

Validation Of a Transition Readiness Assessment Questionnaire (TRAQ 3.0) For Youth and Young Adults with Special Health Care Needs

David Wood, MD^{1,2}, William Livingood, PhD^{1,2}, Edessa Jobli, MD², Deborah Ducett, MSW¹, Linda Edwards, MD.³

1. University of Florida, College of Medicine-Jacksonville, Department of Pediatrics, Jacksonville, FL 2. Duval County Health Department, Institute for Health Policy, Evaluation and Research, Jacksonville, FL; 3. University of Florida, College of Medicine-Jacksonville, Department of Medicine

Abstract

Validation Of A Transition Readiness Assessment Instrument For Youth With Special Health Care Needs Enrolled In JaxHATS, Jacksonville Health And Transition Services Program

David Wood, MD, William Livingood, PhD, Edessa Jobli, MD, Deborah Ducett, MSW and Linda Edwards, MD

Background: Validated questionnaires to measure skills and abilities for successful health care transition for Youth with SHCN are not available.

Objective: To present results of validation and reliability testing of the Transition Readiness Assessment Questionnaire (TRAQ 3.0) for youth with special health care needs.

Methods: We developed a Transition Readiness Assessment Questionnaire based on a review of the existing literature and on a theoretical framework of skills needed to navigate health care transition successfully. For each identified area or skill we applied as a measurement scale the five stage Stages of Change model. The instrument was sent to experts in the field of health care transition, and they were asked to prioritize items and provide feedback on item content. A revised version was administered to 15 youth and tested for readability and clarity. The resultant questionnaire has 11 subscale scores and is organized in the following 3 domains; *Managing Your Own Health Care, Interacting with Health Care Providers, and Other Transition Activities.* The questionnaire was administered to 48 adolescents. The JaxHATS nurse care coordinator, who knew the youth well and was blinded to the patients' scores, rated each youth on the 11 subscale scores. Cronbach alphas were conducted on patient subscale and domain scores. Patient and staff scores were tested for agreement using t-tests, correlations, and the Kappa statistic for agreement. Factor analysis was conducted on both patient and staff subscale scores.

Results: Cronbach alpha on patient subscale scores were greater than 0.8 for all but 3 subscales (Medical History, 0.54, Self Management, 0.70, Use Community Resources, 0.65). Cronbach alphas for the 3 Domain scores were 0.93 for *Managing Your Own Health Care*, 0.91 for *Interacting with Health Care Providers* and 0.88 for *Other Transition Activities*. Correlations between scale scores of the patient and clinician were all positive and ranged from 0.62 on the *Medical History* scale to 0.213 on the *Community Services Scale*, with most patient/clinician correlations ranging from 0.2-0.4. Patient/Clinician Domain score correlations ranged from 0.47 to 0.28, which are in the moderate range. Factor loadings verified three underlying Domains with overlap between the patient and clinician generated factors.

Conclusions: We have developed a new tool to assess readiness for transition entitled the Transition Readiness Assessment Questionnaire 3.0. While still in the development stage, it demonstrates good face validity, excellent internal reliability, and modest criterion validity. There is moderate agreement between the youth and the clinician on the 3 Domain scores. The TRAQ 3.0 Questionnaire is a useful tool to assess transition readiness in Youth with Special Health Care Needs.

Background

- The stage of emerging adulthood is one in which youth face a number of challenges and transitions in their path to independent adulthood, including transitioning from high school to college, work or vocational training; forming more independent romantic relationships or independent households, having children and transitioning from the pediatric health care system to the adult health care system.
- Youth with special health care or educational needs face significant obstacles as they age out of highly supportive child health care and educational services.
 - Assume responsibility for their own health care utilization
 - Assume responsibility for their own disease management
 - Pursue educational/vocational goals
 - Develop Independent living skills.

- Youth are at various stages of readiness to assume these responsibilities.
- Transitioning behaviors can theoretically be supported through science-based assessment and interventions.
- A validated Transition Readiness Assessment Questionnaire would help both pediatric and adult providers, as well as programs specifically focused on transition, better understand and support the transition process

Objective

- To develop and validate a tool to assess transition readiness for youth with special health care needs

Methods

To develop the items for the Transition Assessment Questionnaire we :

- Conducted a review of the existing literature
- Identified 10 existing transition assessment tools with 79 medical care and disease management oriented items and 113 other transition oriented items.
- Consolidated the items into 62 items by removing redundant questions & changing statements of knowledge and skills to behavior statements
- We applied the Trans-theoretical Model of Prochaska & DiClemente to create Likert response categories for each of the behaviors (see below)
- The 62 item questionnaire was sent to experts in the field of health care transition, and they were asked to prioritize items and provide feedback on item content. As a result we reduced the number of items to 42.
- Ethnographic interviews with 15 adolescents to clarify wording, check literacy level
- The resultant questionnaire has 11 subdomains and is organized in the following 3 domains;
 - Managing Your Own Health Care,*
 - Interacting with Health Care Providers, and*
 - Other Transition Activities.*
- The questionnaire was administered to 48 adolescents.
- The JaxHATS nurse care coordinator, who knew the youth well and was blinded to the patients' scores, rated each youth on the 11 subscale scores.
- Cronbach alphas were conducted on patient subscale and domain scores. Patient and staff scores were tested for agreement using t-tests, correlations, regression analysis.

| Stages of Change Model | | |
|-------------------------|--|---|
| Stage | Definition | Survey Response Categories |
| Precontemplation | Has no intention of taking action within the next 6 months | I do not need to do this |
| Contemplation | Intends to take action in the next 6 months | I do not know how but I intend to learn |
| 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 |
| Action | Has changed behavior for less than 6 months | I have started doing this |
| Maintenance | Has changed behavior for more than 6 months | I always do this when I need to |

Format of the TRAQ 3.0 Questionnaire

Patient Name: _____ Date: _____ Person Completing Survey: _____

JaxHATS Evaluation Tool - CLIENT

Direction: The JaxHATS Program would like to know how you describe your skills in the areas that are important in your care. Your answers will help us provide services and education that will be important in preparing you to transition to adult health care. There are no right or wrong answers and your answers will remain confidential and private. Please check the box that you feel best describes you.

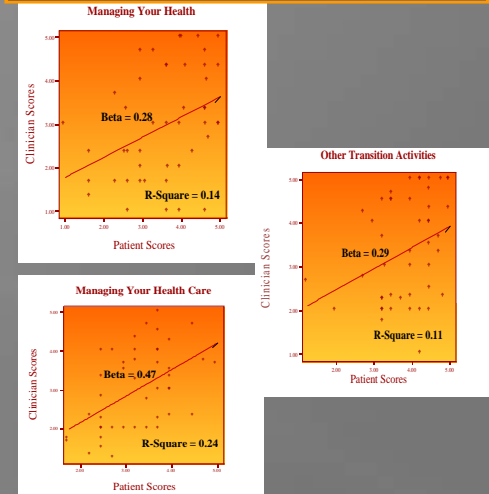
| | I do not need to do this | I do not know how but I want to learn | I am learning to do this | I have started doing this | I always do this when I need to |
|--|--------------------------|---------------------------------------|--------------------------|---------------------------|---------------------------------|
| TO ACCESS MEDICAL CARE, DO YOU ... | | | | | |
| 1. Call the doctor's office (Ex. Pediatrician, Family doctor or Specialty care doctor) to make an appointment? | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 2. Follow-up on any referral for tests or check-ups or labs? | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 3. Arrange for your ride to medical appointments? | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

Results

Correlation of Patient and Clinician Scores by Domain and Category

| Domain & Subdomain | Cronbach | Correlation with Clinician Assessment | P-value |
|---|----------|---------------------------------------|---------|
| Managing Your Health | .93 | .278 | .061 |
| <i>Taking care of yourself</i> | .70 | .317 | .034 |
| <i>Medications</i> | .88 | .318 | .033 |
| <i>Equipment and Supplies</i> | .94 | .183 | .300 |
| Managing Your Health Care | .91 | .468 | .001 |
| <i>Accessing Care</i> | .91 | .296 | .000 |
| <i>Keeping a Health History</i> | .54 | .622 | .003 |
| <i>Communicating with the doctor or nurse</i> | .69 | .367 | .014 |
| <i>Health Insurance</i> | .81 | .212 | .167 |
| Other Transition Activities | .88 | .299 | .044 |
| <i>Jobs and School</i> | .82 | .294 | .136 |
| <i>Activities of daily living</i> | .87 | .241 | .111 |
| <i>Personal Safety</i> | .90 | .171 | .267 |
| <i>Community Resources</i> | .65 | .013 | .936 |

Regression of Patient Scores on Clinician Scores for the 3 Transition Domains



Conclusions

We developed and fielded a new questionnaire to assess readiness for transition that has 3 domains and 11 subdomains. For the 48 patients that filled out the questionnaire and for whom we had clinician ratings we found that :

- The domains and subdomains had good internal reliability
- The domains of "Managing Your Health Care" and "Other Transition Activities" were significantly correlated to clinician ratings ($r = .296, p = .001$ and $r = .299, p = .044$ respectively) "Managing Your Health" had borderline significant correlation with clinician ratings ($r = .278, p = .061$)
- The subdomains of "Communicating with the Doctor or Nurse" and "Keeping a Health History" had the highest correlation with clinician scores
- Agreement between the clinician and youth is better for behaviors that are more easily observable. There is less agreement for behaviors related to health self-management and for behaviors that are less easily observable by the clinician
- Low agreement may be a factor of youth developmental level or communication between the youth and clinician. We plan to do the following to analyses to investigate the potential explanations for the low agreement:
 - Obtain multiple clinician ratings for each patient
 - Analyze subgroups such as age (early vs. late transition); gender; health condition