



Development and Implementation of the Readiness Assessment of Emerging Adults With Type 1 Diabetes Diagnosed in Youth (READDY) Tool

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Type 1 diabetes is a common chronic condition in children; treatment plans are complex, and lifelong self-management is required (1). Depending on age at diagnosis, initial education is often focused toward adult caregivers, with patients assuming more responsibility for themselves over time (2). Transition of health care from pediatric systems to adult systems is a challenging process, especially for those with chronic conditions such as diabetes (3–5). Multiple studies have demonstrated that adolescents and emerging adults (AEAs) with diabetes are prone to interrupted care and are at risk for poor health outcomes between late adolescence and their mid-20s (6–12), during which time the demands of increased responsibility for self-management of diabetes care must be integrated into the competing developmental tasks of becoming an adult. For example, emerging adults are establishing financial independence, moving out of the parental home, exploring work and professional roles, and developing new social relationships (13). The combination of a complex medical condition, variable levels of independent diabetes management skills, and lapses in health care between pediatric and adult care systems all contribute to increased mortality and morbidity, including increased risk for developing acute disease complications (e.g., diabetic ketoacidosis and severe hypoglycemia), as well as potentially unrecognized chronic disease complications resulting from lack of screening and routine prevention services (7,14,15).

Increasingly, clinical guidelines and the research literature (6,16–20) recognize the significance of planned transition for AEAs with diabetes. Examples of online resources include

materials from the Endocrine Society (available from www.endocrine.org/guidelines-and-clinical-practice/transitions/tid). A well-planned transition process that includes active participation by AEAs may promote higher levels of success as indicated by patient-reported satisfaction with care, effective self-management after transfer, and clinical outcomes (21–24). A 2011 consensus statement from the American Academy of Pediatrics (25), along with related resources from the Center for Health Care Transition Improvement (available at www.gotttransition.org) and the Ready, Steady, Go Transition to Adult Care program in the United Kingdom (26), set forth specific recommendations and guidelines for planning the transition from pediatric to adult care that included identification of patient-specific health care needs, education, and disease management.

General transition readiness assessment tools, including the Transition Readiness Assessment Questionnaire (TRAQ), have been developed and validated with heterogeneous samples of AEAs with chronic health conditions (27,28) and include items addressing such topics as taking medications and obtaining prescription refills. However, transition readiness may vary based on self-management requirements and skill acquisition for a particular type of chronic condition and individual characteristics (29), and these details may not be captured in a general assessment tool. Condition-specific transition readiness tools for patients with cystic fibrosis, HIV, kidney and liver transplant, and sickle cell disease have been published (30). Similar to other chronic conditions, in a population with type 1 diabetes, general tools are insufficient to identify topics specific to diabetes self-management

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<https://doi.org/10.2337/ds18-0075>

This article contains supplementary data online at <https://spectrum.diabetesjournals.org/lookup/suppl/doi:10.2337/ds18-0075/-/DC1>.

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knowledge and behaviors relevant to longitudinal transition preparation.

In recognition of the clinical need for an innovative and systematic approach to assessing readiness for transition to adult care for AEAs with diabetes, a novel clinical tool, Readiness for Emerging Adults with Diabetes Diagnosed in Youth (READDY), was developed. The tool is designed to assess self-reported confidence levels on diabetes-specific health knowledge and skills. In this framework, higher confidence in one's ability to perform health-related skills indicates a higher level of readiness for transition. A Likert reporting scale enables clinicians to identify priority topics for educational interventions and follow changes in responses over time.

The purpose of this article is to describe the development, subsequent refinement, and implementation of READDY, a clinically relevant patient-reported, diabetes-specific transition readiness assessment tool.

Research Design and Methodology

Development of the READDY Tool

The READDY tool was originally designed by social workers ($n = 3$), a psychologist ($n = 1$), pediatric and adult endocrinology providers ($n = 5$), certified diabetes educators ($n = 2$), and a registered dietitian ($n = 1$) at the Seattle Children's Hospital (SCH) diabetes center. The item pool was generated after a review of the literature, including content derived from existing recommendations available from national resources (31,32). The stem for each item on the READDY tool is, "I am able to . . ." followed by various diabetes management skills for which participants independently rate their confidence level. Response options are closed-ended on a Likert scale, coded as 1 (Haven't thought about it), 2 (I plan to start), 3 (No, I still need lots of practice), 4 (Somewhat, but I need a little practice), and 5 (Yes, I can do this). Items are organized into four topics: 1) Diabetes Knowledge: "knowing the facts about diabetes," 2) Health System Navigation: "taking care of my own medical visits," 3) Insulin Self-Management: "insulin and diabetes management including insulin pump skills" (when relevant), and 4) Health Behaviors: "skills for college and living independently."

Initial Implementation and Data Collection

At SCH, the READDY tool was used at the time of a routine in-person medical or social work visit for patients ≥ 15 years of age to identify gaps or barriers in transition preparation and facilitate a discussion about needs. Dates of data collection were between April 2010 and July 2012. At the Cincinnati Children's Hospital Medical Center (CCHMC), patients ≥ 15 years of age were asked to complete the

READDY at routine in-person diabetes clinic visits between October 2012 and August 2013.

Institutional review board approval was obtained at SCH and CCHMC to examine data for research purposes. In addition to the READDY tool, demographic and clinical variables, including age, sex, race/ethnicity, age at diabetes diagnosis, and glycemic control as measured by A1C were collected via medical record review performed by the first author. Data from SCH were de-identified and sent to CCHMC for analysis.

Participants

Participants include 104 patients with type 1 diabetes seen at one of two sites: SCH ($n = 48$) and CCHMC ($n = 56$). Patients fluent in English and able to answer questions independently (i.e., without the help of a parent, friend, or caregiver) were asked to complete the tool. Exclusion criteria included inability to answer questions independently and patient, parent, or clinician report of profound to moderate developmental disability.

Statistical Analysis

ANOVA was performed to examine differences in item responses between the Cincinnati and Seattle sites; only arranging for transportation to medical appointments differed ($P < 0.05$). Confirmatory factor analysis (CFA) (33) was used to examine item contributions for each of the four topics in READDY: Diabetes Knowledge, Health System Navigation, Insulin Self-Management, and Health Behaviors. Model fit was assessed using a combination of fit indices: χ^2 significance tests and values for comparative fit indices (CFI), root mean square error of approximation (RMSEA), and standardized root mean square residual (SRMR). A model is considered to have ideal fit when the χ^2 significance test is > 0.05 ; good fit when the CFI value is ≥ 0.95 , the RMSEA value is ≤ 0.06 , and the SRMR is ≤ 0.08 ; and acceptable fit when the CFI is near 0.9 and the RMSEA and SRMR are near 0.1 (34). Items with significant factor loadings across multiple READDY topics were removed to reduce collinearity. After CFA, qualitative review was performed by a team of stakeholders, including patients, to review items removed from the tool. At that time, stakeholders developed replacement items for content that had been removed but was considered clinically meaningful.

Results

Demographics

Across the two sites, patients were diagnosed with type 1 diabetes and were between the ages of 15 and 24 years (mean

19.42, SD 6.25), were primarily female (55%), and were predominantly white (89%). The majority (57%) were treated with multiple daily insulin injections, and the remainder were on insulin pump therapy. The average age at diagnosis was 12.25 years (SD 6.69). Mean A1C was 9.04% (SD 1.93). Patients from the two sites were similar overall; no demographic differences between the two sites were statistically significant ($P > 0.10$ for all).

CFA of READDY

Model fit for each of the four topic areas was as follows:

- **Diabetes Knowledge.** The model for this topic (6 items) had excellent fit: $\chi^2(9) = 12.68$, $P = 0.18$, CFI = 0.98, RMSEA = 0.06, SRMR = 0.04.
- **Health System Navigation.** The model for this topic (12 items) had acceptable fit: $\chi^2(50) = 82.94$, $P < 0.01$, CFI = 0.92, RMSEA = 0.08, SRMR = 0.09.
- **Insulin Self-Management.** The model for this topic (4 items) had excellent fit: $\chi^2(2) = 1.49$, $P = 0.47$, CFI = 0.99, RMSEA = 0.01, SRMR = 0.02.
- **Health Behaviors.** The model for this topic (10 items) had acceptable fit: $\chi^2(35) = 70.43$, $P < 0.01$, CFI = 0.89, RMSEA = 0.10, SRMR = 0.12.

Outcomes of Qualitative Stakeholder Review

After CFA, READDY items were reviewed for content validity with several AEs and with an interdisciplinary transition team of ~10 members inclusive of clinicians, researchers, social workers, diabetes educators, psychologists, and patient and parent representatives over a series of four 1-hour sessions. Additional qualitative feedback was solicited from patients and parents during clinical encounters to confirm that the questions and response choices were being understood and interpreted correctly.

For the benefit of brevity, items with unclear wording or outdated clinical utility (e.g., “Have at least two [paper] copies of clinic records for last two visits, labs done in last year, and other pertinent records”) were identified as candidates for removal. Several items had clinically relevant content but were removed due to compound wording (e.g., “Describe how alcohol and tobacco affect blood sugar”). These items were then revised by creating discrete statements (“Describe how alcohol affects blood sugar” and “Describe how tobacco affects blood sugar”) and added back into the tool. Additional editing was performed to remove unnecessary qualifying words or phrases. For example, “Teach a roommate or friend about signs and treatment of hypoglycemia without being embarrassed” was edited into “Teach a roommate or friend about signs and treatment of

hypoglycemia.” After adjustment for these compound or missing items, the revised READDY tool consists of 44 items. Supplementary Appendix S1 provides a list of all items. A formatted copy of the tool is available on request.

Discussion

READDY is a transition readiness assessment tool with diabetes-specific content that provides patient-reported confidence in four topics (Diabetes Knowledge, Health System Navigation, Insulin Self-Management, and Health Behaviors) that are relevant to transition readiness for AEs with diabetes. Here, we have described the initial development of the tool, CFA of responses from two geographical sites, refinement after review by content experts, and clinical implementation for transition planning at two diabetes centers.

Clinical Care Innovation

READDY is a clinically useful tool used routinely at both SCH and CCHMC to collect patient-reported outcomes to drive educational interventions as part of transition planning. The tool was originally given in paper-and-pencil format, but both sites have found that electronic administration facilitates recording of responses for tracking over time, as well as communication of topics among interdisciplinary team members.

For the purpose of clinical care, mean scores for each of the four topics are calculated. Higher scores indicate more confidence in readiness for transition and lower scores indicate lower confidence. The mean scores highlight priority areas for intervention (e.g., start with lower mean scores and follow longitudinally for progress in these areas). Members of the interdisciplinary diabetes education team have expertise in targeted interventions within each topic area. For example, social workers focus on Health System Navigation responses and diabetes nurse educators focus on Insulin Self-Management topics. Even if AEs respond with high levels of confidence, diabetes educators are trained to ask follow-up questions to elicit opportunities to practice skills and demonstrate competence. As part of standardized implementation, a diabetes transition curriculum based on items in the READDY tool was developed at CCHMC, and a version of READDY for AEs with type 2 diabetes is underway at SCH and CCHMC.

The READDY tool was developed within two diabetes centers but has since been shared with other diabetes centers for use in clinical care. It is now in use at a dozen diabetes centers across the country. The authors maintain a

creative commons license and share the tool freely, but ask centers who are interested in using the READDY tool for clinical care to sign an agreement allowing us to track its use. Data collection is underway at multiple sites to enable review of a larger sample of patients to evaluate variable responses to the READDY across the country. Further investigation of the psychometric characteristics and clinical utility of the READDY over time (35), including examining its correlation with existing validated general transition readiness tools such as the TRAQ, is warranted.

Limitations

Given that the READDY tool is a self-report of confidence to perform certain diabetes-related tasks, it will be important to link these AEA patient-reported outcomes with subsequent observed competence in skill demonstration for diabetes care providers and educators. In addition, the current study did not examine the potential relationship between the READDY tool and post-transfer adult health outcomes or parent reporting of perceived readiness. Additional research is needed to determine whether responses on the READDY tool can predict glycemic levels (e.g., A1C or time in the target glycemic range measured by continuous glucose monitoring systems), length of time between last pediatric care visit and first adult care visit after transfer, prescription refills, and health care utilization (e.g., emergency room visits).

Because the present study presents readiness ratings from a single time point, longitudinal tracking of the READDY scores and subsequent adult health outcomes in AEAs with diabetes needs to occur across both pediatric and adult care settings. Of note, Kelly et al. (36) have begun to evaluate the impact of peer and provider relationships of AEAs on 1-year follow-up on transition readiness and health outcomes and offer additional suggestions for areas important for future research (e.g., day-to-day issues of transition to adulthood such as cooking meals). Next steps for prospective research on READDY should also consider the impact of social supports and anticipatory guidance (37). In addition, future iterations of items on READDY will be more attuned to person-centered language recommendations (38).

Conclusion

Increasingly, clinical guidelines and the research literature recognize the significance of planned transition for AEAs with diabetes. READDY is a clinically relevant patient-reported transition readiness assessment tool that has been successfully implemented by diabetes educators at multiple centers to guide interventions as a part of transition planning. An innovative aspect of the READDY tool is the model for care delivery that integrates a transition readiness

assessment with opportunities for ongoing longitudinal interventions based on patient-directed responses. Specifically, READDY answer responses include both a present and future intention (i.e., “I plan to start”) that provides insights into topics patients are motivated to explore.

Ultimately, the clinical utility of this transition readiness assessment tool will depend on verification that patients’ self-reported confidence in doing diabetes self-management tasks predicts their adult care outcomes. This will aid in determining whether the READDY tool is an accurate predictor of successful transition from pediatric to adult care. In the interim, the READDY tool can support transition preparation programs by providing a standard mechanism to identify diabetes-relevant education needs and thereby provide appropriate and timely anticipatory guidance and in vivo skill acquisition to enhance the ability of AEAs to live well with their diabetes, especially during developmental and health system transitions.

ACKNOWLEDGMENTS

The authors would like to acknowledge the multidisciplinary education teams at both centers for contributions to implementation of the diabetes transition programs, as well as the participating patients and families.

DUALITY OF INTEREST

No potential conflicts of interest relevant to this article were reported.

AUTHOR CONTRIBUTIONS

S.D.C., J.P.Y.-F., and J.C.K. researched data and wrote and edited the manuscript. L.K.G., G.W., and A.H. researched data and reviewed the manuscript. S.B. analyzed data and wrote and edited the manuscript. S.D.C. is the guarantor of this work and, as such, had full access to all the data in the study and takes responsibility for the integrity of the data and the accuracy of the data analysis.

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