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## A Parental Report of Youth Transition Readiness: The Parent STARx Questionnaire (STARx-P) and Re-evaluation of the STARx Child Report

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## ABSTRACT

**Purpose:** The STARx Questionnaire is a self-report measure of health care transition (HCT) readiness in youth with chronic diseases. We aimed to improve reliability and generalizability of the STARx and report initial reliability data on the STARx-P Questionnaire, a self-report measure of parent perspective on their child's HCT readiness. **Methods:** Participants were recruited in several clinics from a large academic hospital in the southeastern USA and via the therapeutic summer camp for children with chronic disease. Children with chronic conditions responded to the 18-question STARx Questionnaire and their parents responded to the parent version, the STARx-P Questionnaire.

**Results:** IRB-approved consents were obtained from 341 parents (89.4% mothers) and 455 children (Mean age  $12.28 \pm 2.53$ ; 36.9% Males; 68.6% Caucasian; 22.6% African-American). The most common diagnoses were kidney disease, inflammatory bowel disease, diabetes, cerebral palsy, sickle cell, and cystic fibrosis.

Principal component analysis of the STARx-P Questionnaire identified three major subscales in both the child and parent-report: Disease Knowledge, Self-management and Provider Communication. Internal reliability was moderate to good ( $\alpha = 0.545-0.759$ ).

**Conclusions:** The STARx-P Questionnaire and STARx Version 4 Questionnaire have demonstrated initial reliability in this multi-institution study. It is the first HCT readiness questionnaire that includes a parent-proxy report which is needed in studies of non-verbal and/or developmentally delayed children. Parent-report can also give unique insights not obtained from self-reports.

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### Background

Since most adolescents and young adults (AYA) with a chronic illness will survive into adulthood, (Scal, Larson, Ireland, & Blum, 2003; Van Dyck, Kogan, McPherson, Weissman, & Newacheck, 2004) careful consideration and planning of the transition from pediatric to adult-oriented care is needed for AYA with chronic illness. Guidelines have emphasized that one of the components of effective transition is transition readiness assessment throughout a patient's adolescent years to ensure they have the skills necessary to function optimally in adult-oriented care (Cooley et al., 2011).

Transition readiness assessments for AYA have been developed and their psychometric properties have been assessed (Cohen et al., 2015; Ferris et al., 2012; Ferris et al., 2015; Sawicki et al., 2011; Wood et al., 2014). Parental report of AYA transition skills are an important addition to AYA assessments of transition readiness as some AYA may not be able

to complete assessments, due to being too young to understand the tool or due to having a disability. Also, AYA and parent assessments do not always correlate (Bagheri, Peyman, Tashakor, Kouhpayeh, & Riazi, 2014; Gutierrez-Colina, Eaton, Lee, LaMotte, & Blount, 2015; Vanoni, Suris, von Scheven-Gete, Fonjallaz, & Hofer, 2016) and parental report may give a unique perspective on transitioning. For example, when parents perceive their children as unable to perform certain self-management skills, independent of whether the child agrees with this, they may be unwilling to allow their child to take responsibility for their own care which may hamper development of health care transition skills. Thus, validated assessments of AYA transition readiness from the parent perspective are needed. Tools previously validated in AYA have been used with parents, but are not ideal due to the fact that they have been previously tested in small populations, (Betz, 2009) have not been validated for use with parents, (Sawicki, Kelemen, & Weitzman, 2014) or are diagnosis specific (Fredericks et al., 2010; Kaugars, Kichler, & Alemzadeh, 2011; Stephany et al., 2015; Telfair, Myers, & Drezner, 1994).

To that end, we have developed the STARx-P, a tool to elicit a parental assessment of AYA transition readiness. This tool was derived from the

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Successful Transition to Adulthood with Therapeutics = Rx (STARx) Questionnaire. The STARx was developed in collaboration with AYA with a variety of illnesses (Ferris et al., 2015) and has been assessed to evaluate its internal reliability, (Ferris et al., 2015) factor structure, (Ferris et al., 2015) concurrent validity, (Cohen et al., 2015) and predictive validity. (Cohen et al., 2015) The sample used for the previous version of the STARx consisted of 194 AYA from a single hospital in the southeastern US. The majority of these AYA were older (mean age 17.5) and had chronic kidney disease or inflammatory bowel disease. Additionally, the internal reliability of the STARx Version 3 was low. Therefore, there is a need to study the psychometric properties of the STARx in a sample with more diverse chronic conditions, families from a variety of health care settings, and younger patients.

We chose to do a combined analysis of the STARx-P in parents and the STARx in children. This allows for an opportunity to improve the internal reliability of the STARx through a better understanding of its underlying factor structure in AYA populations and assess the STARx-P for a comparable factor structure. Thus, in this study, our aims were to 1) improve the internal reliability of the STARx and 2) determine the underlying factor structure of the STARx-P for parents and examine the tool's internal reliability and internal consistency.

## Methods

### Sample

Subjects were recruited from specialty clinics at a large university hospital in the southeastern United States and from Victory Junction Therapeutic Camp in 2014 or 2015. Clinic attendees aged 12 to 18 were approached by the research team in person, and the research team approached families of all camp attendees aged 6–17 via e-mail. Consents and assents were obtained from both the patient and their parent. For those who attended clinic, paper consents were completed in person, and for those attending camp, electronic consents were completed online via Qualtrics™ survey software. Because both the STARx and STARx-P include questions about medication management, we limited our sample only to AYA who were taking at least one medication. Participants had to be able to independently complete the STARx Questionnaire as determined by their physician if they were recruited in clinic or by their parent if recruited from camp. There were no other exclusion criteria.

### Measure

Patients completed the STARx version 3 (Ferris et al., 2015), which was developed using triangulated methods (item development, pilot testing, reliability and factor structure). Parents completed the STARx-P, which was based on the STARx Questionnaire. The STARx version 3 was heavily pilot-tested for clarity, and thus, the items in the STARx-P mirror the previously validated STARx questions, replacing “you” with “your child” for each item. For example, a question in STARx version 3 reads, “In the past year, how often did you need someone to remind you to take your medicines?” while the corresponding STARx-P question reads, “In the past year, how often did your child need someone to remind him/her to take their medicines?” The Fleisch-Kincaid Grade Level Index for the STARx-P Questionnaire is 3.7.

Answer choices for both the STARx and STARx-P were presented in a Likert Scale format, with ratings ranging from 1 (never) to 5 (always). All questionnaires were administered online through the secure Qualtrics™ survey platform (qualtrics.com). Because the questionnaires were completed in Qualtrics and participants had to answer every question in order to submit the survey, no partially completed questionnaires were submitted.

## Analysis

IBM SPSS Statistical Program Version 23 was used for data analysis. Principal component analysis with Varimax rotation (Costello & Osborne, 2005) was used to determine the underlying structure of items and to identify items that can be deleted from the final version of the questionnaire. A scree plot was used to assess the number of factors and to be thorough the solutions with one less or one more factor than suggested by scree test were evaluated as well to examine if this improved the interpretability of the solution. Items were retained only if their factors loaded to >0.30 and did not load on multiple items (>0.30 on more than two factors and/or at least 0.20 difference between loadings on two factors). Principal component analyses were initially performed on child report (STARx) to verify the published structure and internal consistency checked with Cronbach's alpha. Next, a principal component analysis was performed on the parent-reported version (STARx-P) to verify the same structure was found. Internal consistency of the newly developed subscales was also checked for the parent-version with Cronbach's alpha.

Pearson correlation between the subscales of the STARx-P and STARx versions of the questionnaire were performed, and paired *t*-tests were used to examine differences between parent and child self-report of transition readiness.

## Results

### Sample Description

A total of 455 AYA and 341 parents completed the questionnaires. A total of 8 families did not complete all demographic measures, but were still included because respective STARx and STARx-P Questionnaires

**Table 1**  
Sample characteristics.

Parent characteristics (N = 341)		N (%) or mean (S.D.)
Site of recruitment		
Clinic		22 (6.5)
Victory junction camp		319 (93.5)
Youth age		12.32 ± 2.72
Gender		
Female		305 (89.4)
Male		27 (7.9)
Unknown		9 (2.6)
Race		
Caucasian		271 (79.5)
African-American		52 (15.2)
Other		18 (5.3)
Education level		
Less than high school		4 (1.2)
Completed high school		19 (5.6)
Some college or more		300 (88.0)
Unknown		18 (5.3)
Relationship to youth		
Parent		332 (97.4)
Other caregiver		9 (2.6)
Youth sample characteristics (N = 455)		N (%) or mean (S.D.)
Site of recruitment		
Clinic		194 (42.6)
Victory junction camp		261 (57.4)
Age		12.28 ± 2.53
Gender		
Male		168 (36.9)
Female		259 (56.9)
Unknown		8
Race		
Caucasian		312 (68.6)
African-American		103 (22.6)
Other		32 (7.0)

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