead researchers to develop interventions to increase self-care behaviors. Patterns of self-care independence may also be important, since adolescence is a particularly challenging and ever-changing time. Patients may increase their independence at times, but then require more assistance from parents when they sick or when they are stressed with final exams. This increase and decrease in independence may be appropriate as the patient learns when to ask for help. Researchers would need to measure these life events in order to better understand patterns of self-care independence.

Another limitation of the self-care independence measure is the scale for responses. The current measures, both SCIS and SCIS-SR, elicit “yes” or “no” answers with regard to specific self-care behaviors. It would be interesting to pilot other scales in order to understand how adolescents gain partial independence for some behaviors rather than others. Another way to determine the growth of self-care independence would be to give ranges of percent of responsibility for treatments, such as “I am responsible for my nebulized antibiotics” with choices ranging from “0 to 25% of the time,” “25 to 50%,” “50 to 75%,” and “75 to 100% of the time.” This would provide additional information to allow researchers to compare which behaviors for which the patient is more or less responsible.

An improved version of this self-care independence scale could be a useful tool to measure the patient’s perception of their own behaviors related to caring for their CF. In a recent study (Modi et al., in press), adherence was shown to drop around mid-adolescence as parents were

providing less supervision and adolescents were failing to take over their treatments. It would be interesting to understand how the adolescents perceive this process of the parent stepping back and increasing the expectations for their child. Similarly, an improved SCIS and SCIS-SR may allow for the researchers and clinicians to measure whether parents perceive that their adolescents are doing more of their treatments than what they actually accomplish. Thus, it is critically important for health care providers to understand the developmental process of changes in responsibility for the patient's treatment regimen.

### **Patient and Parent Reports of Self-Care Independence**

The second aim of the study sought to examine the relationship between patient and parent report of self-care independence. Patients and parents showed moderate agreement about the patients' self-care independence, which provided support for the hypothesis. Although the difference was not statistically significant, parents endorsed two more behaviors than patients did. This suggests that, on average, parents might perceive that the patient is doing more of their treatments independently than what is being done. Parents have been found to supervise adolescents less than younger adolescents and pre-adolescents (Modi et al., in press). Unfortunately, adherence was also lower in the mid-adolescence age group. This suggests that parents may need to monitor adolescents as they increase their self-care independence. Adolescents may have primary responsibility for their treatments, but parents may need to continue to monitor the patients through this time period.

### **Psychosocial Variables and Self-Care Independence**

The third aim of the study was to examine the relationship between psychosocial variables and self-care independence. None of the variables (executive function, family functioning, or parental distress) were related to self-care independence. While these psychosocial variables have been shown to relate to adherence, measures of adherence do not necessarily indicate the

person who is primarily responsible for implementing the treatment regimen. This null result may have been largely due to the difference between adherence and self-care independence. Adherence can be defined as the amount of treatments performed divided by the prescription. Self-care independence, in this study, does not account for the prescription, and is a description of how much the adolescent does on his or her own.

### **Self-Care Independence and Ratings of Readiness to Transfer**

This study sought to examine the relationship between self-care independence and readiness to transfer, given the theoretical assumption that more independence will be related to more readiness. This hypothesis was not supported. Specifically, self-care independence did not account for any of the variance in ratings of readiness to transfer from pediatric to adult care. This finding was consistent across ratings of readiness to transfer by all the members of the medical team. The lack of correlation between self-care independence and readiness to transfer may have been due in part to the limitations with this measure. For example the restriction of range of self-care independence scores may have reduced the opportunity to observe a relationship. In addition the small sample size may have resulted in less power to detect differences. Additionally, important aspects of self-care independence may be missing from the measure. For example, understanding insurance policies may be important for a patient who has been on their parent's plan which only lasts until a certain age. All of the patients in the adult clinic were receiving Medicaid. Acquiring this coverage may require a long waiting period around the same time that the patient may be transitioning to the adult clinic. Thus, the addition of questions about other independent health promoting behaviors might increase the association between self-care independence and readiness to transfer.

Despite the lack of relationship between self-care independence and readiness to transfer, these analyses provided interesting results. Demographic variables, specifically age and disease

severity, were associated with the medical team's ratings of readiness to transfer. These variables accounted for about 60% of variance, which provides empirical support for the qualitative results from the ranked reasons for their ratings of readiness to transfer. Despite the small sample size, age and health status accounted for a substantial amount of the variance in readiness to transfer. The medical team generally rated older and healthier patients as more ready to transfer to adult care. This is the first study to empirically support this idea which has been described in the literature in studies involving anecdotal evidence and general practice survey results.

Age is cited as the most common reason that a patient was transferred to the adult clinic (Anderson et al., 2002; Flume et al., 2001). This study provides empirical support that age of the patient in the pediatric clinic influences all members of the CF team's rating of readiness to transfer. Age may be a proxy for other factors, such as cognitive development or emotional maturity. Emotional maturity was a reason for ratings of readiness by the parent and social worker, and the top reason for physicians. The age at which a patient begins to attend adult clinic may be flexible or rigid. Rigidity of the age of transfer is particularly true for inpatient units. If a patient who is 18 years old, and is generally seen in the pediatric clinic, goes to the emergency room for care, this patient will likely be hospitalized in the adult unit. This "in-hospital transition" may be more stressful for the patient, family, and pediatric team (Parker, 2007, p. 427). If age of transfer to adult care is set and inflexible, there are a number of programs to prepare patients in advance, which have support from patient satisfaction (Craig, Towns, & Bibby, 2007). Often times these studies are case descriptions where the standard of care includes transition preparation, like joint clinics between pediatric and adult providers, without comparison to control groups.

In a survey of CF center directors, disease severity was also described as a criterion for deciding when to transfer patients (Flume et al., 2001). Physicians have described hesitation to transfer patients who are particularly ill. This study statistically demonstrated this relationship. While it is understandable that a CF exacerbation is not an ideal time for transfer to adult care, patients who become more ill may benefit from adult care as they become older. Other medical issues, such as CF-related diabetes and consideration of transplant, might be more common in adult settings. Thus, it may be important to anticipate these issues when discussing the topic of transition with patients and parents. On the other hand, patients may be more hesitant to transfer when they are sick. They may also benefit from remaining with a medical team who is familiar with their history, personal and medical, at points of important decision making and treatment.

In order to more thoroughly understand readiness to transfer, correlations among the psychosocial variables and ratings of readiness were examined. A moderate correlation was found between knowledge and the medical team's ratings of readiness to transfer. Only for nurses, knowledge was associated with readiness to transfer, above and beyond the contribution of age and health status. Nurses may have more insight into the patient's level of knowledge related to managing their CF, due in part to the role of nurses which often includes CF education. They may perceive that higher knowledge is related to more readiness to transfer. One possible mechanism for this relationship may be through adherence. This study found that poor adherence was noted as a reason for lower ratings of readiness to transfer. Anthony and colleagues (1999) found that increase knowledge was related to more adherence to enzymes. Thus, if knowledge is related to adherence and adherence is a reason for readiness, nurses may be interpreting that knowledge is related to readiness.

Patients and physicians noted lack of knowledge about disease as a reason for being less ready to transfer care. Although knowledge was not related to patient-report self-care independence, the perceived knowledge of the patient was related to how the medical team rated the patient's readiness with more perceived knowledge being related to increased readiness. The medical team might estimate the patient's knowledge in a number of ways. Adherence may suggest knowledge, as a patient who performs their treatments is assumed to have an understanding of what they are prescribed to do and reasons why. Patients who talk more during their visit, describe their treatment regimen in detail, or ask more questions may be perceived as more knowledgeable. Knowledge can be measured directly by assessment, such as the multiple-choice questionnaire used in this study. In addition, skills tests conducted by a nurse may be informative in determining the patients' understanding and ability to correctly use medications and equipment. Use of knowledge questionnaires and skills testing may directly inform treatment. Treatment may include specific remediation of knowledge deficits. Numerous nursing education tools are available to address particular issues. For example, the STARBRIGHT program *Fitting CF in Your Life Everyday* has been shown to significantly improve overall knowledge (Davis, Quittner, Stack, & Yang, 2004). Although knowledge was only weakly related to self-care independence, it was related to the nurse ratings of readiness. Knowledge has been described as a precursor to behavior change, particular in terms of adherence in pediatric patients with cystic fibrosis (Anthony et al., 1999; Ievers et al., 1999).

The examination of the psychosocial variables and ratings of readiness to transfer revealed a lack of association for most informants. This may be due in part to the peripheral nature of family functioning and parental distress. While these variables are likely to influence the patient in many ways, they may have an indirect impact on readiness to transfer. Statistical

modeling techniques, which require large samples, may be able to detect this impact and pathways through other variables. The generality of the psychosocial variables may be another reason for the lack of association with readiness to transfer. For example, family functioning is comprised of a number of subscales encompassing topics like communication, affect, and behavioral control. The analyses in this study examined the general family functioning composite. The family functioning measure includes general items, not specifically related to transferring to adult clinic. Scores on this measure may indicate relatively good or bad family functioning, but the scores do not provide information regarding communication about transition. Executive functions are directly related to the patient, but were not related to the ratings of readiness to transfer. This may have been due in part to the use of the Global Executive Composite rather than specific behaviors. This composite is comprised of a number of subscales, including metacognition behaviors (e.g., working memory, planning, and task completion) and behavioral regulation behaviors (e.g., shifting attention, emotional control). Specific subscales, such as task completion, that relate more directly to medical behaviors may relate to readiness to transfer. Due to the small sample size and lack of specific hypotheses, subscales of family functioning and executive functions were not evaluated.

Correlations between psychosocial variables and the nurse rating of readiness were found for parental distress and family functioning. Only family functioning was associated with the nurse rating above and beyond the contribution of age and health status. This finding suggested that worse family functioning was related to more readiness. Nurses may be aware of disagreements between parents and adolescents as the adolescents may be seeking more independence. Families may need to communicate and collaborate less if the adolescent is successfully preparing to transfer to adult clinic. The role of the family would be less centrally

involved once the patient has transferred. In that sense, this finding may not reflect pathological family functioning but perhaps reflect a change in roles. Future studies should examine whether nurse's ratings of readiness to transfer are influenced by general family dysfunction or by specific transition- or CF-related disagreements. Nurses may be exposed to more family interactions due to the increased time they spend with families in clinic, in hospital, and during phone consultations. Adolescents who are having more strained interactions with their parents may also be striving for increased independence. Despite the previous potential explanation for this finding, it is in contrast to literature regarding better family functioning and better adherence.

In their reasons for ratings of readiness, members of the medical team noted that adherence was important in their decision. This reason was given mostly in cases of low ratings of readiness, such that poor adherence was related to less readiness. Future studies examining readiness to transfer would benefit from measuring adherence, in order to quantitatively test the role of adherence in readiness to transfer. If adherence is related to successful transfer to adult care, interventions can be used to improved adherence through changing behaviors and improving family functioning.

Clinically, the rating of readiness to transfer revealed interesting agreement, as well as discrepancies, among the informants. Although the ratings of readiness to transfer were correlated between patients and parents, patients and physicians, and among the medical team, physicians and parents ratings were not related. This suggests that increased communication between parents and team members may be necessary to prepare parents for transition. The nurse and the parent appear to agree, which suggests that the nurse or other member of the team may have a sense of the parent's comfort with transition. As a small number of patients and parents continue to be hesitant to leave due to the positive relationship with pediatric team, it

may be important to make additional efforts for clear communication and preparation in advance with some families. These issues of communication and relationships between families and teams are appropriate referrals for pediatric psychologists. Consultation and treatment by a pediatric psychologist may promote improved communication among and between the medical team and family members, through spending time evaluating concerns about transition and developing specific interventions to address those concerns.

### **Limitations**

A number of limitations of the study have been noted previously, such as the lack of prescription and treatment regimen information and the lack of measures of adherence. The measure of self-care independence was not developed in this study, but rather was adapted from an existing parent-report version. The limited age group resulted in restriction of range, particularly for the self-care independence measure. The small sample size presents a number of limitations. In particular the large number of analyses run may be susceptible to type I error. The small sample size may have suppressed the strength of some of the relationships and would not have allowed for the examination of a mediator model, had the assumptions been met. The low number of patients recruited from the adult clinic may have hindered the possibility of detecting discriminative validity. Additionally, the generalizability of the findings is limited by the small sample size and the demographic characteristics of the sample, such as the predominantly Caucasian ethnicity of the sample. Due to the cross-sectional nature of the study, regressions cannot be used to predict readiness to transfer. The variables of interest can only be described as correlates of readiness. A longitudinal study would allow for the examination of the ability of these variables to predict readiness to transfer, as well as successful transition.

### **Strengths**

To the author's knowledge, this was the first study to examine correlates of readiness to transfer to adult care in cystic fibrosis. This study provides statistical evidence that older age and better health are related to being more ready to transfer according to members of the medical team. This study was conducted across four Cystic Fibrosis Foundation accredited centers in the mid-West, South, and SouthEast parts of the country. Although some of the analyses examined variables from a single informant, the most interesting findings included demographic variables and multiple informants, which reduced bias. This study was well received by the participating centers and was described as a timely investigation. As patients are living longer, CF teams are dedicated to the best care for the patients and participating in research to inform their practice.

### **Future Directions**

Although some reasons for readiness to transfer to adult care were identified for members of the medical team, less is known about the reasons for patient and parents ratings of readiness to transfer. Flume and colleagues (2001) found that a close relationship with the pediatric team and hesitation toward the adult team were barriers to transition. The current study replicated this qualitative finding. Future studies should seek to better understanding variables that influence the patients and parents readiness. In addition rating of readiness should be compared to successful transition in the future.

Patients and parents frequently noted liking the pediatric team as a reason for not being ready to transfer to adult centers. This can be addressed by the pediatric team providing support for the family to meet and become comfortable with the adult team. This may require different approaches or models of transition, such as joint clinics between pediatric and adult staff. Such programs exist and have demonstrated some positive results in terms of satisfaction. Future studies should prospectively examine the impact of transition programs, such as joint clinics, on

the successful transition of patients. A number of transition programs have been developed based on developmental and disease-specific tasks (e.g., Knauth, Verstappen, Reiss, & Webb, 2006). For example, a program for adolescents with cardiac conditions consists of a curriculum addressing developmental issues, like pregnancy and career planning, as well as disease-specific tasks, like monitoring symptoms and accessing care. No outcome research studies exist regarding transition in pediatric chronic illness, particularly in CF (Parker, 2007). One study describes the usefulness of a case manager in an anecdotal case study (Rearick, 2007). It may also be important to compare joint clinics with standard care in order to evaluate whether the benefits outweigh the effort and costs. This analysis of cost-benefit is difficult to quantify as many CF team members are dedicated to the success of individual patients. Thus, one more successful transition experience may be worth the extra effort. Asking the parents and patients for ratings of readiness and reasons for their ratings in advance may help providers identify the 10% of patients who are especially hesitant to leave the pediatric team.

Outcome research regarding successful transition has been conducted in the area of pediatric cardiac disease. In one study, successful transition was defined as at least one visit to the adult clinic in the past year (Reid et al., 2004). Correlates of successful transition include living closer to the adult clinic, more pediatric cardiac surgeries, and older age at time of transfer of care. Successful transition was not related to family income or whether the patient lived with their parents. Similarly, income was not related to ratings of readiness to transfer. This study may serve as an example of designing a study to evaluate successful transition in cystic fibrosis.

Transition continues to be an emotionally laden topic for patients, families, and providers. Future studies should continue to examine this emotional component of health care, as well as

evaluate the process of successfully transitioning patients with cystic fibrosis from pediatric to adult centers.

APPENDIX A  
SELF-CARE INDEPENDENCE SCALE-SELF REPORT FORM

Directions: For each of the following self-care behaviors, please circle "yes" if you have learned the behavior or "no" if you have not learned the behavior. "Learning a behavior" is defined as the stage when you are able to independently initiate or perform the behavior without receiving a prompt or requiring information to perform the behavior correctly. When evaluating items, please disregard issues of noncompliance and inconsistent performance.

Do you or can you:

*Diet and High Calorie Nutritional Supplements:*

1. Monitor changes in weight?	Yes	No
2. Explain how the body uses food as energy?	Yes	No
3. Make changes in diet to adjust for weight loss?	Yes	No
4. Pick out high calorie foods?	Yes	No
5. Remember the number of meals and snack to eat in a day?	Yes	No
6. Know to eat high fat/high calorie foods?	Yes	No
7. Eat recommended amounts of foods?	Yes	No
8. Name high calorie nutritional supplements?	Yes	No
9. Know when to take high calorie nutritional supplements?	Yes	No
10. Know how many nutritional supplements to take each day?	Yes	No

*Enzymes:*

11. Know when to take enzymes?	Yes	No
12. Know the brand name(s) of the enzymes prescribed?	Yes	No
13. Know how many enzymes to take with meals and snacks?	Yes	No
14. Take enzymes in capsule form?	Yes	No
15. Explain what enzymes do in the body?	Yes	No

*Medications and Vitamins:*

16. Name what antibiotics are prescribed?	Yes	No
17. Know when to take antibiotics?	Yes	No
18. Take antibiotics as prescribed?	Yes	No
19. Explain what antibiotics do in the body?	Yes	No
20. Learn the types of antibiotics prescribed?	Yes	No
21. Use nasal sprays?	Yes	No
22. Name the nasal sprays prescribed?	Yes	No

23. Know when to use nasal sprays?	Yes	No
24. Name the vitamins prescribed?	Yes	No
25. Remember the dose of each vitamin?	Yes	No
26. Swallow vitamins with water?	Yes	No
27. Remember to take vitamins?	Yes	No
28. Know when to take vitamins each day?	Yes	No
<i>Lung Clearance Behaviors:</i>		
29. Enlist the help of another to perform chest physiotherapy?	Yes	No
30. Explain why to perform chest physiotherapy?	Yes	No
31. Know how many times each day to perform chest physiotherapy?	Yes	No
32. Know how long to perform each treatment?	Yes	No
33. Name prescribed medications to be taken before chest physiotherapy?	Yes	No
34. Know how many times each day to use the Flutter?	Yes	No
35. Use a Therapy vest?	Yes	No
36. Know when to use the therapy vest?	Yes	No
37. Know how many times each day to use the therapy vest?	Yes	No
<i>Aerosols:</i>		
38. Use an aerosol?	Yes	No
39. Name prescribed aerosols?	Yes	No
40. Know when to perform each aerosol treatment?	Yes	No
<i>Medical Care and General Knowledge:</i>		
41. State the name of your Pulmonologist.	Yes	No
42. Recognize the symptoms of an infection and tell someone about it.	Yes	No
43. Talk to others about Cystic Fibrosis.	Yes	No
44. Tell teachers about school absences due to clinic appointments or infection.	Yes	No

APPENDIX B  
RATING OF READINESS TO TRANSFER

ID of patient:

Date: \_\_\_\_/\_\_\_\_/\_\_\_\_

1. How ready is \_\_\_\_\_ to transfer from the pediatric to adult CF clinic?

Not at all ready	Somewhat ready	Could transfer with hesitation	Ready with no concerns	Has been ready
1	2	3	4	5

2. Please rank the top 3 reasons for choosing your rating above:

- \_\_\_ Age
- \_\_\_ Health status (e.g., disease severity, other medical issues)
- \_\_\_ Emotional maturity
- \_\_\_ Issues related to current functioning
- \_\_\_ Developmental issues (e.g., reproduction, discussing drug and alcohol use)
- \_\_\_ Other: \_\_\_\_\_

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## BIOGRAPHICAL SKETCH

Kristen Marciel received her bachelor's degree in child development at Vanderbilt University in 2001 and her master's degree in clinical psychology at the University of Florida in 2004. She was awarded the Doctor of Philosophy degree of clinical psychology in May 2008 and plans to pursue a career in pediatric psychology. Her primary research interest is the psychological impact of chronic illnesses, such as cystic fibrosis, on children and their families.