



Implementation of a Diabetes Transition of Care Program

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ABSTRACT

For adolescents with diabetes, ineffective health care transition to adult health services may result in suboptimal adherence to medical supervision, leading to poor glycemic control, increased diabetes complications, and hospitalization. Despite national recommendations, few youth receive the needed preparation to transition to adult health services. A data transition registry was created at a large Midwest urban academic medical center to identify patients 14 years and older with Type 1 diabetes. Thirty-nine patients with Type 1 diabetes were identified, and 33 were eligible to begin transition planning. Baseline Transition Readiness Assessment Questionnaires (TRAQs) were completed in 21 (64%) of the 33 identified patients, with a mean TRAQ skill score of 66.62 out of 100. There was no correlation between better TRAQ scores and hemoglobin A1c level. Participants had lower baseline TRAQ scores for appointment keeping and tracking health issues. Participants were confident managing daily activities, talking with providers, and managing medications. *J Pediatr Health Care.* (2017) *31*, 215-221.

KEY WORDS

Adolescents, diabetes, transition registry, transitioning care

BACKGROUND

Smooth transition of care for adolescents with Type 1 diabetes to adult-oriented health care is especially important because regular medical supervision is necessary to reduce the onset and progression of diabetes-related complications (Peters, Laffel, & The American Diabetes Association [ADA] Transitions Working Group, 2011). The boards of the American Academy of Pediatrics (AAP), the American Academy of Family Physicians (AAFP), and the American College of Physicians (ACP)–American Society of Internal Medicine approved a consensus statement on health care transitions for young adults with special health care needs in 2002. This policy emphasizes the importance of providing high-quality, developmentally appropriate, and uninterrupted health care services to all youth transitioning to adulthood and provides general guidelines to support them during the transition. Nearly a decade later, a more detailed expert clinical report was published to outline best practice to transition youth to adult health settings (AAP, AAFP, and ACP, 2011). Transition planning is also a core indicator of adolescent and young adult health (Healthy People 2020, 2012).

The ADA has a position statement describing a framework for health care delivery during the transition period for adolescents with diabetes (Peters et al., 2011). The ADA provides best practice recommendations to transition adolescents, including beginning the process during the early adolescent years, gradual transfer of diabetes tasks from caregiver to adolescent, preparing youth to assume more responsibility for health care decisions and management (e.g., ensuring a proper amount of medication and supplies, scheduling

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appointments), thorough preparation for the differences in care in adult settings, and effective communication with the accepting provider (Peters et al., 2011).

The “Got transition” initiative is a national effort to provide transition resources to all adolescents, their families, and providers (Center for Health Care Transition Improvement Project Team, 2014). In particular, preparing youth with chronic health conditions for the eventual transition to adult-oriented health care requires individualized planning and ongoing skills development and acquisition.

Despite national recommendations for a transition standard of care, of the estimated 4.5 million youth in ages 12 to 18 years with special health care needs in the United States, only 40% are receiving the necessary preparation from health care teams to transition from pediatric to adult services (McManus et al., 2013). Currently, health care teams are working to increase adolescent transition-related skills, but most programs are not assessing patient transition readiness as a standard of care (McManus et al., 2013; Sawicki et al., 2011). Some transition challenges include limited research on best practice transition models, expectations by adult providers, absence of defined transition readiness criteria, psychosocial changes of adolescence, and deficient health care provider training to work with young adults (Peters et al., 2011).

LITERATURE REVIEW AND SYNTHESIS

Effective transition to adult-oriented care has been found to be challenging for patients, caregivers, and providers secondary to adolescent lifestyle changes, risk-taking behaviors, competing work or school demands, and less parental supervision. These challenges often take precedence over diabetes care (Peters et al., 2011). Patients and families desire a gradual transition process from pediatric-centered care to adult care, but all too frequently the transition occurs abruptly without adequate preparation (Busse et al., 2007; Hilliard et al., 2014; Reiss, Gibson, & Walker, 2005; Tuchman, Slap, & Britto, 2008). The recommendation is to introduce the transition by 14 years of age and to begin transition preparation at least one year before changing to adult services (AAP, AAFP, and ACP, 2011; Peters et al., 2011). Time of transfer to adult care should be based on an adolescent’s readiness and skill acquisition (e.g., ability to negotiate the adult health care system), not on a predetermined age (Reiss et al., 2005).

Fears and anxiety about the unknown, differences in the approach to care in adult settings, and sadness about leaving the pediatric provider all contribute to a patient’s reluctance to transition (Bowen, Henske, & Potter, 2010; Kipps et al., 2002; Hilliard et al., 2014; Tuchman et al., 2008). Young adults often

struggle to adjust to the increased level of autonomy expected of patients in the adult health care setting (Wood et al., 2014). Although patients and their families desire guidance when transferring to adult diabetes teams, patients often do not receive recommendations or introductions from their pediatric providers (Busse et al., 2007; Garvey et al., 2012; Hilliard et al., 2014).

Transition of care challenges reinforce why adherence to medical supervision around the time of transfer to adult care is not optimal for many youth with diabetes. In a retrospective study conducted by Kipps et al. (2002), it was observed that clinic attendance rates for patients with Type 1 diabetes declined to 61% after transition to adult care, especially for those with worse glycemic control. In the multicenter Search for Diabetes in Youth study, participants were found to have 2.5 times higher odds of poor glycemic control after transition to adult care compared with those continuing to receive pediatric health supervision (Lotstein et al., 2013). A large Canadian retrospective study found that in the 2 years after transition to adult care, rates of hospitalization for acute hyperglycemia increased from 7.2 to 9.5 cases per 100 patient-years (Nakhla, Daneman, To, Paradis, & Guttmann, 2009).

Although a small sample size was used, findings from Cadario et al. (2009) show that patients with a structured diabetes transition program had significantly less time between the last pediatric visit and the first adult visit and better clinic attendance compared with those without coordinated transition of care. Cadario et al. also found that the group with an organized transition process had a significant decrease in hemoglobin A1c (HbA1c) levels, suggesting that coordinated transition of care can contribute to improved glycemic control.

Although there are no known published randomized controlled trials evaluating diabetes transition of care models (Hanna & Woodward, 2013), available evidence suggests that early planning, provider continuity, and intense care coordination can result in increased patient satisfaction, improved clinic attendance, better glycemic control, and decreased hospitalization rates (Cadario et al., 2009; Kipps et al., 2002; Nakhla et al., 2009; Vidal et al., 2004). Garvey et al. (2012) found that patients with strong transition preparation were significantly less likely to report a gap of greater than 6 months between pediatric and adult clinic visits, and thorough transition preparation correlated with better patient satisfaction. In a study of adolescents with Type 1 diabetes, participants emphasized the importance of early transition preparation and developmentally appropriate care (Hilliard et al., 2014).

In summary, the evidence supports the need for a structured framework for transition of care for

adolescents with Type 1 diabetes to adult-oriented care. Adolescents and their families prefer a gradual and coordinated transition to reduce fears and anxieties. Additional guidance is required to increase adolescent autonomy in their Type 1 diabetes management. There is limited literature on successful models for the transition of adolescents with Type 1 diabetes to adult-oriented care.

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PURPOSE

This quality improvement initiative is founded on the “Got transition” initiative ([Center for Health Care Transition Improvement Project Team, 2014](#)); national guidelines from the [AAP, AAFP, and ACP \(2011\)](#); and the ADA recommendations for transition of care ([Peters et al., 2011](#)). The purpose of the study was to evaluate transition readiness of adolescents 14 years of age and older with Type 1 diabetes to determine their self-advocacy and self-management skills.

The overall goal was to build a sustainable model for adolescents with Type 1 diabetes to transition to adult-oriented care. The first implementation goal of this quality improvement project was to create a data registry to identify all adolescents 14 years of age and older with Type 1 diabetes. The second goal was to complete baseline transition assessment questionnaires on all adolescents with Type 1 diabetes identified by the registry.

SETTING AND TARGET POPULATION

The setting was a pediatric endocrine subspecialty clinic located within a nonprofit, 664-bed Midwest urban academic medical center serving a diverse ethnic and socioeconomic population. In addition to the main campus, there are two offsite satellite clinics where pediatric providers evaluate patients with Type 1 diabetes monthly. The academic medical center has a large adult diabetes clinic housed within the same campus as the pediatric diabetes clinic, and they communicate with each other via a shared electronic medical record (EMR).

Two pediatric endocrinologists lead the pediatric diabetes clinic, serving approximately 75 patients of all ages with Type 1 diabetes. Patients eligible to begin transition planning were 14 years of age or older with a diagnosis of Type 1 diabetes. Exclusion criteria included youth with Type 1 diabetes with developmental disabilities, steroid-induced diabetes, and diabetes acquired from underlying conditions (e.g., cystic fibrosis).

METHODS

The organization’s internal review board approved the diabetes transition of care program as a quality improvement project. The interprofessional medical team for this project included pediatric and adult endocrinologists, a certified diabetes educator (CDE), a pediatric psychologist, a nurse project coordinator, and a pediatric dietician. Information technology experts built the transition data registry and developed an electronic version of the transition readiness questionnaire.

Measures Used to Collect Data

Transition data registry

A diabetes transition registry was created within the EMR to track the number of patients 14 years and older with Type 1 diabetes and their progress toward transferring to adult care. The registry sorted by diagnosis and recognition of diabetes on the problem list. Weekly chart audits were performed to confirm or reconcile the diagnosis of Type 1 diabetes in the patient’s problem list. The CDE and endocrinologists were informed on how many and which patients needed transition readiness screening each week based on chart audits.

Additional information automatically collected for the registry included medical record number, name, date of birth, age, most recent transition readiness assessment questionnaire score, most recent HgA_{1c}, last date of pediatric diabetes clinic visit, and comorbidities (e.g., depression, hypoglycemic unawareness), and insurance information. Adult diabetes clinic visits after transition were also automatically tracked in the registry for future long-term clinic attendance evaluation. This part of the registry was not pertinent for the pilot study, because no patients transitioned during the study period. The transition data registry automatically updated when new patients (e.g., new diagnosis or transfer from another organization) with Type 1 diabetes were seen in clinic.

Transition Readiness Assessment Questionnaire (TRAQ)

The TRAQ tool ([Figure](#)) measures general transition readiness (i.e., not diabetes specific) and was administered as a youth self-report tool in this study. The TRAQ Flesh-Kincaid reading grade level is 5.7, and it was available in English and Spanish versions ([Sawicki et al., 2011](#)). The TRAQ is a validated 20-item ordinal scale instrument with two domains, skills for self-management and advocacy ([Sawicki et al., 2011](#); [Wood et al., 2014](#)). The questionnaire consists of five subscales: appointment keeping, tracking health issues, managing medications, talking with providers, and managing daily activities ([Wood et al., 2014](#)). Each question was evaluated with a 5-point Likert scale. A score of 80 verified that a patient participated in every

FIGURE. The Transition Readiness Assessment Questionnaire.

Transition Readiness Assessment Questionnaire (TRAQ)					
	No, I do not know how	No, but I want to learn	No, but I am learning to do this	Yes, I have started doing this	Yes, I always do this when I need to
Managing Medications	1 point	2 points	3 points	4 points	5 points
1. Do you fill a prescription if you need to?					
2. Do you know what to do if you are having a bad reaction to your medications?					
3. Do you take medications correctly and on your own?					
4. Do you reorder medications before they run out?					
Appointment Keeping					
5. Do you call the doctor's office to make an appointment?					
6. Do you follow-up on any referral for tests, check-ups or labs?					
7. Do you arrange for your ride to medical appointments?					
8. Do you call the doctor about unusual changes in your health (For example: Allergic reactions)?					
9. Do you apply for health insurance if you lose your current coverage?					
10. Do you know what your health insurance covers?					
11. Do you manage your money & budget household expenses (For example: use checking/debit card)?					
Tracking Health Issues					
12. Do you fill out the medical history form, including a list of your allergies?					
13. Do you keep a calendar or list of medical and other appointments?					
14. Do you make a list of questions before the doctor's visit?					
15. Do you get financial help with school or work?					
Talking with Providers					
16. Do you tell the doctor or nurse what you are feeling?					
17. Do you answer questions that are asked by the doctor, nurse, or clinic staff?					
Managing Daily Activities					
18. Do you help plan or prepare meals/food?					
19. Do you keep home/room clean or clean-up after meals?					
20. Do you use neighborhood stores and services (For example: Grocery stores and pharmacy stores)?					

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aspect of the individual subscales, with a maximum score of 100 indicating that the patient was independently completing all necessary self-management and advocacy skills.

Patients completed the TRAQ tool during their routine clinic visits approximately every 3 months. The screening tool was administered and scored by the CDE in a face-to-face encounter. The CDE transferred written answers to the EMR for automatic scoring and to establish a permanent record for future assessment and evaluation of transition readiness. TRAQ scores were interpreted by the CDE and endocrinologist and were used clinically in two ways: (a) to help providers identify areas in which adolescents need

more guidance and (b) to help providers determine when a patient is ready to transfer to adult services.

RESULTS

Transition Data Registry Results

The transition data registry consisted of 39 patients 14 to 21 years of age with Type 1 diabetes. Of the 39 patients identified by the registry, six patients were not included in the pilot study because they had already transitioned to adult care, had transferred care to another organization, or did not have a documented encounter in the last 12 months. This left 33 patients eligible for transition planning. See [Table 1](#) for characteristics of patients identified in the transition registry.

TABLE 1. Characteristics of patients (N = 33) identified in the transition registry

Characteristic	Value
Ethnicity, n (%)	
Hispanic	9 (27.3)
African American	14 (42.4)
Non-Hispanic White	10 (30.3)
Insurance, n (%)	
Private payer	19 (57.6)
Public aid	14 (42.4)
Sex, n (%)	
Female	14 (42.4)
Male	19 (57.6)
Age in years, mean (range)	16.64 (14–21)
Mean HgA1c level	9.54%

TRAQ Results

Baseline transition readiness was assessed in 21 of the 33 originally identified registry patients (64%). The mean HgA1c level for the 21 patients completing the TRAQ was 9.85%. The overall mean TRAQ skill score was 66.62 out of 100 (maximum possible score) with a standard deviation of 16.36. See Table 2 for the results of each TRAQ skill category. The Pearson coefficient (0.180) found no significant correlation between a high TRAQ score and a lower HgA1c.

DISCUSSION

Results

The low baseline mean TRAQ score (66.62) indicates that starting the transition process early in adolescence is critical. It can take several years for patients to gradually assume responsibility for comprehensive Type 1 diabetes management. Future studies can evaluate if improved TRAQ scores correlate with increasing age.

Of the five TRAQ categories, participants had lower baseline scores in the areas of appointment keeping and tracking health issues. This indicates that these two skill areas need more focused education with specific goal setting. Knowledge of health insurance and medical payments, under the appointment-keeping category, were also low scoring in research completed by Sawicki et al. (2011). Talking with providers was a strong skill area for patients in our study (mean score = 9.05/10) and parallels Sawicki et al.'s research. The mean score for managing daily activities, which in-

cludes skills such as meal preparation and use of neighborhood stores, was 12.19 out of 15. In the category of managing medications, patients had a mean score of 14.42 out of 20. These results indicate that patients feel confident in their medication management, but this does not correlate with the HgA1c mean level of 9.85%. The mean HgA1c level well above the ADA target of less than 7.5% for adolescents is a reminder that adolescence is a challenging time, especially for youth with Type 1 diabetes (Chiang, Kirkman, Laffel, & Peters, 2014). More emphasis on development of specific action goals targeting reduction of HgA1c level is necessary. A longitudinal study and larger sample size have the potential to show a correlation between higher a TRAQ score and a lower HgA1c level.

Of the five TRAQ categories, participants had lower baseline scores in the areas of appointment keeping and tracking health issues.

Limitations

There were multiple barriers to administering the TRAQ. Providers in the clinic decided that assessing transition readiness in newly diagnosed adolescents with Type 1 diabetes would be inappropriate. The optimal time to begin transition planning in adolescents with recent Type 1 diabetes diagnoses is unclear. Another barrier to TRAQ administration was patient complexity and their needs at the time of the appointment. For example, a patient changing from multiple daily injections to an insulin pump requires extensive education, and there is not time for transition planning.

There were limited opportunities to assess transition readiness at the offsite clinics because of work flow milieu and time constraints. Face-to face TRAQ data collection was avoided to reduce response bias by self-report, which could affect result validity (Newcomer & Triplett, 2010). The TRAQ Likert scale format was more time efficient when adolescents responded by self-report. An inherent limitation of the TRAQ is that it is a measurement of general transition readiness but is not diabetes specific. There are no specific, validated tools at this time to assess transition

TABLE 2. Results for the Transition Readiness Assessment Questionnaire skills (n = 21)

Skill	Mean score	SD	Maximum tool score	Patient maximum score	Patient minimum score
Managing medications	14.52	3.459	20	20	8
Appointment keeping	18.14	7.337	35	34	7
Tracking health issues	10.71	5.130	20	18	3
Talking with providers	9.05	1.774	10	10	4
Managing daily activities	12.19	2.822	15	15	6

readiness in patients with Type 1 diabetes. Plans for eliminating TRAQ assessment barriers include electronic patient completion of the TRAQ to reduce transcription error and best practice alerts in the EMR to increase TRAQ administration consistency.

Organizations that do not partner as closely with adult diabetes centers may have added challenges with transition planning. Communication between pediatric and adult diabetes centers can be challenging without a shared EMR. This limitation can be diminished using free tool kits (Center for Health Care Transition Improvement Project Team, 2014), creating a data registry in the EMR, and potentially hiring a care coordinator.

Communication between pediatric and adult diabetes centers can be challenging without a shared EMR.

CONCLUSION

The existing transition of care program for patients with Type 1 diabetes is a major building block for preparing all chronically ill adolescents cared for within the same health system for the shift to adult care. The transition data registry was found to be useful as an effective method to track adolescents with Type 1 diabetes and identify adolescents who had no encounters with the diabetes health team in 12 months. The development of the registry adds the ability to follow patient attendance in the adult diabetes clinic within the academic medical center to evaluate for gaps in care after transition.

A transition of care program was implemented to meet national standards of care to better prepare adolescents with Type 1 diabetes and their families for adult health services. The transition process can take up to 4 years and varies from patient to patient, reinforcing the need for transition plans that are gradual, individualized, family centered, and coordinated. Routinely assessing transition readiness beginning in early adolescence is essential to prepare youth for the increased self-management and self-advocacy skills they must obtain as they reach adulthood.

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