



Evaluation of readiness to transfer to adult healthcare: What about the well adolescent?



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ABSTRACT

Background: Understanding readiness to transfer from pediatric to adult healthcare is important for all youth; however, research and implementation guidelines in this area have emphasized youth seen in pediatric subspecialty settings. The purpose of this study was to develop an approach for evaluating transition readiness in a primary care setting, collect pilot data that examined the transition readiness of teens in that program, and implement assessments as part of clinical care.

Method: Forty boys and girls aged 12–22 were recruited from an adolescent medicine outpatient program in a large children's hospital. The first 10 adolescents provided responses to questions and participated in cognitive interviewing. Questions changed minimally and responses from all 40 participants were combined. After the study visit, a researcher compared participant responses to electronic medical records and coded responses for accuracy. The survey consisted of 41 transition readiness items from previously published measures.

Results: The research team was able to develop a tool to assess transition readiness within a clinical setting. When administered to participants from that program, participants demonstrated poor transition readiness. Modifications were made based on participant feedback and implementation in the clinical setting. Clinicians were successful with administering transition readiness assessments.

Conclusions: It appears that even in youth who are generally well, transition readiness is low. Transition readiness assessments can be implemented in the primary care setting, and have been useful for guiding clinical care. Additional barriers and next steps will be discussed.

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1. Background

Over the last three decades, transition to adult healthcare has been discussed extensively in the medical literature^{1–4}. Healthcare transition is defined as the process of preparing youth to: (a) assume autonomy and self-management in their healthcare, (b) be knowledgeable of their health conditions and the healthcare system, and (c) move from pediatric to adult care models.^{5,6} Published guidelines, empirical studies, and measures of transition readiness have targeted youth seen in pediatric subspecialty care settings. However, recent pediatric guidelines¹ and the National Center for Health Care Transition Improvement⁷ suggest that

transition readiness and healthcare transfer should be part of general practice for *all* youth. This includes establishing a transition policy, tracking and monitoring the transition process, assessing transition readiness, planning for transition with patients and families, establishing the patient in an adult healthcare model, and confirming the handoff of the patient with an adult provider.⁷

The vast majority of adolescents and young adults (80%) do not have a chronic condition of childhood⁸; however, there is an absence of empirical evidence about transition readiness for youth who are generally well (i.e., youth with acute health issues or chronic conditions that can be controlled without subspecialists) in the published literature. Drawing from the larger body of work examining healthcare utilization, there is clear evidence that lack of insurance and poor continuity of care contribute to increased morbidity in the general young adult population with and without chronic conditions.^{9–13} Young adults are least likely to identify a provider they are established with for healthcare⁹ and rely on costly emergency care to meet acute healthcare needs¹⁴ or may forgo healthcare completely.⁹ There is potential to improve the detrimental impacts of disengagement from primary care among

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young adults by improving the transition from pediatric to adult healthcare systems within the primary care setting.

Currently, it is not clear how to feasibly assess readiness to transfer to adult healthcare within a pediatric primary care setting. The recommendation to include transition readiness as part of clinical practice⁷ emphasizes the use of a transition readiness assessment, which can be implemented in clinic and used to inform pediatric clinician–patient discussions about the pending transfer to adult healthcare providers. Transition readiness assessments have been developed for a variety of disease-specific contexts (e.g., sickle cell disease,¹⁵) as well as for youth with any chronic condition (e.g., Transition Readiness Assessment Questionnaire (TRAQ).¹⁶) Across these measures, there is a reliance on self-report rather than on a comparison between patient responses and provider knowledge of each patient's health needs.¹⁷ Further, while item responses have been developed to parallel stages of change,¹⁸ there is not a clear strategy for how to follow up with self-management coaching based on item responses. Finally, there is a dearth of measures that are applicable for youth without chronic conditions, despite the guidelines for assessing transition readiness in all youth.⁷

1.1. Clinical context

In response to the 2011 clinical recommendations about the transition from pediatric to adult care,¹ the freestanding children's hospital within which this study occurred began the process of developing a clinical service of combined internal medicine/pediatrics trained physicians who could assist with providing consultative care for healthcare transitions, across primary and subspecialty care settings. Those providers were housed within the hospital's Division of Adolescent Medicine (now Adolescent and Transition Medicine) and primarily work out of the adolescent medicine clinical space. The launch of this clinical service spurred leadership within Adolescent and Transition Medicine to take additional steps toward improving healthcare transition for all primary care patients, including assessments of transition readiness. A transition readiness assessment that could be used with adolescent medicine and transition medicine patients was identified as a priority by leadership in both clinical services. This work was accomplished in part through the work of two internal medicine/pediatrics providers, a nurse, and a research psychologist.

1.2. Study goals

The purpose of this study was two-fold: First, to develop a transition readiness assessment tool for adolescents, based on published scales of transition readiness,^{18–24} that could be administered to all youth seen in a pediatric primary care setting, draw on patient and provider knowledge of each patient's health, and support discussions that would lead to behavior change; and second, to pilot the readiness assessment tool with participants from the primary care setting, both to identify the baseline state of transition readiness in the current population and to establish preliminary validity of the tool.

2. Method

2.1. Tool development

A review of existing tools developed to assess transition readiness was conducted. This study drew on the TRAQ,¹⁸ the University of North Carolina TRxANSITION measure,¹⁹ the Self-Management Skills Assessment Guide,²² and the Readiness to Transition Questionnaire.²³ Across these measures, a pool of 93

items was created. Our multidisciplinary team reviewed items to eliminate questions from the pool that were not applicable to the majority of adolescents seen in primary care (e.g., "Getting monthly labs"). Consensus across the multidisciplinary team was required before an item could be eliminated. Questions assessing similar abilities or underlying constructs were either combined or one item was chosen, to minimize redundancy. Questions were structured to either be open-ended (e.g., What are the names of your medications?) or closed-ended (e.g., My parents will let me manage my own healthcare, response options: 1—not at all true, 2—partially true, 3—completely true). Open-ended questions were designed to be compared to the electronic medical record, and clinicians could identify patient responses as completely, partially, or not accurate. After the multidisciplinary team eliminated non-applicable and redundant items, 41 questions assessing transition readiness remained in the pool and were included in the initial transition readiness assessment tool. Items were grouped to reflect the general constructs of health knowledge, self-management behaviors, and social behaviors and supports.

Drawing on theoretical models explaining motivation and behavior change in adolescence (e.g., health belief model^{26,27}), additional questions assessing the potential for behavior change were also included for the constructs targeted in the initial assessment. This included whether adolescents believed they could be successful in doing specific tasks or behaviors (i.e., self-efficacy²⁸) and how important or worth their effort participants perceived tasks or behaviors to be. Both self-efficacy and perceived value are informative for predicting outcomes and guiding clinical interventions.²⁹

2.1.1. Procedures

The administration and evaluation of items from the transition readiness assessment tool for research purposes was approved through the hospital's Institutional Review Board. A waiver of parental consent was obtained. Study personnel provided information about the study's purpose, risks, and benefits. Participants under 18 provided assent; those 18 and older provided consent to participate. Participants were recruited through flyers displayed in our outpatient Teen Health Center (THC) and were all primary care patients. The THC is located in an urban Midwestern city at a freestanding academic pediatric medical center. Exclusion criteria included (1) inability to independently answer questions, (2) presence of a moderate intellectual disability (determined by attending physician), (3) receiving care from any adult medical care provider or pediatric subspecialty provider, and (4) inability to read and communicate in English.

Participants were given a copy of the survey; study personnel read the survey aloud and wrote down participant responses. The first 10 participants were also asked to engage in cognitive interviewing,³⁰ vocalizing any thoughts about confusing language, what they thought the questions meant, and thoughts about why the question was being asked. Based on feedback from those participants, some items were modified slightly (e.g., "I am optimistic about handling my health in the future" modified to "I feel positive about handling my health in the future"). The last 30 participants were encouraged to ask question about anything they were confused by, but did not engage in cognitive interviewing. Participants were compensated with a gift card at the end of the study. After the study visit, the second author (a clinician practicing in the THC) compared documented responses to the participant's electronic medical record and coded responses as either completely, partially, or not accurate.

2.1.2. Participants

Forty participants ages 12 to 21 were recruited from an outpatient teen health center. The THC experiences an average of

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