



ELSEVIER

 JOURNAL OF
 ADOLESCENT
 HEALTH

www.jahonline.org

Original article

Development and Validation of the Adolescent Assessment of Preparation for Transition: A Novel Patient Experience Measure



Gregory S. Sawicki, M.D., M.P.H.^{a,b,c,*}, Katharine C. Garvey, M.D., M.P.H.^{a,c,d}, Sara L. Toomey, M.D., M.P.H., M.Phil., M.Sc.^{a,c}, Kathryn A. Williams, M.Stat.^e, Yuefan Chen, M.S.^a, J. Lee Hargraves, Ph.D.^f, Jessica Leblanc^f, Mark A. Schuster, M.D., Ph.D.^{a,c}, and Jonathan A. Finkelstein, M.D., M.P.H.^{a,c}

^a Division of General Pediatrics, Boston Children's Hospital, Boston, Massachusetts

^b Division of Respiratory Diseases, Boston Children's Hospital, Boston, Massachusetts

^c Department of Pediatrics, Harvard Medical School, Boston, Massachusetts

^d Division of Endocrinology, Boston Children's Hospital, Boston, Massachusetts

^e Clinical Research Center, Boston Children's Hospital, Boston, Massachusetts

^f Center for Survey Research, University of Massachusetts, Boston, Massachusetts

Article history: Received December 22, 2014; Accepted June 5, 2015

Keywords: Health care transition; Patient experience; Quality measurement; Survey development

A B S T R A C T

Purpose: Significant gaps exist in health care transition (HCT) preparation that can impact care and outcomes in young adults with chronic illness. No quality measure exists to directly assess adolescent experiences of HCT preparation. Our objective was to develop an adolescent-reported measure of the quality of HCT preparation received from pediatric health care providers.

Methods: The Adolescent Assessment of Preparation for Transition (ADAPT) is a 26-item mailed survey designed for completion by 16- and 17-year-old adolescents with a chronic health condition. Adolescents from three samples (two large Medicaid insurance plans [n = 3,000 each] and one large tertiary care pediatric hospital [n = 623]) were mailed the survey. An iterative developmental process included focus groups and cognitive interviews, and validity was assessed using confirmatory factor analysis and ordinal reliability coefficients.

Results: Reliability and validity was evaluated for the following three prespecified composite measures: (1) counseling on transition self-management; (2) counseling on prescription medication; and (3) transfer planning. Across the three samples, all but one measure had good internal consistency (ordinal reliability coefficient $\geq .7$). Confirmatory factor analysis using tetrachoric correlation coefficients was stable across samples and supported the construct validity of the first two composite measures.

Conclusions: ADAPT is a reliable, validated instrument measuring the quality of HCT preparation experiences reported by adolescents with chronic disease. ADAPT will enable clinical programs and health care delivery systems to assess the quality of HCT preparation and provide targets for improvement in adolescent counseling related to transition.

© 2015 Society for Adolescent Health and Medicine. All rights reserved.

IMPLICATIONS AND CONTRIBUTION

The Adolescent Assessment of Preparation for Transition is a 26-item survey with good psychometric properties that fills a quality measurement gap in key areas of preparation for transition from pediatric to adult-focused health care. Adolescent Assessment of Preparation for Transition enables health systems to assess transition preparation quality and provide targets for improvement.

Conflicts of Interest: No authors have any conflicts of interest to report.

* Address correspondence to: Gregory S. Sawicki, M.D., M.P.H., Boston Children's Hospital, 300 Longwood Avenue, Boston, MA 02115.

E-mail address: gregory.sawicki@childrens.harvard.edu (G.S. Sawicki).

The process during which adolescents and young adults move from pediatric-focused to adult-focused health care delivery systems, referred to as health care transition (HCT), has the central goal of providing adolescents with uninterrupted, high-quality, and

developmentally appropriate care [1]. Lack of effective HCT may contribute to fragmentation of health care and increased risk for adverse health outcomes, particularly for youth with chronic health conditions [2].

There is consensus that initial preparation for HCT should start in early adolescence and involve individualized counseling, planning, and skills development [1,3]. However, national data demonstrate a lack of attention to implementing recommendations for HCT preparation, with little improvement over the last several years. In the 2001 National Survey of Children with Special Health Care Needs (NS-CSHCN), a minority of parents reported having discussed transition with their child's physician [2], and only 30% had a plan for addressing transition needs [4]. In both the 2005–2006 and 2009–2010 NS-CSHCN, this percentage improved, but remained <50% [5,6]. Almost all assessments of HCT preparation are from parent or caregiver reports. An exception is the 2007 Survey of Adolescent Transition and Health, which targeted young adults aged 19–23 years. Even in this survey, less than half of respondents reported receiving counseling around transition [7].

Preparation for HCT should include the acquisition of self-care skills, development of a transition plan, and promotion of increased responsibility for chronic condition management [3]. Examples of self-management and self-advocacy skills include scheduling medical appointments, obtaining medications and prescription refills, having one-on-one conversations with medical providers, being familiar with their medical history, understanding health insurance coverage, and feeling empowered to manage medical conditions. The Maternal and Child Health Bureau has reported a core transition services quality measure based on parent-reported data from five questions in the NS-CSHCN [8]. Although many of these skills have been incorporated into patient-reported transition readiness scales and skills checklists such as the Transition Readiness Assessment Questionnaire (TRAQ) [9–12], a patient-reported experience measure on HCT preparation does not exist. Measures of patient experience are an important component of health care quality. Patient experience quality measures capture information on what patients value and what they directly observe, and they can capture data for which patients are generally the best source [13].

The Agency for Healthcare Research and Quality and the Centers for Medicare and Medicaid Services established the Pediatric Quality Measurement Program to enhance and develop evidence-based pediatric quality measures including measures on transition from child- to adult-focused care [14]. Because HCT preparation is primarily a series of interactions with clinicians, obtaining reports from youth directly about their experience is critical to understanding the current quality of health care delivery during HCT for this population. As part of the Pediatric Quality Measurement Program, we developed the Adolescent Assessment of Preparation for Transition (ADAPT) survey to serve as a reliable, validated, patient-reported instrument to measure the quality of experiences with HCT preparation in populations of adolescents with chronic health conditions.

Methods

Measure development

We developed the ADAPT survey to measure adolescent-reported experiences of HCT preparation. An initial list of key concepts and possible survey questions were created after a

series of interviews with experts in the field, review of existing measures of transition readiness and preparation, and review of prior parent-reported survey questions on HCT [9,15]. Subsequently, 11 focus groups were conducted in three U.S. cities to explore parent and youth experiences with various processes of care involved in HCT, including self-management education, care coordination, and communication with health care providers around transition planning and transfers of care. Focus groups consisting of either adolescents with a chronic health condition, young adults with a chronic health condition, or parents of such youth were conducted in English and Spanish and included a diverse spectrum of youth and parents with regard to sex, race, ethnicity, and type of chronic health condition. We synthesized focus group findings to inform the draft survey, with questions written at or below a sixth grade reading level. We then conducted 26 cognitive interviews over four rounds to assess whether the intended respondents, 16- to 17-year-old adolescents with chronic health conditions, understood each of the survey items. The cognitive interview protocol contained candidate questions from the draft survey followed by pre-specified cognitive probes to evaluate the understandability of specific words and phrases and to clarify participant thought processes in answering the questions and selecting response options. Participants were also given the opportunity to suggest alternative language for specific items. After the cognitive interviews, a final survey was developed for field testing.

Field testing of the final ADAPT survey was conducted with samples of health plan members with chronic illness and patients receiving care in a variety of pediatric clinical programs (primary care and specialty programs) at a large, freestanding children's hospital. The survey was mailed to the parent or guardian with a cover letter asking to give the questionnaire to the adolescent to complete based on his or her own experience. Youth respondents were asked to identify a "main health care provider" and were directed to answer all subsequent questions in relation to their interaction with that provider over the previous 12 months. A postage-paid return envelope was included. A second survey packet was sent after about 30 days to non-respondents. Respondents received a \$10 gift card for completing the survey. Each participating institution's institutional review board approved the study.

The final survey includes 26-items with 12 items specifically measuring the quality of care received in three major areas: (1) counseling on transition self-management; (2) counseling on prescription medication; and (3) transfer planning (Table 1). Each set of questions assesses the extent to which the components of preparation for a specific aspect of HCT occurred, as reported by the adolescent. The survey also includes questions on each respondent's frequency of visits to the identified main health care provider, self-reported health status, and key demographic characteristics (age, sex, education, race/ethnicity).

Field test participants

Two health plans, AmeriHealth Caritas in Pennsylvania (AHCP), a Medicaid managed care health plan serving individuals across two regions in Pennsylvania (Health Plan 1), and Texas Children's Health Plan, a pediatric-focused Medicaid health plan serving individuals in Texas (Health Plan 2), each distributed mailed surveys to a simple random sample of parents of 16- to 17-year-old youth identified as having a chronic disease. Chronic disease status was determined using the pediatric medical

Download English Version:

<https://daneshyari.com/en/article/10511499>

Download Persian Version:

<https://daneshyari.com/article/10511499>

[Daneshyari.com](https://daneshyari.com)