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CLINICAL STUDY

A Clinical Tool to Measure the Components of Health-Care Transition from Pediatric Care to Adult Care: The *UNC TR_xANSITION Scale*

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Abstract

Objective: To describe the development of the *University of North Carolina (UNC) TR_xANSITION Scale* that measures the health-care transition and self-management skills by youth with chronic health conditions. **Methods:** Item and scale development of the *UNC TR_xANSITION Scale* was informed by two theoretical models, available literature, and expert opinion interviews and feedback from youth with chronic conditions, their parents, and interdisciplinary collaboration. Through an iterative process, three versions of the scale were piloted on a total of 185 adolescents and emerging adults with different chronic illnesses. This clinically administered scale relies on a semi-structured interview format of the patient and does not rely solely on patient report, but is verified with information from the medical record to validate responses. **Results:** Following the item development and the three iterations of the scale, version 3 was examined in a more intensive fashion. The current version of the *UNC TR_xANSITION Scale* comprises 33 items scattered across the following 10 domains: Type of illness, Rx=medications, Adherence, Nutrition, Self-management, Informed-reproduction, Trade/school, Insurance, Ongoing support, and New health providers. It requires approximately 7–8 min to administer. With a sample of 128 adolescents and young adults, ranging in age from 12 to 20, inter-rater reliability was strong ($r = 0.71$) and item-total correlation scores were moderate to high. Content and construct validity were satisfactory, and the overall score was sensitive to advancing age. The univariate linear regression yielded a beta coefficient of 1.08 ($p < 0.0001$), indicating that the total score increased with advancing age. Specifically, there was about a one point increase in the total score for each year of age. **Conclusion:** The *UNC TR_xANSITION Scale* is a disease-neutral tool that can be used in the clinical setting. Initial findings suggest that it is a reliable and valid tool that has the potential to measure health-care transition skill mastery and knowledge in a multidimensional fashion.

Keywords: transition, transition scale, adolescents, young adults, emerging adults, health-care transition, disease self-management, transition tool

INTRODUCTION

Medical advances over the past 25 years have led to improved survival rates among individuals with a range of childhood chronic illnesses.^{1–4} In the United States, it is estimated that more than 500,000 adolescents with special health-care needs transfer into adult-focused health-care systems annually.⁵ For adolescents and young adults with chronic illnesses, additional health-related challenges make the health-care transition process perilous as medical, psychological, and socioeconomic factors (e.g., loss of health

coverage or lack of employment) result in unmet health-care needs.⁶

Given its complexity, the health-care transition process requires that adolescents and young adults acquire knowledge and skills that result in improved self-management of their illnesses.^{7–9} Yet, there is a paucity of evidence to substantiate transition programs' effectiveness in documenting adolescents' and young adults' progression along the continuum of transition preparation or to validate programs' accuracy in assessing young adults' readiness for transfer to an adult health-care provider.¹⁰ In an

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earlier review of transition studies done between 1982 and 2003, Betz noted that few, if any, of these studies described the development of measures for assessing transition progress, readiness for transfer, or program effectiveness.¹¹ Unfortunately, this observation remains about the same nearly a decade later.

Available Health-Care Transition Measures

When the available health-care transition measures are surveyed, nearly all of them are disease-specific^{12–17} and, consequently, not easily adapted to other disorders or disease conditions. Moreover, all of the existing health-care transition instruments rely solely on self-report. Although this is not an uncommon strategy for collecting such data from older adolescents and young adults, it does raise concerns about the reliability of the data. Self-report data can be plagued by both over- and under-reporting of concerns and are best used when combined with other sources of information. Although initial strides have been made in the past decade, the availability of a health-care transition instrument for adolescents and young adults that is disease neutral, is brief, and tests mastery without relying solely on self-report continues to be needed by professionals.

The Purpose of This Study

The primary purpose of this article is to describe the theoretical foundation, development, and preliminary psychometric properties of the *UNC TR_xANSITION Scale*. This instrument was designed with input from adolescent and young adult patients with a number of different chronic illnesses and via input from multiple professionals dealing with transition issues in their clinical settings. This scale purports to measure knowledge and skill mastery and key areas critical for health-care transition readiness and provides a mechanism for health-care professionals to diagnose and facilitate the health-care transition process for adolescents and young adults as well as to monitor their progress.

MATERIALS AND METHODS

We describe the development of the *UNC TR_xANSITION Scale* based on the theoretical framework we followed and item development. The results from our pilot testing and how we standardized and produced preliminary normative data are presented followed by preliminary reliability and validity estimates.

Theoretical Framework

Theoretical grounding for the structure and content of items that comprise the *UNC TR_xANSITION Scale* originates from two sources: (1) a 2001 report of the Academy of Science and (2) self-determination theory.^{18,19} Taken together, these two theoretical models provided the foundation for the development of the items for the *UNC TR_xANSITION Scale*.

The Academy of Science report cites three empirically based principles that promote learning with understanding: (1) assessment of an individual's preconceptions, (2) provision of new information at an appropriate level and in an appropriate format, and (3) opportunities for the learner to apply the new information.¹⁸ To incorporate these principles into the *UNC TR_xANSITION Scale*, items were created that asked patients to assess their disease knowledge and ability to complete self-management tasks (i.e., adherence to medical treatment, scheduling appointments). For example, in relation to knowledge and understanding about medications, the patient is first asked to provide the name of each medication, followed by questions on the purpose of each medication, and finally, the possible health outcome(s) if the medications are not taken or not taken properly. If the patient does not know the correct answers to these questions, guided patient education can take place based on the areas of need.

Self-determination theory emphasizes the innate psychological need for competence, relatedness, and autonomy as important sources of personal motivation.¹⁹ Previous studies have indicated that this theory of health behavior is a useful framework for achieving a more clear understanding of self-management of glycemic control among adult patients with diabetes mellitus.²⁰ For the *UNC TR_xANSITION Scale*, the self-management items assess the patient's autonomy regarding taking medications appropriately, filling prescriptions in a timely manner, obtaining medications, and contacting a physician with specific questions or concerns about the medication.

Item Development

As seen in Table 1, the item development for the *UNC TR_xANSITION Scale* followed a number of key steps. First, in addition to the inclusion of the theoretical orientations noted above, a thorough review of the health-care transition literature was examined to identify evidence-based areas of concern with respect to the knowledge and skills necessary for a successful health-care transition.^{11,12,16,21–25} This included a review of the PubMed database for English-based articles and a review of specific websites devoted to transition programs. These procedures resulted in a review of 1620 manuscripts, of which 315 met criteria for review. Of the available websites, there were 33 national and international websites affiliated with transition programs. Of these programs, most of them had materials on transition to be shared with patients, including some type of measurement scale; however, none of the tools were accompanied by psychometric data.

Second, semi-structured interviews were conducted with national and international experts in the field of health-care transition (see Acknowledgment section). The questions posed to each expert included the following: (a) What is the current state of health-care transition research, particularly with respect to measurement? (b) Are there effective clinical tools to assess the process of transition? (c) What do you consider critical areas of

Table 1. Development of the *UNC TR_xANSITION Scale* across the three versions.

	Version 1	Version 2	Version 3
No. of questions	37	47	33
Formal input from	Patients Adolescent specialist Pediatric specialists/ subspecialists Med/peds specialist Nurse practitioners Specialty nurses Psychologist Recreation therapist Social worker Nutritionist Transition coordinator Internal medicine specialists and subspecialists Medical anthropologist Epidemiologists Health behavior specialist	Patients Adolescent specialist Pediatric specialists/ subspecialists Med/peds specialist Nurse practitioners Specialty nurses Psychologist Internal medicine specialists and subspecialists Transition coordinator	Patients Adolescent specialist Pediatric specialists/ subspecialists Med/peds specialist Nurse practitioners Specialty nurses Internal medicine specialists and subspecialists Psychologist Transition coordinator
Data collected through	Focus groups, semi-structured interviews	Focus groups and focused interviews	Focused interviews, 35 digitally recorded
Adolescent and young adults' diagnoses	IBD = 21 CKD/HTN = 61 Renal transplant = 10	IBD = 27 CKD/HTN = 9	IBD = 46 CKD/HTN = 51 Renal transplant = 11 SLE = 1 SCD = 13 Diabetes mellitus = 6
Domain changes	A = Allergy	A = Allergy was changed to A = Adherence	A = Adherence retained

Note: IBD, inflammatory bowel disease; CKD/HTN, chronic kidney disease/hypertension; SLE, systemic lupus erythematosus; SCD, sickle cell disease.

skills and knowledge for a successful health-care transition? Notes from the interviews were analyzed for generic skills (e.g., disease-neutral) or domains there were deemed characteristic of a patient's readiness for transfer.

Third, based on the first two steps, 10 conceptual domains were identified for targeted items: *Type of illness*, *Rx=medications*, *Allergies*, *Nutrition*, *Self-management*, *Informed-reproduction*, *Trade/school*, *Insurance*, *Ongoing support*, and *New health provider*. Ultimately, these domains contributed to the acronym for the scale (i.e., *TR_xANSITION*). Items were crafted for each of these domains and version 1 of the *UNC TR_xANSITION Scale* was created.

Pilot Testing

Version 1 consisted of 37 items across the 10 conceptual domains and yielded a raw score for each of the domains. For each of the items, a transition coordinator rated the responses based on the participants' knowledge level or skill level using the following scale: 0 = inadequate knowledge/skill; 0.5 = partial knowledge/skill; and 1 = adequate knowledge/skill. Version 1 was piloted with 92 adolescents, aged 14.4–19.4 years, and represented the conditions of inflammatory bowel disease, chronic kidney

disease/hypertension, and renal transplant. Items were revised based on feedback from clinicians with respect to clarity, clinical utility, alignment with their respective domain, and adherence to theoretical tenets of the scale. This process led to item deletions, additions, and modifications, including the elimination of the allergy domain and its items and the addition of the adherence domain. These changes contributed to version 2.

Version 2 consisted of 47 items across the 10 domains using 36 adolescents, aged 13.7–21.4 years for pilot testing purposes. Chronic health conditions for this pilot investigation included inflammatory bowel disease ($n = 27$) and chronic kidney disease/hypertension ($n = 9$). Item development followed the same set of procedures as described for version 1, with focus groups and focused interviews being conducted with patients, adolescent specialists, nurse practitioners, psychologists, and other specialists in health-care transition. This process contributed to the current version of the scale, the *UNC TR_xANSITION Scale*, which comprises 33 items across the 10 conceptual domains. The participant characteristics for each of the three scale versions are provided in Table 2. The current version of the scale is contained in Appendix or can be retrieved from the

Table 2. Participant characteristics across the three versions of the UNC TR_xANSITION scale.

	Version 1	Version 2	Version 3
Number of participants (<i>n</i>)	92	36	128
Mean age (SD)	17.5 (1.5)	16.8 (2.1)	16.5 (1.9)
Age range in years	14.4–19.4	13.7–21.4	12.5–20.7
Mean age at diagnosis (SD)	11.9 (2.6)	12.3 (3.6)	9.5 (5.3)
Females (%)	11 (52)	21 (58)	65 (51)
Race: <i>n</i> (%)			
Blacks	4 (19)	11 (31)	56 (44)
White	17 (81)	22 (61)	62 (48)
Hispanics	0 (0)	3 (8)	6 (5)
Other race	0 (0)	0 (0)	4 (3)
Adherence: <i>n</i> (%) ^a			
Adherent	19 (90)	32 (89)	105 (82)
Nonadherent	2 (10)	4 (11)	23 (18)
Insurance status: <i>n</i> (%) ^a			
Self-pay	1 (5)	0 (0)	5 (4)
Medicare/Medicaid	6 (29)	11 (31)	59 (46)
Private	14 (66)	25 (69)	65 (51)

Note: ^aDefined by medical record review.

following web address: unckidneycenter.org/hcprofessionals/transition. All aspects of this study were approved by the university Institutional Review Board.

Standardization and Preliminary Normative Data

To develop standardization procedures, version 3 of the UNC TR_xANSITION Scale was completed with 128 patients with various chronic medical conditions. The target population was English-speaking adolescent and young adult patients, aged 12–22 years of age, from the following subspecialty clinics: nephrology, hypertension, gastroenterology, rheumatology, diabetes, and sickle cell disease. These participating subspecialty clinics were chosen based on the providers' interests in health-care transition for their patients. As can be seen in Table 1, these conditions included inflammatory bowel disease (*n* = 46), chronic kidney disease/hypertension (*n* = 51), renal transplant (*n* = 11), systemic lupus erythematosus (*n* = 1), sickle cell disease (*n* = 13), and diabetes mellitus (*n* = 6). The transition coordinator identified and enrolled eligible consecutive participants. Ineligible patients from these clinics were those who did not meet

our age criteria, were cognitively impaired based on the health provider's opinion, or who did not have English fluency. The sociodemographic features of the standardization sample for version 3 can be seen in Table 2.

The UNC TR_xANSITION Scale was conducted by the transition coordinator or other designated professional for a specialty clinic who had been trained in the delivery of the questions and answer rating. Each of the questions was asked of the patients and answers were recorded based on the responses. Parents remained present during the administration of version 3, but were asked to remain silent. This allowed for educating both the patients and the parent(s) about the issues of health-care transition once all of the responses were provided for each of the 33 items. Based on digital recordings of 35 of these participants, version 3 required approximately 7–8 min to administer (mean = 7.56 min, SD = 0.11 min).

Scoring of the UNC TR_xANSITION Scale follows a simple procedure such that each domain is equal to 1 point, thus resulting in a 10-point total score with higher scores reflecting a higher degree of health-care transition readiness. The scores (i.e., 0, 0.5, 1) for items within a domain are weighted such that the total will equal to a total domain score of 1. Consequently, scores are calculated for each specific domain, with a range of 0–1, and the overall total transition score, having a range of 0–10. Preliminary normative data for this sample (i.e., weighted means and standard deviations) for each of the subscales and the total score can be seen in Table 3 for younger (12–16 years of age; *n* = 50) and older (17–21 years of age; *n* = 78) participants.

Preliminary Reliability Estimates

Initial reliability estimates for the UNC TR_xANSITION Scale were derived from inter-rater reliability calculations. Using 35 digitally recorded interviews from the transition coordinators, two independent members of the research team who were blinded to the specific cases assessed the extent of agreement on responses to the items. This resulted in a weighted kappa statistic of 0.71 (95% CI: 0.64, 0.77), suggesting good inter-rater reliability of the scoring of the scale.

Table 3. Raw score means and standard deviations for version 3 of the UNC TR_xANSITION scale.

Subscale	Younger (ages 12–15) (<i>N</i> = 50)		Older (ages 16–20) (<i>N</i> = 78)		Total sample (<i>N</i> = 128)	
	Mean	SD	Mean	SD	Mean	SD
Type of illness (T)	0.70	0.29	0.78	0.29	0.75	0.29
Medications (Rx)	0.80	0.19	0.82	0.21	0.81	0.20
Adherence (A)	0.83	0.20	0.83	0.22	0.83	0.21
Nutrition (N)	0.74	0.30	0.84	0.23	0.80	0.26
Self-management (S)	0.26	0.16	0.37	0.23	0.33	0.21
Informed-reproduction (I)	0.26	0.30	0.41	0.28	0.35	0.30
Trade/school issues (T)	0.46	0.16	0.55	0.26	0.52	0.23
Insurance issues (I)	0.37	0.25	0.59	0.32	0.50	0.32
Ongoing support (O)	0.82	0.35	0.92	0.22	0.88	0.28
New health providers (N)	0.40	0.30	0.50	0.32	0.46	0.32
Total score	5.61	1.26	6.58	1.41	6.22	1.41

Internal consistency refers to the accuracy with which a set of items taps the target domain or construct in which the items are placed. Initial internal consistency for the *UNC TR_xANSITION Scale* was explored using item-total correlations. First, we examined the relationship of each of the items with their respective domain score. Second, we examined the relationship of each of the items with the overall total score for the scale. Third, we examined the domain score to the overall total score. As seen in Table 4, each of the items significantly correlated in a moderate to strong fashion ($r > 0.42$) with their respective domains. This indicates that the items were correctly aligned within their respective domains. Similarly, the correlations of each of the items with the overall total score fell within a similar range, although more variability was present here. Selected items that were strongly correlated with their domain score, but were weakly correlated with the overall score, included: Adherence item #3 ($r = 0.44$), Nutrition item #1 ($r = 0.60$), Self-management items #5 ($r = 0.42$) and 7 ($r = 0.44$), Informed reproduction item #3 ($r = 0.48$), and Trade/school issues item #1 ($r = 0.42$). Finally, the correlations between each of the domains and the total

score also were examined. These correlation coefficients were moderate to strong, ranging from 0.34 to 0.74. The subscales with the highest correlations were Type of illness ($r = 0.74$), insurance ($r = 0.70$), and self-management ($r = 0.64$). The lowest correlation was between Ongoing support and the total weighted score ($r = 0.34$). Taken together, these item/domain-total correlations reflected relatively good internal consistency of the items. These correlations can be seen in Table 4.

Temporal stability, or test-retest reliability, is particularly important when a test is attempting to measure specific traits that are likely to change very little over a specific time. In this instance, the very nature of transition implicates change over time, so classic test-retest strategies likely would prove less useful in evaluating any type of transition scale. In this regard, we conducted univariate linear regression to determine how sensitive the *UNC TR_xANSITION Scale* was to increasing age. The univariate linear regression yielded a beta coefficient of 1.08 ($p < 0.0001$), indicating that the total score increased with advancing age. Specifically, there was about a one point increase in the total score for each year of age.

Table 4. Correlations between items, subscales, and total scores for the *UNC TR_xANSITION scale*.

Subscale	Individual question	Correlation of each subscale with total score (r)	Correlation of individual question with subscale (r)	Correlation of individual question with total score (r)
T (Type of illness)	T ₁	0.74	0.64	0.45
	T ₂		0.74	0.62
	T ₃		0.78	0.52
Rx (Medications)	R ₁	0.61	0.70	0.41
	R ₂		0.69	0.32
	R ₃		0.73	0.46
	R ₄		0.74	0.52
A (Adherence)	A ₁	0.49	0.82	0.38
	A ₂		0.85	0.46
	A ₃		0.44	0.16
N (Nutrition)	N ₁	0.52	0.60	0.28
	N ₂		0.74	0.38
	N ₃		0.70	0.37
S (Self-management)	S ₁	0.64	0.64	0.43
	S ₂		0.71	0.52
	S ₃		0.68	0.50
	S ₄		0.63	0.37
	S ₅		0.42	0.25
	S ₆		0.61	0.32
	S ₇		0.44	0.23
I (Informed-reproduction)	I ₁	0.53	0.65	0.31
	I ₂		0.50	0.38
	I ₃		0.48	0.18
	I ₄		0.75	0.42
T (Trade/school issues)	T ₁	0.62	0.42	0.42
	T ₂		0.54	0.18
I (Insurance issues)	I ₁	0.70	0.69	0.49
	I ₂		0.74	0.52
	I ₃		0.73	0.52
	I ₄		0.71	0.47
O (Ongoing support)	O ₁	0.34	–	0.34
N (New health providers)	N ₁	0.57	0.81	0.49
	N ₂		0.79	0.42

Preliminary Validity Estimates

The content validity of the conceptual domains and associated items of the *UNC TR_xANSITION Scale* was determined by our early efforts with national experts and clinicians in the field of transition as well as patients immersed in the transition process. During the item development and piloting stages of versions 2 and 3 of the *UNC TR_xANSITION Scale*, information was obtained from these sources and items were modified accordingly so as to reflect good content validity. This process was supported by our moderate to strong item-total correlations noted above for version 3 of the scale. Similarly, construct validity is an extension of content validity and attests to whether a set of items appropriately relate to the construct in question (i.e., health-care transition). Again, the procedures followed to modify this instrument through its different versions would indicate that the *UNC TR_xANSITION Scale* has good construct validity.

DISCUSSION

Disease-specific knowledge and self-management skills are necessary to acquire in health-care transition, and the assessment of these factors in adolescents and young adult as they move into this phase of life is critical to facilitating their health-care transition.^{24,25} The acquisition of disease self-management skills involves learning a number of complex medical concepts (e.g., home dialysis for end-stage kidney disease patients) and eventual change from parent/guardian-directed care to self-management.¹ This study provides the initial findings describing one of the first tools to examine these issues. The *UNC TR_xANSITION Scale* provides for a brief, reliable, and valid assessment of health-care transition readiness for adolescents/emerging adults in a nondisability-specific fashion as it does not rely solely on patient self-report, but verifies information from the medical record. The *UNC TR_xANSITION Scale* was designed so that health-care providers may easily assess a patient's competency in knowledge and skill mastery associated with their health-care transition regardless of the disease in question. In addition to being disease neutral, this scale captures the most likely important areas of health-care transition (e.g., disease and treatment knowledge, treatment adherence, and health self-management). Furthermore, the *UNC TR_xANSITION Scale* is a semi-structured, clinically feasible interview tool that can be administered by anyone within a health-care team, possibly including trained paraprofessionals as long as they are trained in its administration. In contrast to self-report measures, on this scale the validity of the patient's responses can be assessed by the health professionals either during the interview and/or by examining specific information contained in a patient's medical chart (i.e., if a patient identifies the name of a medication, the interviewer can verify that this medication was prescribed to the patient). This instrument also uses

feedback approaches to help guide health-care providers to praise the adolescent on knowledge/skills they have already mastered, help them improve on tasks they perform adequately, and help them focus on the areas where they have the lowest competencies; however, this latter aspect of the scale will require additional investigation to develop an empirical basis for this apparent positive feature of the scale.

Other scales are disease-specific. For example, Buran et al.¹⁵ provided a health transition scale that assessed the medical, social, psychosocial, and economic needs of young adults with neural tube defects. Kennedy et al.¹⁶ described another instrument that assessed the medical and nonmedical needs of young adults with spina bifida. Cappelli et al.¹² provided an instrument that assessed the transfer readiness of young adults with cystic fibrosis. Wiener et al.¹⁴ developed a health-care transition tool specifically for adolescents and young adults with HIV. While these measures provide indices for various health-care transition issues for specific conditions, none of them will have utility across disorders. Finally, Sawicki et al.¹⁷ designed a self-report measure to assess health-care transition across disorders using a sample of 16–26-year-old patients with special health-care needs.

The *UNC TR_xANSITION Scale* appears sensitive to the issues of advancing chronological age; consequently, it has the potential to assess progressive levels of achievement over time across each of the 10 domains. In turn, this should facilitate ongoing feedback to the patient (and parent/guardians) until competency in targeted domains is achieved. For example, one way to use the scale would be to reassess the patient every 6 months until they are deemed ready to transition into adult care. The standardization of the scoring system (score range of 0–10), reflecting the minimum and maximum points a patient can score regardless of the number of items per subscale, allows for comparing score profiles over time. This also will help both the providers and patients recognize on which of the 10 subscales competency has been achieved and on which ones there still needs improvement. Furthermore, because the scale is disease-neutral, it allows for condition-specific treatment/care changes (e.g., dialysis to kidney transplantation) that can occur, providing patients the opportunity to learn/demonstrate new knowledge and skills often associated with changes to their treatment/care regimen.

Limitations of this study should be noted. First, we used convenience samples of patients from university-based health-care clinics that were self-selected, but the demographic characteristics of our cohort include representation of most minority groups and a balance between public and private insurance coverage. Second, we allowed the parents to remain in the room while the patients were being interviewed, which may have influenced the patients' responses; however, this scenario does replicate the patient/parent education sessions as they currently happen in the subspecialty clinics. While the children were being interviewed, the parents also

have the opportunity to learn about their child's current health-care transition knowledge and disease self-management skills. A third limitation is that this scale cannot yet be used in non-English-speaking patient populations or with developmentally or cognitively impaired patients. Future scale development for this instrument will need to take into account these vulnerable and underserved patient populations.

There is an imperative need for adolescents/emerging adults to be adequately prepared to transition into adult health-care services in order to minimize the occurrence of adverse health outcomes associated with an unsuccessful transition. The *UNC TRANSITION Scale* is a tool that has the potential to facilitate this process and may be used to assess achievement/mastery of health-care transition knowledge and skills in patients with different chronic medical conditions. Unlike the work by three other groups,^{17,26,27} our scale was developed in a moderate-size cohort of adolescents who represent multiple medical conditions and does not rely solely on self-report. This scale provides practitioners with immediate data that can direct their interventions while adolescents and emerging adults are attending their clinic. The development of the *UNC TRANSITION Scale*, however, is not complete. Additional psychometric efforts directed toward validity of the scale are needed, particularly with respect to its internal structure (e.g., factor analysis) and its criterion validity (e.g., concurrent and predictive validity). Future research efforts with this scale should also focus on the degree of change that occurs on the overall score and its subscales following an active intervention to improve specific domains of transition as individuals advance in age. Nevertheless, the *UNC TRANSITION Scale* appears to be a clinically viable and user-friendly tool that can be utilized in clinical settings wherein health-care transition is important to the success of the patients.

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APPENDIX. UNC TR_xANSITION SCALE™ FOR ADOLESCENTS AND YOUNG ADULTS

Instructions: Read the question to the patient and circle the choice on the right that best describes the patient’s

response. Sum the scores for each section in the “Subtotal” row. Not all questions may be applicable to each patient. Divide the subtotal by the number of applicable questions in each section to obtain the “Proportion.”

Type of chronic health condition	Correct	Nonspecific	Does not know
1 What is the name of your health condition?	1.0	0.5	0.0
2 What physical symptoms do you experience because you have [name of health condition]?	1.0	0.5	0.0
3 How might [name of health condition] affect your health in the future?	1.0	0.5	0.0
<i>Sum the scores for this section</i>	Subtotal T		_____ out of 3
<i>Divide the subtotal by the number of applicable questions</i>	Proportion T		

R _x : Medications	Can name all	Can name some	Cannot name any
4 What are the names of the medicines, vitamins, and/or supplements your doctor has asked you to take for your health condition? [If possible, write meds in advance and circle them as the patient names them]	1.0	0.5	0.0

5 When are you supposed to take [name each medication, vitamin, and supplement patient should be taking]?	1.0	0.5	0.0
6 What is the purpose of [name each medication, vitamin, and supplement patient should be taking]?	1.0	0.5	0.0
7 What could happen if you do not take [name each medication, vitamin, and supplement patient should be taking] like your doctor has asked you to?	1.0	0.5	0.0
<i>Sum the scores for this section</i>	Subtotal R _x		_____ out of 4
<i>Divide the subtotal by the number of applicable questions</i>	Proportion R _x		

Adherence	Yes	Sometimes	No
8 In a typical week, do you usually miss a full day of medicine, either because you forgot to take it or did no’t want to take it?	0.0	0.5	1.0
9 Do you usually have trouble remembering to take your medicines every day?	0.0	0.5	1.0
10 Do you usually come to your doctor appointments when they are scheduled?	1.0	0.5	0.0
<i>Sum the scores for this section</i>	Subtotal A		_____ out of 3
<i>Divide the subtotal by the number of applicable questions</i>	Proportion A		

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Nutrition	Knows definitely	Has an idea	Does not know	
11 When choosing foods and drinks, do you read the nutrition labels on them to find out if they are healthy choices for you?	1.0	0.5	0.0	
12 Are you supposed to follow any special diet because you have [name of health condition]?	1.0	0.5	0.0	
13 [if the patient is on a special diet] What are examples of the foods and/or drinks that you should have more or less of?	1.0	0.5	0.0	N/A
<i>Sum the scores for this section</i>				Subtotal N
<i>Divide the subtotal by the number of applicable questions</i>				Proportion N
				_____ out of (2 or 3)

Self-management skills	Yes	Sometimes	No	
14 Do you usually remember to take your medicines on your own?	1.0	0.5	0.0	
15 Does someone usually have to remind you to take your medicines?	0.0	0.5	1.0	
16 Do you usually call in your prescription refills yourself?	1.0	0.5	0.0	
17 Do you usually pick up refills from the pharmacy yourself?	1.0	0.5	0.0	
18 Do you yourself usually call or email your doctor when you have a question or need to speak with him/her?	1.0	0.5	0.0	
19 Do you usually make your own doctor appointments?	1.0	0.5	0.0	
20 [if the patient has medical procedures to perform] Do you usually perform your medical procedures yourself (catheterization, insulin shots, etc.?)	1.0	0.5	0.0	N/A
<i>Sum the scores for this section</i>				Subtotal S
<i>Divide the subtotal by the number of applicable questions</i>				Proportion S
				_____ out of (6 or 7)

Note: Some patients may be too young for the following questions to be appropriate. Score these patients as 0s, as these are important skills not yet obtained.

Issues of reproduction	Knows definitely	Has an idea	Does not know	
21 Would your health condition likely affect your ability to [if female] become pregnant? [if male] get someone pregnant?	1.0	0.5	0.0	
22 [Females only] What are the risks you might face if/when you become pregnant because you have [name of health condition]?	1.0	0.5	0.0	
23 [Females only] Do you take any medicines that would be harmful to an unborn baby if you became pregnant?	1.0	0.5	0.0	N/A
24 Can you tell me ways sexually active people help protect themselves from unwanted pregnancy or STDs?	1.0	0.5	0.0	
<i>Sum the scores for this section</i>				Subtotal I
				Male
				Female
<i>Divide the subtotal by the number of applicable questions</i>				Proportion I
				_____ out of 2
				_____ out of 4

Trade/School	Knows definitely	Has an idea	Does not know	
25 What are your future plans in regards to school and/or a job?	1.0	0.5	0.0	
26 How will your current health insurance status change when you turn 18 and/or are no longer a full-time student?	1.0	0.5	0.0	
<i>Sum the scores for this section</i>				Subtotal T
<i>Divide the subtotal by the number of applicable questions</i>				Proportion T
				_____ out of 2

Insurance	Knows definitely	Has an idea	Does not know	
27 What is health insurance and why is it important to have?	1.0	0.5	0.0	
28 What is the name of your current health insurance provider?	1.0	0.5	0.0	
29 [If he/she is currently insured] At what age will your current health insurance coverage end?	1.0	0.5	0.0	N/A
30 How can you get health insurance coverage for yourself when you are an adult?	1.0	0.5	0.0	
<i>Sum the scores for this section</i>				Subtotal I _____ out of (3 or 4)
<i>Divide the subtotal by the number of applicable questions</i>				Proportion I

Ongoing support	Self	Parents/friends	Does not know	
31 When you are an adult, who will manage your health condition, for example, help you remember to take your medicines, call in prescription refills, pick up meds from pharmacy, and make doctor appointments?	1.0	0.5	0.0	
<i>Sum the scores for this section</i>				Subtotal O _____ out of 1

New health-care providers	Knows definitely	Has an idea	Does not know	
32 When it is time for you to switch to an adult doctor, how will you find one?	1.0	0.5	0.0	
33 In order to get your medical records transferred to another doctor, what is required to make this happen?	1.0	0.5	0.0	
<i>Sum the scores for this section</i>				Subtotal N _____ out of 2
<i>Divide the subtotal by the number of applicable questions</i>				Proportion N

Raw total score	Sum all section subtotals here (max 33)			
T.R_x.A.N.S.I.T.I.O.N score™	Sum all section proportions, or divide the raw total score by the total number of eligible questions (max 10)			

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