



## How Do Youth with Cystic Fibrosis Perceive Their Readiness to Transition to Adult Healthcare Compared to Their Caregivers' Views?☆



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### ABSTRACT

**Purpose:** To describe how perceived stages of change for self-care management skills varies by age in youth with cystic fibrosis in preparation for transition to adult healthcare, to compare caregiver perception of youth readiness for self-care, and age/frequency of transition discussion with provider.

**Design and Methods:** The Transition Readiness Assessment Questionnaire and a modified version (TRAQ-C) for caregivers were used for data collection. Descriptive statistics, simple linear regression, and *t*-tests were employed.

**Results:** Regression equations suggest that age predicts youth perception of self-care management skill in all five domains on the TRAQ ( $p \leq .009$ ). A paired *t*-test compared the overall TRAQ and TRAQ-C mean scores between dyads. Youth rated themselves significantly higher in perception of self-care skill management ( $m = 3.187$ ,  $sd = 0.769$ ) than caregivers ( $m = 2.490$ ,  $sd = 0.788$ ;  $t = 7.408$ ,  $df = 51$ ,  $p < .001$ ). Sixteen was the average age of transition discussion for both youth and caregiver. Reported frequency of discussion varied considerably.

**Conclusions:** Although increasing age predicts perception of self-care management, many youth age 18–22 were still only contemplating or starting to learn skills. Skill level perceptions between youth and caregiver differed, but scores from all self-care management domains followed a similar trend. Discussions with providers began later than guidelines recommend and were often not recognized as such by youth.

**Practice Implications:** Results underscore the importance of beginning transition discussion and skill evaluation in youth with cystic fibrosis at an early age, incorporating caregivers' perception in the process.

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When cystic fibrosis (CF) was first recognized in 1938, children died in infancy (Davis, 2006). As the disease was better understood, care was delivered in a pediatric environment, which in the United States was often centered in CF focused clinics set up to provide care based on emerging evidence. Today, with improved care, the predicted median age of survival is in the early 40s in highly resourced countries (Cystic Fibrosis Foundation, 2014; Cystic Fibrosis Worldwide, 2017). Therefore, most patients with CF will spend the majority of their lives as an adult in general or specialty practice. At present, there is no cure for CF, and maintaining health requires life-long self-care management, including specific skills of 1) managing medications, 2) appointment keeping, 3) tracking health issues, 4) talking with providers and 5) managing

daily activities. In childhood, parents or other caregivers manage these activities, but youth with CF must eventually assume considerable self-care management skills in order to gain independence and to optimize longevity and quality of life.

Although the literature on transition to adult healthcare for young people with chronic health problems is abundant, findings from these studies primarily center on transition readiness through the perception of the family caregiver or physician. Little research has been conducted determining transition readiness from the perspective of youth or with consideration of specific self-care skills that are required for optimal outcomes (Betz, Lobo, Nehring, & Bui, 2013). Research on the patient/caregiver dyad has also been limited.

Healthcare transition readiness research for a variety of chronic conditions includes studying its relationship with age, and themes of perceived facilitators and perceived barriers to transition. Correlations between transition readiness and increasing age have been found; however, studies varied by disease category, along with variance in geographical location (McPherson, Thaniel, & Minniti, 2009; van Staa, van der Stege, Jedeloo, Moll, & Hilberink, 2011). Furthermore, inconsistencies in methods, a lack of reported psychometrics for instruments

**Abbreviations:** CF, cystic fibrosis; TRAQ®, Transition Readiness Assessment Questionnaire; TRAQ-C, Transition Readiness Assessment Questionnaire adapted for caregivers.

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utilized, and differing questions posed, make it difficult to compare the relationship between transition readiness and age across studies and hinders analysis (McPherson et al., 2009; van Staa et al., 2011).

Guidelines developed to promote healthcare transition, using age as a criterion, have been based on expert opinion and general agreement with no indication of specific evidence, and lack theoretical frameworks (Cooley & Sagerman, 2011). Recommendations by The American Academy of Pediatrics (AAP; Cooley & Sagerman, 2011) include transition discussion by age 12 with some families, while the US Department of Health and Human Services' Maternal and Child Health Bureau (2011) recommends use of a standardized transition assessment tool completed by youth starting at age 14 to assess and reassess their ability to successfully transition to adult healthcare. Updated guidelines aligning with AAP recommendations include transition policy discussion at age 12, with transition readiness assessments conducted regularly at age 14 Got Transition™ (2014). According to some experts, transition should begin to occur near the time of diagnosis, with consensus that starting the process in adolescence is too late (Binks, Barden, Burke, & Young, 2007; Reiss, Gibson, & Walker, 2005; Watson, 2005).

Transition readiness research from the perspective of youth with chronic illnesses reveals facilitators to transition including greater discussion from care providers related to transition and youth involvement in the process of care management (Anthony et al., 2009; Lindsay, Kingnorth, & Hamdani, 2011; Soanes & Timmons, 2004; van Staa et al., 2011). Barriers reported by youth included uncertainty of when self-care begins as well as caregiver reluctance to relinquish control and welcome youth autonomy (Anthony et al., 2009; Bregnballe, Schiotez, & Lomborg, 2011; Karlsson, Arman, & Wikblad, 2008; Knauth, Versteppehn, Reiss, & Webb, 2006; Michaud, Suris, & Viner, 2007; Tuchman, Schwartz, Sawicki, & Britto, 2010).

Caregivers' transfer of youth daily healthcare management must occur with clear understanding for youth to assume self-care. Previous researchers have found that youth with chronic conditions are often overprotected and unsure of their role in health self-management (Brunfield & Lansbury, 2004), and therefore it is important to determine the delineation of responsibilities from both the caregiver and the youth's perspective. In order to achieve a successful transition to adult healthcare it is necessary to determine the youth's current readiness to assume a greater role in the skills required to manage their chronic condition and the caregiver's investment in the transition process.

Since the discovery of the diagnosis of CF occurs during infancy or early childhood, the caregiver has carried out the management of their child's medical care. The gradual assumption of self-care management required for managing CF transitions from caregiver to youth occurs as youth gain more maturity and responsibility for their health.

Frequent transition discussion and planning appears to be a key element in youth preparation for transition to adult healthcare, yet discussion and planning for transition has been found to be low in clinical practice (Knapp, Huang, Hinojosa, Baker, & Sloyer, 2013). Furthermore, few researchers have examined youth perceptions of self-management skills necessary for transition to adult healthcare (Sawicki et al., 2011; Wood et al., 2014) with few finding youth/caregiver congruence using validated measures (Sawicki, Kelemen, & Weitzman, 2014).

Because transition to self-care requires changes in behavior, the Stages of Change Model (Prochaska and DiClemente, 1986) was used to guide development of the TRAQ and this research. The five stages of this model are: Pre-contemplation, Contemplation, Determination, Action, and Maintenance. The purpose of this study was to determine how stages of change for self-care management skills are reported by both youth with CF and their major caregivers for each of the five identified self-care activities, to determine how readiness for self-care varies by age group and skill, and how similar youth and caregivers are in reporting readiness for self-care in preparation for transition to adult healthcare. Also reported is age of youth at first transition discussion and frequency of discussion as stated by youth and caregivers.

## Methods

### Design

This study used a descriptive, correlational, cross-sectional design to investigate how perception of stage of change readiness for self-care management skills in preparation for transition to adult healthcare is reported by youth with CF. Furthermore; stage of change for transition readiness is related by age for five self-care management activities and is compared with caregiver perception of transition readiness. Frequency of discussion and age of first discussion with provider were also queried. Five simple linear regressions were utilized to predict youth perception of the five self-care activities based on age.

### Setting

Participants were recruited from four pediatric CF clinics in Central and North Florida, USA. Youth and their caregivers were approached for study inclusion during routine quarterly medical clinic visits. Institutional Review Boards approved this as a research study from the four participating clinics and the University of Central Florida.

### Sample

The study population included a purposeful total sample of 58 youth with CF age 14–22 ( $m = 16.5$ ) years and 52 caregivers. The selection of a minimum age of 14 was based on the AAP clinical report that calls for initiating a “jointly developed transition plan with youth and parents” beginning at this age (Cooley & Sagerman, 2011, p. 185). Youth ages were grouped into three age categories, based on beginning developmental stage in high school 14–15 years ( $n = 19$ ), last 2 years of high school 16–17 years ( $n = 24$ ), and expected age beyond conclusion of grade school 18 and older ( $n = 15$ ). These groups were used to determine how stage of change varies across the self-care management skills in the five subscales by age.

### Survey Measures

The measure used to determine readiness for healthcare transition was the TRAQ (Wood et al., 2014). The TRAQ is a validated 20-item scale measuring self-care management skills required in healthcare transition. Questions include domains of medication management, appointment keeping, tracking health issues, talking with providers, and managing daily activities. The TRAQ is a self-assessment measure using a Likert-type scale (1–5) based on the behavior Stages of Change Model (Prochaska & DiClemente, 1986). Each activity is rated at one of five levels depending on which of the following answer options the participant selects: (1) “No, I do not know how”, corresponding with the pre-contemplation stage (2) “No, but I want to learn”, corresponding with the contemplation stage (3) “No, but I am learning to do this”, corresponding with the determination stage. Answers affirming performance of task include (4) “Yes, I started doing this”, corresponding with the action stage and (5) “Yes, I always do this when I need to”, corresponding with the maintenance stage (Table 1). There are 20 questions and overall scores range from 20 to 100.

**Table 1**

Stage of change with corresponding youth response.

Note. Legend for Figs. 1–5 (TRAQ) and Fig. 6 (TRAQ and TRAQ-C comparison)

Stage of change	Youth response
Maintenance	Yes, I always do this when I need to
Action	Yes, I started doing this
Determination	No, but I am learning to do this
Contemplation	No, but I want to learn
Precontemplation	No, I do not know how

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