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Self-Management and Transition Readiness Assessment: Development, Reliability, and Factor Structure of the STARx Questionnaire

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Introduction: The Self-Management and Transition to Adulthood with Rx = Treatment (STARx) Questionnaire was developed to collect information on self-management and health care transition (HCT) skills, via self-report, in a broad population of adolescents and young adults (AYAs) with chronic conditions.
Methods: Over several iterations, the STARx questionnaire was created with AYA, family, and health provider input. The development and pilot testing of the STARx Questionnaire took place with the assistance of 1219 AYAs with different chronic health conditions, in multiple institutions and settings over three phases: item development, pilot testing, reliability and factor structuring.
Results: The three development phases resulted in a final version of the STARx Questionnaire. The exploratory factor analysis of the third version of the 18-item STARx identified six factors that accounted for about 65% of the variance: Medication management, Provider communication, Engagement during appointments, Disease knowledge, Adult health responsibilities, and Resource utilization. Reliability estimates revealed good internal consistency and temporal stability, with the alpha coefficient for the overall scale being .80. The STARx was developmentally sensitive, with older patients scoring significantly higher on nearly every factor than younger patients.
Conclusion: The STARx Questionnaire is a reliable, self-report tool with adequate internal consistency, temporal stability, and a strong, multidimensional factor structure. It provides another assessment strategy to measure self-management and transition skills in AYAs with chronic conditions.
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WITH AN INCREASING number of patients with pediatric-onset chronic conditions surviving into adulthood, a need to focus on the self-management and health care transition (HCT) from pediatric to adult health care has

become paramount (Callahan, Todd, Winitzer, & Keenan,2001; DeBaun & Telfair, 2012; Gortmaker & Sappenfield, 1984; McDonald & Craig, 2004; Reiss, Gibson, & Walker, 2005). Health care providers now need to not only help these adolescents and young adults (AYAs) understand their chronic condition, but teach them to self-manage their disease so that they can be self-sufficient adults. Poor HCT to adult-focused services can lead to detrimental health outcomes, as documented across several health conditions (Ferris & Mahan, 2009; Gurvitz & Saidi, 2014; Lotstein et al., 2013).

AYAs with chronic conditions are typically accustomed to their families assisting with their health care regimen. During the process of HCT, it is important for these AYAs to take over the duties related to managing their health, such as organizing their medications, calling the pharmacy for refills, adhering to a prescribed diet and medications, understanding insurance and communicating with their physician. A planned HCT allows youth to achieve better outcomes as they move into adult-focused health settings (Callahan et al., 2001). To facilitate the HCT process, though, there is a need for efficient and accurate assessment of HCT readiness, particularly with respect to developing and monitoring targeted strategies to facilitate HCT readiness.

Measuring HCT is essential for health care providers to understand their patients' self-management skills. It is still undecided what is the "best" way, and when is the "best" time, to transition an AYA into adult-focused services, and it remains undetermined what are the most important factors that define a successful transition (Fenton, Ferris, Ko, Javalkar, & Hooper, 2015). Creating measures that assess health care transition and self-management skills will guide interventions designed to improve HCT that are fundamental to success in the adult world.

The Current Study

Most published self-report health care transition readiness tools are disease-specific in their focus (Fredericks et al., 2010; Gilleland, Amaral, Mee, & Blount, 2012). To date, only a few generic tools that measure HCT in youth with chronic health conditions are available: the self-report TRAQ (Sawicki et al., 2011) and the provider-administered $TR_xANSITION$ Scale™ (Ferris et al., 2012). The $TR_xANSITION$ Scale™ does not solely rely on self-report as the youth must prove mastery of transition readiness skills before getting score points (Ferris et al., 2012). Given the need for a reliable, self-report HCT readiness tool that complements the $TR_xANSITION$ Scale™, we sought to develop and validate the disease-neutral Self-Management and Transition to Adulthood with R_x = Treatment ($STAR_X$) Questionnaire. The $STAR_X$ Questionnaire was designed for use across a range of literacy levels, different types of chronic conditions, and via several administration platforms (paper and pencil, or on-line).

Methods

The $STAR_X$ Questionnaire was developed in three stages over the course of two years and included the input of AYAs with chronic conditions, their parents, and a team of interdisciplinary collaborators from multiple institutions in the US, Mexico and England (see Acknowledgments section). Collaborators provided input regarding the questions and themes contained in the scale. Pilot testing was conducted with patients from the US only. The initial development of the $STAR_X$ Questionnaire involved triangulated methods (including quantitative and qualitative), and three phases: (1) item development; (2) pilot testing of the items and response format (Pham, 2008); and (3) testing of reliability and factor structure. Table 1 depicts the patient characteristics, the patients' diagnoses included, and the changes to this instrument through different phases of scale development.

Phase 1: Item Development

In Phase 1, items were written based on published transition models and policies (i.e., Got Transition), interviews with a number of relevant and key stakeholders (AYAs with chronic conditions, their parents, and health care providers) to define the realm of possible HCT-related items, and review of other available scales. Items were drafted so that they could be included in a self-administered, close-ended response instrument. In addition to the review of transition policies, models, and available transition scales, for the exploratory interviews 29 participants (ages 15–21) with either chronic kidney disease (CKD) or end-stage kidney disease (ESKD) were recruited. This sample was selected because AYAs with these conditions can experience a large disease burden based on their number of medications and complex self-care regimen. Each AYA was interviewed using a semi-structured guide with questions focusing on topics such as knowledge of their disease, engagement, independence, self-efficacy to transition, self-management, medication-related issues and transition concerns or expectations.

In conjunction with the few available transition measures, the exploratory interviews helped identify key domains that guided the creation of 19 key items included in a preliminary draft of the instrument. These 19 items were divided into 3 sections ("How often have you done the following things?," "How much do you know?," and "How easy or hard is it for you to do the following things?"), with two of the sections including a 5-point Likert scale and one section a 4-point Likert scale. To optimize reliability, two items were reversed scored. To pre-test the items in the measure, the $STAR_X$ Questionnaire was administered to 11 patients with CKD/ESKD aged 15 to 21 years. "Thinkaloud" techniques (Bolton & Bronkhorst, 1996; Sudman, Bradburn, & Schwarz, 1996) were used to help understand the reasoning participants employed while answering the questions. This technique allowed assessment of the comprehensibility, readability,