

Measuring the Transition Readiness of Youth with Special Healthcare Needs: Validation of the TRAQ—Transition Readiness Assessment Questionnaire

Gregory S. Sawicki,¹ MD, MPH, Katryne Lukens-Bull,² MPH, Xiaoping Yin,³ MS, Nathan Demars,¹ MS, I-Chan Huang,⁴ PhD, William Livingood,^{3,5} PhD, John Reiss,⁶ PhD, and David Wood,^{3,5} MD, MPH

¹Division of Respiratory Diseases, Children's Hospital Boston, Harvard Medical School, ²Office of Research Affairs, University of Florida, College of Medicine, Jacksonville, ³Center for Health Equity and Quality Research (CHEQR), University of Florida, College of Medicine, Jacksonville, ⁴Department of Epidemiology and Health Policy Research and Institute for Child Health Policy, College of Medicine, ⁵Department of Pediatrics, University of Florida, College of Medicine, Jacksonville, and ⁶Institute for Child Health Policy, University of Florida

Objective The aim of this study was to develop the Transition Readiness Assessment Questionnaire (TRAQ), a measure of readiness for transition from pediatric to adult healthcare for youth with special health care needs (YSHCN). **Methods** We administered TRAQ to 192 YSHCN aged 16–26 years in three primary diagnostic categories, conducted factor analysis, and assessed differences in TRAQ scores by age, gender, race, and primary diagnosis type. **Results** Factor analysis identified two TRAQ domains with high internal consistency: Skills for Self-Management and Skills for Self-Advocacy. Each domain had high internal consistency. In multivariate regression models, older age and a primary diagnosis of an activity limiting physical condition were associated with higher scores in Self-Management, and female gender and a primary diagnosis of an activity limiting physical condition were associated with higher scores in Self-Advocacy. **Conclusions** Our initial validation study suggests the TRAQ is a useful tool to assess transition readiness in YSHCN and to guide educational interventions by providers to support transition.

Key words adolescents; chronic illness; health care services.

Introduction

It is estimated that about 10 million children and youth aged 0–17 years in the United States have special health-care needs (SHCN) (Newacheck & Kim, 2005), defined as “increased risk for a chronic physical, developmental, behavioral, or emotional condition which requires health and related services of a type or amount beyond that required by children generally” (McPherson et al., 1998). The proportion of children with special needs increases with age, and due to advances in medical care, 90% of children with conditions that were previously fatal in childhood are surviving into adulthood. Estimates show that in the United States alone, 500,000 adolescents with SHCN reach age 18 each year (American Academy of Pediatrics,

2002; Perrin, Bloom, & Gortmaker, 2007). It is broadly acknowledged that the process of preparing youth with SHCN and disabilities for the eventual transition to adult healthcare should start in early adolescence and involve individualized planning and ongoing skills development (American Academy of Pediatrics, 2002). Experts and guidelines recommend that the timing of the transfer to adult care should be based on a young person's readiness and ability to negotiate the adult healthcare system (Reiss, Gibson, & Walker, 2005). However, for many adolescents with chronic conditions this transition to adult care is disorganized and results in both decreased access to care and impaired health and function (Rosen, Blum, Britto, Sawyer, & Siegel, 2003). The timing of

All correspondence concerning this article should be addressed to Gregory Sawicki, MD, MPH, Division of Respiratory Diseases, Children's Hospital Boston, 300 Longwood Avenue, Boston, MA 02115, USA.
E-mail: gregory.sawicki@childrens.harvard.edu

Journal of Pediatric Psychology 36(2) pp. 160–171, 2011
doi:10.1093/jpepsy/jsp128

Advance Access publication December 29, 2009

Journal of Pediatric Psychology vol. 36 no. 2 © The Author 2009. Published by Oxford University Press on behalf of the Society of Pediatric Psychology. All rights reserved. For permissions, please e-mail: journals.permissions@oup.com

transfer appears to be based primarily on age. Youth may also be precipitously discharged out of pediatric care when they display “adult behaviors,” such as becoming pregnant, abusing illegal substances, challenging authority, becoming sexually active, or being adjudicated to the juvenile justice system (Reiss & Gibson, 2002; Rosen, 1995).

National surveys of parents or guardians of YSHCN have found that only 50% report having discussed transition with their adolescent’s physician (Lotstein, McPherson, Strickland, & Newacheck, 2005) and only 30% had a plan for addressing those needs (Scal & Ireland, 2005). These studies show that a minority of YSHCN, regardless of the severity of their health condition, are receiving transition services from their healthcare providers. Because the move to adult healthcare represents a critical stage in the life course of young adults, sub-optimal transition experiences may not only impede access to needed medical care but may also undermine education and/or vocational training, severely limiting opportunities for a successful and productive adulthood (Halfon & Hochstein, 2002).

The process of preparing youth for the move to adult care has been studied in diverse patient populations, including cystic fibrosis (Anderson, Flume, Hardy, & Gray, 2002; Brumfield & Lansbury, 2004; Flume, Anderson, Hardy, & Gray, 2001; Flume, Taylor, Anderson, Gray, & Turner, 2004; McLaughlin et al., 2008), congenital heart disease (Knauth, Verstappen, Reiss, & Webb, 2006; Lyon, Kuehl, & McCarter, 2006; Reid et al., 2004), diabetes (Van Wallegghem, Macdonald, & Dean, 2008), asthma (Houtrow & Newacheck, 2008), HIV (Wiener, Zobel, Battles, & Ryder, 2007), mental health conditions (Marcer, Finlay, & Baverstock, 2008; Singh, Paul, Ford, Kramer, & Weaver, 2008), and neuromuscular disease (Binks, Barden, Burke, & Young, 2007). There is consensus that successful transition requires that youth acquire skills in the areas of self-care, healthcare decision-making, and self-advocacy that will prepare them to “take more responsibility for their health and health care” (Institute of Medicine, 2007). The acquisition of behaviors that support self-care, healthcare decision-making, and self-advocacy is influenced by a complex interaction of factors including the youth’s own cognitive maturity and/or development, type and complexity of physical and mental health issues, health system and insurance supports, and barriers and family resources (Kelly, Kratz, Bielski, & Rinehart, 2002). For example, youth with cognitive impairment develop independent living skills at a different trajectory than youth with primarily physical impairments; however, youth with cognitive

impairments may have access to additional supports to assist with the transition process (Forbes et al., 2001).

While many clinical programs are striving to enhance the acquisition of transition-related skills of the adolescents they serve, it appears that these programs do not include an assessment of the youths’ transition readiness as part of routine healthcare (Scal, Evans, Blozis, Okinow, & Blum, 1999). For example, a recent survey of cystic fibrosis care centers found that less than half of the programs consistently perform readiness assessments and less than 20% have a program to foster the development of self-management skills and knowledge for transition (McLaughlin et al., 2008).

One potential impediment to the incorporation of transition readiness skill development into clinical practice is the lack of a validated, patient-centered instrument to assess youths’ ability to make appointments, understand their medications and other skills needed for transition. A number of checklists exist in the unpublished literature and are used by some transition programs. The checklists generally ask the respondent to indicate yes or no if they do or do not have a particular HCT-related knowledge or skill. We felt the “no” response set did not adequately describe the different levels of “readiness” states one can be in prior to skill acquisition and mastery. Furthermore, these checklists measure many different overlapping constructs or skills reflecting different stages on a continuum of readiness with no consistent application of the Stages of Change model of readiness. The availability of a validated self-administered assessment tool that consistently measured stages of readiness for each transition-related skill would help child health providers identify areas in which the youth need education and training to achieve autonomy, but would also guide providers, families, and youth on readiness for transition to adult care. This ordinal scale over a continuum for each construct has an advantage of greater sensitivity to change than would be associated with a dichotomous variable for each construct. In this study, we sought to develop and validate an instrument to assess transition readiness skills among a diverse group of youth or young adults with SHCN. We adopted the framework of the Stages of Change Model, also referred to as the Transtheoretical Model (Prochaska & DiClemente, 1986) because it focuses on the decision-making of the individual, as opposed to social or biological influences of behavior. The approach requires the assessment of a person’s stage of readiness for adopting particular behaviors and has been adapted in other studies of positive and negative health behavior change, decision-making, and readiness assessment (Narayan, Steele-Johnson, Delgado, & Cole, 2007; Prochaska, 2008). The Stages of Change

Model was originally developed from clinical practice for the treatment of addictive behaviors; however, it has been used to assess health-related behavior changes, many of which involve self-management and self-advocacy, critical skills for youth to acquire during healthcare transition (Rollnick, Mason, & Butler, 1999). While the stage construct is the key organizing construct of the model, the most important aspect of this construct is that change is a developmental process reflecting a continuum of maturation that is usually acquired over time. On the basis of our clinical experience we felt this approach was consistent with the developmental process of skill acquisition during emerging adulthood and healthcare transition (Arnett, 2000). In addition, applying the transtheoretical model as a construct for assessing skills related to healthcare transition provides important guidance to the provider on how intervene to support movement toward skill acquisition while supporting patient autonomy (Prochaska & DiClemente, 1986).

In this article, we review the process of identifying specific behaviors relevant to healthcare transition, formulation of questions to assess these behaviors, the process for item reduction, the development of the scale structure, and validity and internal reliability testing of the Transition Readiness Assessment Questionnaire (TRAQ). We describe the fielding of the questionnaire to a large cohort of youth with special healthcare needs. Based on studies on the pattern of acquisition of developmental milestones of emerging adulthood, we hypothesized a priori that healthcare transition skills, as reflected by TRAQ scores, would differ based on age and gender. Since adolescent girls and young women may achieve developmental milestones earlier than adolescent boys or young men, we hypothesized that females would demonstrate higher transition readiness scores as compared to age-matched males (Cohn, 1991). Similarly, we hypothesized that older adolescents would have higher transition readiness scores than younger adolescents (Cauffman & Steinberg, 2001). Furthermore, based on studies demonstrating the different developmental trajectories experienced by emerging adults with mental illness and developmental disabilities, we hypothesized that youth with these conditions would have lower TRAQ scores when compared to youth with conditions affecting primarily physical functioning (Young, 2007; Clark & Davis, 2000; Forbes et al., 2001).

Methods

Patient Population

Data was collected on subjects aged 16–26 years from two outpatient clinics, the Jacksonville Health and Transition

Services (JaxHATS) Clinic at the University of Florida, Jacksonville, and the Cystic Fibrosis (CF) Center at Children's Hospital Boston. The JaxHATS Clinic provides comprehensive primary care services, care coordination, and intensive transition support for over 350 youth and young adults with a wide variety of complex health conditions including cerebral palsy, type 1 and type 2 diabetes, spina bifida, cystic fibrosis, sickle cell disease, seizure disorders, autism, and other developmental disabilities. The CF Center at Children's Hospital Boston cares for approximately 560 patients with CF, of whom ~150 are between the ages of 16 and 26 years. At the JaxHATS Clinic, the study questionnaire (TRAQ) was administered to a convenience sample of all eligible youth enrolled in the program between November 2007 and May 2008 as part of routine clinical assessment and care. Data from the surveys was entered into a clinical database. At Children's Hospital, Boston, the study questionnaire was administered to a convenience sample of patients with CF ages 16–26 years during routine CF clinic visits from January through September 2008. Informed consent or assent was obtained from the patient. The study was approved by the Institutional Review Board at both sites.

Data regarding the clinical and demographic characteristics of the patients who participated in the study were obtained through a review of the patient's medical record. We divided the youth in our study into the following three age groups: 16–18, 19–20, 21–26 years, because it allowed an adequate sample size in each group and represented early, middle and late transition age groups. We divided the sample by race into one of two race/ethnicity groups (white or non-white). Based on the clinical data, each subject was assigned to one of the following three primary diagnosis categories: Activity Limiting Physical Condition, Cognitive Impairment, and Mental Health Condition. The Activity Limiting Physical Condition group included subjects with minimal or no cognitive impairment with diagnoses that included cystic fibrosis, cerebral palsy, deafness, type 1 or type 2 diabetes, sickle cell disease, congenital heart disease, chronic pulmonary disease, spinal cord injury, spina bifida, or other chronic conditions which primarily affect the physical health of the youth or young adult. The Cognitive Impairment group included youth or young adults enrolled in the clinical programs who had some degree of cognitive impairment, but who clinicians judged, based on their interaction with them, able to complete the questionnaire on their own. This group included youth with Autism Spectrum Disorder or mild mental retardation. Although these youth or young adults may also have additional conditions, they were placed in the Cognitive Impairment group because their

cognitive impairment was judged to affect their ability to acquire and master skills related to transition more so than their physical health condition. Finally, the Mental Health Conditions group included youth or young adults with a primary diagnosis of attention-deficit hyperactivity disorder (ADHD), learning disabilities, behavior disorders, bipolar disorder, and other mental health conditions which may have a significant impact on the ability to acquire and master skills related to transition.

Instrument Development

The TRAQ was initially developed by investigators at the University of Florida, Jacksonville. Initially, an extensive literature review and a networking exercise of transition programs and transition-related web sites was initiated through the University of Florida's Health Care transition websites and list-serve (Institute for Child Health Policy's Health Care Transitions website, <http://hctransitions.ichp.ufl.edu>). As a result of this search, we found that no tool existed that had been validated; however, we found a number of checklists or questionnaires being used by transition programs which had been developed by clinicians or work groups actively involved in providing healthcare transition. We selected nine questionnaires or checklists (see supplementary material online) that covered a broad range of content. Non-redundant items from the nine checklists were pooled into 79 medical care-related items and 83 employment and community/independent living focused items. We included items related to employment and independent living because these skills (e.g., using public transportation) are critical developmental tasks of transition to adulthood (Arnett, 2000). Moreover, mastery of skills in education, vocation, and independent living influences youths' motivation for mastery of skills related to disease self-management and healthcare utilization (Ryan & Deci, 2000; Clark & Davis, 2000).

Subject content was identified for each item from all of the checklists, and items with common subject matter were combined, many of the items reflecting different stages of readiness related to discrete subject matter. The resultant pool of items assessed knowledge,

attitudes, and behaviors, often of the same construct (e.g., communication with health providers). We reworded all items to be stated as skills rather than knowledge or attitudes, in an effort to focus the assessment on skill acquisition. This reduced the total number of items from 162 to 62. The 62 items were initially organized into 3 domains and 11 subdomains: managing your own health (Self-care, Medications, Medical equipment), interaction with providers (Accessing Medical Care, Keeping a medical history, Communicating with your doctor or nurse, Health insurance), and other transition-related activities (Job or school, Daily living activities, Personal Safety, Community resources).

In designing the TRAQ, we created question response options to represent the five stages of change of the Transtheoretical Model (Table I) and organized them into a 5-point ordinal response scale. We created simple and short phrases that we felt youth could readily understand and use to rate their own stage of skill acquisition. For example, we asked the youth to indicate where the response, "I'm learning to do this," best fit along the continuum of a simplified description of Prochaska's definitions of contemplation, preparation, and action. Using a near-final version of the response categories in ethnographic interviews with 15 youth, we inquired as to whether the wording of the response categories (a) was clear (asking them to interpret the response meaning) and (b) was consistent with the definition of the stage as described by Prochaska. (Prochaska & DiClemente, 1986). There was consensus among the youth that the wording of the responses corresponded to the appropriate definitions of the stages of change.

Overview of Factor Analysis and Validation Analyses

The next stage of the development of the TRAQ consisted of ratings of content/face validity by youth and experts and testing of construct validity, scale-internal consistency, and reliability. As part of the assessment of content/face validity, we focused on the clarity of contents, meaning, wording, and intelligibility of the items. First, we

Table I. Stages of Change Model for TRAQ Development

Stage	Definition ^a	TRAQ response category	TRAQ score
Precontemplation	Has no intention of taking action within the next 6 months	I do not need to do this	1
Contemplation	Intends to take action in the next 6 months	I do not know how but I want to learn	2
Preparation	Intends to take action within the next 30 days and has taken some behavioral steps in this direction	I am learning to do this	3
Action	Has changed behavior for less than 6 months	I have started doing this	4
Maintenance	Has changed behavior for more than 6 months	I always do this when I need to	5

^aSource: Prochaska, J. O., & DiClemente, C. C. (1986). The transtheoretical approach. *Handbook of Eclectic Psychotherapy* (pp. 163–200). New York: Brunner-Mazel.

conducted ethnographic interviews using the questionnaire as the guide with a convenience sample of 15 youth in the JaxHATS clinic. The youth ranged in age from 16 to 23, and were evenly divided by gender. Two-thirds of the youth were black and one-third were white. The 15 youth were not sampled in subsequent fielding of the revised questionnaire. We read each question to the youth, and then asked the youth to explain what the question meant to him or her, and to identify any words, phrases, or concepts that were unclear. Based on the collective feedback from the youth, we rewrote the items to clarify question meaning and simplify the language. After the revision we conducted a reading level analysis and found the questionnaire to have a Flesch–Kincaid Grade Level of 5.7. Second, we utilized a list-serve from the University of Florida on Health Care Transition to identify providers working in transition health programs. Those willing to participate were asked to rate each question from 1 to 5, with 1 = not important and 5 = highly important, to the process of healthcare transition. Furthermore, we asked them to rank each question in order of importance within each of the 11 subdomains. Twelve transition healthcare providers agreed to rate the 62 items in the questionnaire. The 12 providers had an average of 22 years in practice, and 9 years practicing in transition-related services; three were physicians or nurse practitioners, 7 were nurses, and 2 were social workers. Average question rating scores ranged from a high of 4.73 to a low of 2.91. All questions with an average score of 4.0 or above (33 questions) were retained and all items with a score of <4.0 were either eliminated or combined with existing questions based on recommendations from the review providers.

The resulting 33-item questionnaire was fielded to 192 patients at 2 sites and psychometric analyses were conducted, including principal components factor analysis and known-groups analysis, to demonstrate the construct validity, factor structure, and internal reliability of the TRAQ. No youth we approached for the study declined to participate. We examined the distribution of the item scores and imputed the missing item value before conducting psychometric analyses. We examined the mean and standard deviation of individual item score and found that the distribution of item scores was not skewed. We used the class mean imputation method to impute the missing data based on the mean scores of the nonmissing values from the same cell as defined by age group and diagnosis type (Aday, Cornelius, & Cohen, 2006). Fewer than 3% of values for any given question were missing and imputed. Once all missing values were imputed, the dataset was then analyzed using standard descriptive statistics

to summarize the demographic and clinical characteristics of the TRAQ sample and to describe individual item scores and TRAQ domain scores.

Because there is no prior evidence to suggest the structure of a transition readiness measure, to better determine factorial structure of the TRAQ, we conducted a principal component exploratory factor analysis (EFA) using the 33 items being retained in the previous step. Three criteria were used to identify significant factors extracted from the 33 items: (1) the eigenvalue >1, (2) the number of factors at which a clear elbow appears in the scree plot, and (3) the percentage of variance explained by the factors. We rotated the extracted factors using the oblique axes solution to better identify underlying factors as well as establish the relationship of each of the items to one another within the identified factors. The use of an oblique solution instead of an orthogonal solution is based on the evidence that the factors extracted were moderately correlated. We examined the factor loadings of items associated with the extracted factors to retain a subset of items of the TRAQ. Factor loading measures the magnitude or importance of an item to factors, which is equivalent to the correlations between the item and factors. We retained specific items if their factor loadings were >.3 on one factor and ≤.3 on other factors. We deleted those items with factor loadings that were (1) lower than .3 on the extracted factors or (2) larger than .3 and equally loaded on different factors (Sharma, 1996).

We used four external variables to demonstrate construct validity of the TRAQ, including age group (16–18, 19–20, and 21–26 years), gender, race (white and non-white), and diagnosis type (activity-limiting condition and mental health condition or cognitive limitation). We compared the mean domain scores across different categories of a specific known-group. We performed *t*-tests to demonstrate whether the hypothesized relationships between known-groups and TRAQ domain scores were statistically significant. We also performed multivariate linear regression to demonstrate relationships of one known-group with TRAQ domain scores after adjusting for the influence of other known-groups. We calculated Cronbach's alpha coefficient to assess the internal consistency reliability of the TRAQ domains. All analyses were performed with SAS software version 9.1 (SAS Institute, Cary, NC) and a *p*-value <.05 was considered statistically significant.

Results

Patient Demographics

Table II presents the key clinical and demographic characteristics of the 192 patients who completed the TRAQ.

Table II. Clinical and Demographic Characteristics of TRAQ Respondents

	Summary statistics
Number of respondents, <i>n</i>	192
Female, <i>n</i> (%)	107 (56%)
Age (years), mean \pm SD	19.7 \pm 2.3
White race, <i>n</i> (%)	122 (64%)
Primary diagnosis, <i>n</i> (%)	
Activity limiting physical condition	154 (80%)
Cognitive impairment	17 (9%)
Mental health condition	21 (11%)

The majority of the cohort was female (56%) and white (64%) with a mean age of 19.7 years. Most (80%) respondents had a primary diagnostic category of an activity-limiting physical condition, with the most common diagnoses being cystic fibrosis (40%), hematologic disease (8%), diabetes (7%), and cerebral palsy (5%). Cognitive impairment was the primary diagnosis for 9% of the sample, and mental health conditions such as ADHD were the primary diagnosis in 11%.

Factor Analysis

We conducted a principal component factor analysis to assess the factor structure for the TRAQ. Four factors demonstrated an eigenvalue ≥ 1 , which were 9.73, 2.16, 1.57, and 1.26, respectively (Table III). However, a scree plot suggested that a clear elbow emerged with solely the first two factors (eigenvalues 9.73 and 2.16) as compared to the rest of extracted factors. Likewise, the first and second factors account for 68% of the total variance in the transition readiness measurement. Based on these findings, we suggest that two factors (subdomains) are captured by the TRAQ to measure the concept of transition readiness.

We classified items into one of the two domains, and deleted items if they were weakly associated with both domains. Based on the criteria of factor loadings $>.3$ on one factor and $\leq .3$ on the other factor, we assigned 16 items to domain 1 and 13 items to domain 2. We deleted four items because their loadings were $\leq .3$ on both domains. We excluded these four items in the subsequent validation analyses, and these four items are not included in the version of the TRAQ that is presented in the appendix (see supplementary material online). Domain 1 assesses Skills for Chronic Condition Self-Management such as filling prescriptions, understanding treatment side effects, handling medical equipment, and arranging medical follow-up visits. This self-management domain also includes items related to managing finances, health

insurance, and payments for medical equipment and supplies. Domain 2 primarily assesses Skills for Self-Advocacy and Communication with Health Providers and includes items related to skills for communication with the health-care team and items related to managing activities of daily living and use of school and community resources. Table III also shows the individual mean item scores for each of the final 29 items of the TRAQ. Table III also shows the mean domain scores for the final two TRAQ domains. Overall, the mean score for the Self-Advocacy domain was higher than the Self-Management domain (mean 3.86 vs. 3.51). Scores for two domains were moderately correlated ($r = .46$, $p < .0001$), and both domains had high internal consistency, with a Cronbach's alpha of .92 for Self-Management and .82 for Self-Advocacy. The Cronbach's alpha for the entire 29-item questionnaire was .93.

Known-Groups Validity

Table IV shows that TRAQ scores differed based on the respondent's primary diagnosis and age in both domains. For Self-Management, those with activity-limiting health conditions (mean 3.72 ± 0.91) had significantly higher scores than those with either cognitive impairment (mean 2.61 ± 1.03) or mental health conditions (2.67 ± 0.90) ($p < .0001$). For Self-Advocacy, we found the same results with the primary diagnosis group. Older age also led to significantly higher scores in both domains. Females had significantly higher scores for Self-Advocacy (mean 3.99 vs. 3.69, $p = .005$), but not for Self-Management. There was no significant difference in either domain score based on race. Table V shows the multivariate linear regression for the two TRAQ domains. In the regression model, age, gender, diagnosis type, and race were used as independent variables. For Self-Management, older age ($p < .0001$) and a primary diagnosis of an activity-limiting health condition (vs. mental illness/cognitive impairment) ($p < .0001$) were associated with higher scores. For Self-Advocacy, a primary diagnosis of activity-limiting health condition ($p = .007$) and female gender ($p = .006$) were associated with higher scores.

Discussion

In this study, we have presented findings from our initial efforts to develop and validate a self-administered questionnaire, the TRAQ, a tool that measures skills needed to successfully transition from pediatric to adult healthcare and progress in other life areas such as education, work, and daily life.

Table III. Factor Analysis of the TRAQ^a

TRAQ item	TRAQ domain 1: skills for chronic condition self-management	TRAQ domain 2: skills for self-advocacy and healthcare utilization	Item score (mean ± SD)
Eigenvalue	9.73	2.16	
Total variance explained by two domains, %	56	12	
Cronbach's alpha	0.92	0.82	
Domain score (mean ± SD)	3.51 ± 1.01	3.86 ± 0.74	
	Factor loading	Factor loading	
DOMAIN 1: Self-management			
Do you take medications correctly and on your own?	0.46	0.23	4.39 ± 1.10
Do you reorder medications before they run out?	0.63	0.24	3.88 ± 1.48
Do you fill a prescription if you need to?	0.53	0.28	3.88 ± 1.41
Do you arrange for your ride to medical appointments?	0.50	0.22	3.80 ± 1.55
Do you call the doctor's office to make an appointment?	0.64	0.24	3.79 ± 1.33
Do you use and take care of medical equipment and supplies?	0.64	-0.10	3.75 ± 1.51
Do you know the side effects or bad reactions of each medication & what to do if you are having a bad reaction?	0.40	0.30	3.73 ± 1.43
Do you call the doctor about unusual changes in your health (Ex. Allergic reactions)?	0.48	0.30	3.72 ± 1.47
Do you follow-up on any referral for tests or check-ups or labs?	0.67	0.09	3.57 ± 1.43
Do you manage your money & budget household expenses (Ex. use checking/debit card)?	0.39	0.26	3.50 ± 1.46
Do you pay or arrange payments for your medications?	0.70	0.02	3.25 ± 1.59
Do you know what your health insurance covers?	0.63	0.11	3.17 ± 1.41
Do you order medical equipment before they run-out?	0.92	-0.27	3.14 ± 1.62
Do you call the suppliers when there is a problem with the equipment?	0.83	-0.20	3.01 ± 1.61
Do you apply for health insurance if you lose your current coverage?	0.44	0.26	2.79 ± 1.44
Do you arrange payment for the medical equipment and supplies?	0.93	-0.30	2.72 ± 1.64
DOMAIN 2: Self-Advocacy			
Do you answer questions that are asked by the doctor, nurse or clinic staff?	0.03	0.58	4.60 ± 0.91
Do you tell the doctor or nurse what you are feeling?	0.12	0.46	4.57 ± 0.89
Do you keep home/room clean or clean-up after meals?	-0.10	0.56	4.48 ± 1.02
Do you use neighborhood stores and services (Ex. grocery stores and pharmacy stores)?	0.28	0.36	4.37 ± 1.23
Do you ask questions of the doctor, nurse, or clinic staff?	-0.01	0.59	4.26 ± 1.12
Do you help plan or prepare meals/food?	0.08	0.49	4.17 ± 1.25
Do you fill out the medical history form, including a list of your allergies?	0.30	0.42	3.82 ± 1.48
Do you keep a calendar or list of medical and other appointments?	0.25	0.48	3.81 ± 1.43
Do you request and get the accommodations & support you need at school or work?	-0.08	0.54	3.65 ± 1.54
Do you apply for a job or work or vocational services?	0.04	0.47	3.64 ± 1.50
Do you call on and use community support services (Ex. After school programs) and advocacy services (Ex. Legal services) when you need them?	0.12	0.35	3.04 ± 1.56
Do you get financial help with school or work?	0.07	0.47	2.90 ± 1.50
Do you make a list of questions before the doctor's visit?	-0.03	0.47	2.84 ± 1.53

^aThe 3 items removed from the original TRAQ instrument following the factor analysis were: Do you use public transportation when you need to?; Do you use an individualized education plan?; and Do you keep a medical diary?

Table IV. Differences in TRAQ Domain Scores Based on Clinical and Demographic Characteristics

	N	TRAQ Self-management		TRAQ Self-advocacy	
		Mean ± SD	p	Mean ± SD	p
Gender					
Male	85	3.35 ± 1.02	0.06	3.69 ± 0.69	0.005
Female	107	3.62 ± 0.98		3.99 ± 0.67	
Race					
White	122	3.59 ± 1.03	0.13	3.89 ± 0.72	0.4
Non-White	66	3.36 ± 0.93		3.80 ± 0.77	
Primary diagnosis					
Activity limiting health condition	154	3.72 ± 0.91	<.0001	3.94 ± 0.71	0.01
Cognitive impairment	17	2.61 ± 1.03		3.51 ± 0.75	
Mental health condition	21	2.67 ± 0.90		3.56 ± 0.84	
Age group					
16–18 years	66	3.01 ± 1.02	<.0001	3.67 ± 0.77	0.03
19–20 years	69	3.65 ± 0.95		3.98 ± 0.76	
21–26 years	57	3.90 ± 0.84		3.92 ± 0.66	

Table V. Multivariate Regression Analysis of the TRAQ

	TRAQ Self-management		TRAQ Self-advocacy	
	parameter estimate	p	parameter estimate	p
Primary diagnosis group ^a	0.927	<.0001	0.366	0.007
Age (years)	0.127	<.0001	0.024	0.3
Female gender	0.226	0.08	0.29	0.006
White race	0.068	0.6	0.03	0.8
Adjusted R ²	0.27		0.07	

^aActivity-limiting physical condition vs. mental health condition or cognitive limitation.

Criteria for transfer to adult healthcare are quite variable, and often rely on age as the sole determining factor (Betz, 2004). Our goal is to broaden these criteria through a more comprehensive assessment of transition readiness. Although there exist many checklists that assess knowledge or behaviors related to transition, to our knowledge the TRAQ is the first skill-focused tool to assess the developmental process of readiness for health transition for youth with chronic medical conditions. By adapting the Stages of Change model as a framework for responses on the TRAQ, we feel that the instrument can more clearly identify the developmental stage of readiness to transition, and thus allow for appropriate interventions based on the skills assessed. We initially conceived the TRAQ with three domains (managing health, interacting with healthcare providers, and other transition skills), but our factor analysis suggests that the items can be grouped into two clusters. Although there is overlap among the skills

which cluster on each of the two domains, the skills assessed are divided broadly into Self-Management and Self-Advocacy domains. The TRAQ Self-Management domain assesses skills in chronic disease self-management, including skills in managing medication, medical appointments, and health insurance. For youth with chronic medical conditions such as cystic fibrosis, diabetes, or seizures, these skills are essential in maintaining good health outcomes and often require a large time commitment. A study of young adults with congenital heart disease found that successful transfer to adult care was correlated with similar skills such as attending appointments alone and arranging appropriate follow-up (Reid et al., 2004). Conversely, lack of self-management skills has been associated with worse outcomes in young adults with diabetes (Bryden, Dunger, Mayou, Peveler, & Neil, 2003; Bryden et al., 2001; Karlsson, Arman, & Wikblad, 2008).

In our analysis, the highest scoring items (5 = “I always do this when I need to”) in the self-management domain were related to taking medications and filling prescriptions. Medication management is critical in these populations; cystic fibrosis patients, for example, often report needing up to 2 hr a day to complete all their recommended therapies (Sawicki, Sellers, & Robinson, 2009). Youth with chronic diseases may be reporting a high level of comfort and skill in such tasks since they have been taking multiple medications throughout their childhood. By the time they reach adolescence and early adulthood, they have already progressed to the maintenance phase of such skills. Alternatively, these high scores may be due to adolescents rating their behavior as more advanced than it

actually is. Medication nonadherence is a significant problem in adolescents with SHCN (Smith & Shuchman, 2005), and we did not assess adherence as part of our study. Future research will need to account for adherence in assessing such self-management skills. Continued support for the development of chronic condition self-management skills needs to be integrated into transition support programs and services.

Not surprisingly, the lowest scores on the TRAQ were on skills related to maintaining health insurance and ensuring payments for medical care or for other life areas such as education. We assume that for the majority of adolescents and young adults, particularly those with frequent contact with the healthcare system, insurance matters, and healthcare financing are managed by parents or caregivers. Skills related to maintaining insurance become even more critical during transition, as both public and private insurance programs terminate coverage when dependent children reach 18–21 years of age (Callahan & Cooper, 2005). As a result, over one-third of young adults are uninsured and as many as two-third have gaps in insurance during this age period (Callahan & Cooper, 2005). These gaps can have detrimental effects on health outcomes during healthcare transition. In a study of young adults with asthma, it was found that delays and unmet needs for care due to financial reasons were more frequent in young adults than in adolescents (Scal, Davern, Ireland, & Park, 2008). Although we are heartened that the majority of our respondents rated themselves as being in the preparation stage with respect to financial skills (“I am learning to do this”), we believe that transition support programs must do more to educate youth about healthcare financing as part of preparation for transition.

The highest scores on the TRAQ Self-Advocacy domain were on items related to communication with the healthcare team. This is not surprising given the frequency of contact that most YSHCN have with their healthcare providers. Many healthcare providers encourage adolescents to communicate independently with physicians and nurses as a routine part of a healthcare visit, so these transition skills are likely to be achieved earlier than others. Future work is needed to assess how clinicians rate the communication skills of YSHCN. Lower scores in the Self-Advocacy domain were found in skills involving employment, community support services, and financial help. This may simply be a reflection of a lower perceived need for such services, rather than a lack of skills in accessing such services.

In our analysis of differences in TRAQ scores based on clinical and demographic characteristics, we found that

the scores increased in the hypothesized direction with regard to two characteristics: age and primary medical condition. As expected, older age was associated with higher scores in the self-management domain. This suggests that as adolescents with SHCN get older, they are indeed progressing along a path of skill-building in terms of self-management skills. Interestingly, age was not associated with different TRAQ scores on the Self-Advocacy domain, suggesting that these indirect health management skills may be learned at an earlier point in adolescence, possibly through the schools. Secondly, youth with physical health problems scored higher than youth with mental health or cognitive problems in all aspects of the TRAQ. These results suggest that youth with physical health problems, as a group, are more mature and independent with regard to issues of transition than are those with serious mental health problems or cognitive limitations. This group may have had increased continuity of healthcare during adolescence, such as in specialty medical clinics, thus leading to greater opportunities to develop transition skills with support of their healthcare team. As such, providers of support for young adults without a consistent source of healthcare, particularly those with mental health issues, need to acknowledge the differences in readiness achievement (National Center on Youth Transition Initiative, 2007). We also found significant gender differences in TRAQ scores only for the Self-Advocacy domain. The skills assessed in this domain primarily focus on perceived communication abilities and activities related to school, household, and community. Our results suggest that girls perceive their skills in these areas as more developed, perhaps due to gender differences in adolescent maturity, or perhaps due to societal expectations. Such gender differences in adolescent maturity have been found in other studies on health status of young adults. In particular, girls seem to achieve developmental milestones such as marriage, living independently, and having children earlier than boys (Park et al., 2006), and girls mature earlier, as measured by ego development, and the gender gap is not closed until mid-adulthood (Cohn, 1991). Our findings are also similar to studies of emerging adulthood which found that young women had higher relational maturity and expectations in terms of emerging adult skills (Nelson et al., 2007). Whether these gender differences in transition readiness lead to differences in transition outcomes clearly needs further study.

Our study has several limitations. Our original questionnaire comprised three groupings of questions, yet our factor analysis revealed a two-solution factorial structure. As there is overlap between items that comprised the two

factors, this factor structure of the TRAQ may have resulted from the relatively small size of our sample. While our population was diverse with respect to a number of important characteristics such as age and clinical condition, we will need to continue to collect data on a larger cohort to either confirm or modify our findings and to better refine the question wording and factor structure for the instrument. In addition, the data from the TRAQ relies on adolescent self-report of skills and knowledge and did not include any objective measures of whether the adolescent had actually achieved these skills. As such, we are developing parallel questionnaires for caregivers and clinicians for future study and validation. Although we did see differences in TRAQ scores based on diagnostic groupings, we were not able to account for inherent differences in diagnoses or disease severity, including the complexity of care, in the current analyses.

Our work represents the first step in the development of an instrument measuring critical skills needed for successful healthcare transition. We acknowledge that the current two-domain structures presented in this article may change with further study. In future studies we plan to administer the TRAQ to a larger number of YSHCN with a diverse set of health conditions over time. This will allow us to refine the questions and define the domains within the instrument. Future work is also needed to assess the association of TRAQ scores on other measures of self-management, self-determination, and health and transition outcomes such as access to adult providers and completion of educational or vocational goals in young adulthood, and to conduct longitudinal analyses of the TRAQ in order to test predictive validity. Establishing the predictive validity of the instrument will be essential in determining values for the instrument that can be used to determine when a particular youth is developmentally ready to transfer to the adult healthcare system.

In conclusion, this study details the development of a new instrument for assessing readiness for healthcare transition among youth with special healthcare needs. The TRAQ is a practical tool for use in either primary care or specialty healthcare settings in assessing readiness for healthcare transition among youth with SHCN and provides a reliable measure for assessing skills in self-management and self-advocacy. The TRAQ may also be useful for YSHCN, their caregivers, and clinicians as a tool to identify areas for patient education and track progress throughout the transition process. Use of this instrument has the potential to improve transition programs and improve health outcomes during healthcare transition for YSHCN.

Supplementary Data

Supplementary data can be found at: <http://www.jpepsy.oxfordjournals.org/>

Conflict of interest: None declared.

Received January 22, 2009; revisions received November 9, 2009; accepted November 24, 2009

References

- Aday, L. A., Cornelius, L. J., & Cohen, S. B. (2006). *Designing and conducting health surveys: A comprehensive guide* (3rd ed.). San Francisco, CA: Wiley.
- American Academy of Pediatrics. (2002). A consensus statement on health care transitions for young adults with special health care needs. *Pediatrics*, *110*(6 Pt 2), 1304–1306.
- Anderson, D. L., Flume, P. A., Hardy, K. K., & Gray, S. (2002). Transition programs in cystic fibrosis centers: perceptions of patients. *Pediatric Pulmonology*, *33*(5), 327–331.
- Arnett, J. J. (2000). Emerging adulthood. A theory of development from the late teens through the twenties. *American Psychology*, *55*(5), 469–480.
- Betz, C. L. (2004). Transition of adolescents with special health care needs: review and analysis of the literature. *Issues in Comprehensive Pediatric Nursing*, *27*(3), 179–241.
- Binks, J. A., Barden, W. S., Burke, T. A., & Young, N. L. (2007). What do we really know about the transition to adult-centered health care? A focus on cerebral palsy and spina bifida. *Archives of Physical Medicine and Rehabilitation*, *88*(8), 1064–1073.
- Brumfield, K., & Lansbury, G. (2004). Experiences of adolescents with cystic fibrosis during their transition from paediatric to adult health care: a qualitative study of young Australian adults. *Disability and Rehabilitation*, *26*(4), 223–234.
- Bryden, K. S., Dunger, D. B., Mayou, R. A., Peveler, R. C., & Neil, H. A. (2003). Poor prognosis of young adults with type 1 diabetes: a longitudinal study. *Diabetes Care*, *26*(4), 1052–1057.
- Bryden, K. S., Peveler, R. C., Stein, A., Neil, A., Mayou, R. A., & Dunger, D. B. (2001). Clinical and psychological course of diabetes from adolescence to young adulthood: a longitudinal cohort study. *Diabetes Care*, *24*(9), 1536–1540.
- Callahan, S. T., & Cooper, W. O. (2005). Uninsurance and health care access among young adults in the United States. *Pediatrics*, *116*(1), 88–95.

- Cauffman, E., & Steinberg, L. (2000). (Im)maturity of judgment in adolescence: why adolescents may be less culpable than adults. *Behavioural Sciences and the Law*, 18(6), 741–760.
- Clark, H.B., & Davis, M. (Vol. Eds.) (2000). *Systems of care for children's mental health series. Transition to adulthood: A resource for assisting young people with emotional or behavioral difficulties*. Baltimore, MD: Brookes.
- Cohn, L.D. (1991). Sex differences in the course of personality development: a meta-analysis. *Psychology Bulletin*, 109(2), 252–266.
- Flume, P. A., Anderson, D. L., Hardy, K. K., & Gray, S. (2001). Transition programs in cystic fibrosis centers: perceptions of pediatric and adult program directors. *Pediatric Pulmonology*, 31(6), 443–450.
- Flume, P. A., Taylor, L. A., Anderson, D. L., Gray, S., & Turner, D. (2004). Transition programs in cystic fibrosis centers: perceptions of team members. *Pediatric Pulmonology*, 37(1), 4–7.
- Forbes, A., While, A., Ullman, R., Lewis, S., Mathes, L., & Griffiths, P. (2001). *A multi-method review to identify components of practice which may promote continuity in the transition from child to adult care for young people with chronic illness or disability*. Report for the National Co-ordinating Centre for NHS Service Delivery and Organisation R&D (NCCSDO) London, England.
- Halfon, N., & Hochstein, M. (2002). Life course health development: an integrated framework for developing health, policy, and research. *Milbank Q*, 80(3), 433–479, iii.
- Houtrow, A. J., & Newacheck, P. W. (2008). Understanding transition issues: asthma as an example. *Journal of Pediatrics*, 152(4), 453–455.
- Institute of Medicine (2007). *The future of disability in America*. Washington, DC: The National Academies Press.
- Karlsson, A., Arman, M., & Wikblad, K. (2008). Teenagers with type 1 diabetes—a phenomenological study of the transition towards autonomy in self-management. *International Journal of Nursing Studies*, 45(4), 562–570.
- Kelly, A. M., Kratz, B., Bielski, M., & Rinehart, P. M. (2002). Implementing transitions for youth with complex chronic conditions using the medical home model. *Pediatrics*, 110(6 Pt 2), 1322–1327.
- Knauth, A., Verstappen, A., Reiss, J., & Webb, G. D. (2006). Transition and transfer from pediatric to adult care of the young adult with complex congenital heart disease. *Cardiology Clinics*, 24(4), 619–629.
- Lotstein, D.S., McPherson, M., Strickland, B., & Newacheck, P.W. (2005). Transition planning for youth with special health care needs: results from the National Survey of Children with Special Health Care Needs. *Pediatrics*, 115(6), 1562–1568.
- Lyon, M. E., Kuehl, K., & McCarter, R. (2006). Transition to adulthood in congenital heart disease: missed adolescent milestones. *Journal of Adolescent Health*, 39(1), 121–124.
- Marcer, H., Finlay, F., & Baverstock, A. (2008). ADHD and transition to adult services—the experience of community paediatricians. *Child Care Health and Development*, 34(5), 564–566.
- McLaughlin, S. E., Diener-West, M., Indurkha, A., Rubin, H., Heckmann, R., & Boyle, M. P. (2008). Improving transition from pediatric to adult cystic fibrosis care: lessons from a national survey of current practices. *Pediatrics*, 121(5), e1160–e1166.
- McPherson, M., Arango, P., Fox, H., Lauver, C., McManus, M., Newacheck, P. W., et al. (1998). A new definition of children with special health care needs. *Pediatrics*, 102(1 Pt 1), 137–140.
- Narayan, A., Steele-Johnson, D., Delgado, K. M., & Cole, P. A. (2007). Differential effects of pretraining influences on readiness to change. *Journal of Psychology*, 141(1), 47–60.
- National Center on Youth Transition Initiative. (2007). On the move: Helping young adults with serious mental needs transition into adulthood. Retrieved January 5, 2009, from <http://ncty.fmhi.usf.edu/index2.cfm>.
- Nelson, L. J., Padilla-Walker, L. M., Carroll, J. S., Madsen, S. D., Barry, C. M., & Badger, S. (2007). “If you want me to treat you like an adult, start acting like one!” Comparing the criteria that emerging adults and their parents have for adulthood. *Journal of Family Psychology*, 21(4), 665–674.
- Newacheck, P. W., & Kim, S. E. (2005). A national profile of health care utilization and expenditures for children with special health care needs. *Archives of Pediatrics and Adolescent Medicine*, 159(1), 10–17.
- Park, M. J., Paul Mulye, T., Adams, S. H., Brindis, C. D., & Irwin, C. E. Jr. (2006). The health status of young adults in the United States. *Journal of Adolescent Health*, 39(3), 305–317.
- Perrin, J. M., Bloom, S. R., & Gortmaker, S. L. (2007). The increase of childhood chronic conditions in the United States. *JAMA*, 297(24), 2755–2759.

- Prochaska, J. O. (2008). Decision making in the transtheoretical model of behavior change. *Medical Decision Making*, 28(6), 845–849.
- Prochaska, J. O., & DiClemente, C. C. (1986). The transtheoretical approach. In *Handbook of eclectic psychotherapy*. New York: Brunner-Mazel.
- Reid, G. J., Irvine, M. J., McCrindle, B. W., Sananes, R., Ritvo, P. G., Siu, S. C., et al. (2004). Prevalence and correlates of successful transfer from pediatric to adult health care among a cohort of young adults with complex congenital heart defects. *Pediatrics*, 113(3 Pt 1), e197–e205.
- Reiss, J., & Gibson, R. (2002). Health care transition: destinations unknown. *Pediatrics*, 110(6 Pt 2), 1307–1314.
- Reiss, J. G., Gibson, R. W., & Walker, L. R. (2005). Health care transition: youth, family, and provider perspectives. *Pediatrics*, 115(1), 112–120.
- Rollnick, S., Mason, P., & Butler, C. (1999). *Health behavior change: A guide for practitioners*. Edinburgh, UK: Churchill Livingstone.
- Rosen, D. (1995). Between two worlds: bridging the cultures of child health and adult medicine. *Journal of Adolescent Health*, 17(1), 10–16.
- Rosen, D.S., Blum, R.W., Britto, M., Sawyer, S.M., & Siegel, D.M. (2003). Transition to adult health care for adolescents and young adults with chronic conditions: position paper of the Society for Adolescent Medicine. *Journal of Adolescent Health*, 33(4), 309–311.
- Ryan, R.M., & Deci, E.L. (2000). Self-determination theory and the facilitation of intrinsic motivation, social development, and well-being. *American Psychology*, 55(1), 68–78.
- Sawicki, G. S., Sellers, D. E., & Robinson, W. M. (2009). High treatment burden in adults with cystic fibrosis: Challenges to disease self-management. *Journal of Cystic Fibrosis*, 8(2), 91–6.
- Scal, P., Evans, T., Blozis, S., Okinow, N., & Blum, R. (1999). Trends in transition from pediatric to adult health care services for young adults with chronic conditions. *Journal of Adolescent Health*, 24(4), 259–264.
- Scal, P., & Ireland, M. (2005). Addressing transition to adult health care for adolescents with special health care needs. *Pediatrics*, 115(6), 1607–1612.
- Scal, P., Davern, M., Ireland, M., & Park, K. (2008). Transition to adulthood: delays and unmet needs among adolescents and young adults with asthma. *Journal of Pediatrics*, 152(4), 471–475.
- Sharma, S. (1996). *Applied Multivariate Techniques*. West Sussex, UK: John Wiley & Sons:90–143.
- Singh, S. P., Paul, M., Ford, T., Kramer, T., & Weaver, T. (2008). Transitions of care from Child and Adolescent Mental Health Services to Adult Mental Health Services (TRACK Study): a study of protocols in Greater London. *BMC Health Services Research*, 8, 135.
- Smith, B. A., & Shuchman, M. (2005). Problem of non-adherence in chronically ill adolescents: strategies for assessment and intervention. *Current Opinion in Pediatrics*, 17(5), 613–618.
- Van Wallegghem, N., Macdonald, C. A., & Dean, H. J. (2008). Evaluation of a systems navigator model for transition from pediatric to adult care for young adults with type 1 diabetes. *Diabetes Care*, 31(8), 1529–1530.
- Wiener, L. S., Zobel, M., Battles, H., & Ryder, C. (2007). Transition from a pediatric HIV intramural clinical research program to adolescent and adult community-based care services: assessing transition readiness. *Social Work in Health Care*, 46(1), 1–19.
- Young, N. L. (2007). The transition to adulthood for children with cerebral palsy: what do we know about their health care needs? *J Pediatr Orthop*, 27(4), 476–479.