

Transition of care for patients with type 1 diabetes mellitus from pediatric to adult health care systems

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Abstract: Planning for the transition from pediatric to adult healthcare is broadly understood to be beneficial to the quality of care of patients with chronic illness. Due to the level of self-care that is necessary in the maintenance of most chronic diseases, it is important that pediatric settings can offer support during a time when adolescents are beginning to take more responsibility in all areas of their lives. Lack of supportive resources for adolescents with chronic conditions often results in both decreased access to care and impaired health and function likely leading to increased medical costs later. Additionally, fundamental differences in health care delivery exist between pediatric and adult care settings. There is limited empiric data and information on best practices in transition care. In this article we address the importance of bridging pediatric and adult care settings and highlight the challenges and successes of the implementation of the young adult transition clinic program for patients with type 1 diabetes at our facility. We provide recommendations for further research and program implementation with the transition population.

Keywords: Chronic disease; transitional care; type 1 diabetes mellitus (T1DM)

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Introduction and background

Due to transformational advances in research and medical management, children and adolescents with many chronic medical conditions are living into adulthood. Children and young adults with type 1 diabetes mellitus (T1DM) are no exception. Beginning with the invention of insulin in 1921 and continuing with further advances in knowledge of the benefits of intensive diabetes management for prevention and delay of diabetes complications in the early 1990s (1), emerging adults with T1DM are living into adulthood and bridging the spectrum of care from the pediatric to the adult medical care systems. This population of emerging adults then faces the challenge of transitioning from the pediatric to adult diabetes care setting, often at the same

time as other major life changes including independent living, starting undergraduate studies or joining the workforce for the first time, changes in health insurance, and potentially starting a family of his or her own. Several recent publications have noted the lack of evidence-based strategies for transition of emerging adults with a variety of chronic medical conditions (2-4). In particular, managing the transition of young adults with T1DM has led to more discussion and research in this important area. Recognizing these challenges and needs, in 2011, experts with pediatric and adult medical fields published guidelines on providing medical care to emerging adults with T1DM in the position statement "Recommendations for transition from pediatric to adult diabetes care systems" which offers guidelines for health care delivery during the transition from pediatric

to adult health care systems. This statement offers expert consensus opinion on caring for adolescents and young adults with T1DM during the transition period, while recognizing the lack of and need for evidence based studies on transition for adolescents with diabetes (5). Furthermore, the American Diabetes Association's 2017 Standards of Care highlight the importance of transition preparation starting in the preadolescent age (6).

This review focuses on patients with T1DM, although most of the concepts may be transferable to many chronic medical conditions including but not limited to asthma, congenital cardiac disease, pediatric oncologic conditions, and chronic neurologic disorders. These are complex chronic medical conditions requiring multidisciplinary medical care teams. Experts are trained generally in pediatric or adult training systems, where the minority of these specialists completes residency medical training in the United States in the discipline of Internal Medicine-Pediatrics. This is an extended training program that combines training for residents in adult and pediatric health care systems. Further subspecialty or fellowship training then may be sought in pediatric and/or adult training environments. Although few residents complete such rigorous training, ideally, these subspecialists would be comfortable and adept at treating adolescents and emerging adults during the transition of care.

The management of T1DM in the pediatric setting differs in many ways compared to diabetes care by adult providers. In general, pediatricians are not familiar with the needs and challenges of young adults and the adult providers are trained with a different perspective of diabetes management strategies and have dissimilar expectations. Furthermore, the psychosocial environment and expectations differ significantly in the two scenarios, and pediatric and adult providers have different perceptions of the transition process (7,8). In pediatrics, the adolescent and young adult with T1DM receive more support, accountability and supervision by the parents and/or guardian in the home environment as well as from the diabetes management team than what is provided in the adult medical system. This young adult then goes from a closely supervised, joint team approach to diabetes care, suddenly to that of independent and autonomous diabetes care with expectations for self-responsibility in diabetes management almost overnight. Moreover, some adolescents may have known their pediatric diabetes care team for years (even since diagnosis many times) and may be resistant to transitioning diabetes care to a new physician.

Emerging adults with T1DM are facing independent status in many areas of their lives, including diabetes and general health care, finances, living independently, and insurance changes. Many emerging adults are moving out to live on their own or with friends away from their family for the first time, and joining the workforce or continuing education. Young adults with T1DM have unique concerns compared to their compatriots and may be faced with concerns about medical insurance and coverage, including paying for prescriptions, diabetes supplies, and copays for office visits. These competing priorities often result in compromised and interrupted diabetes care and management during this vulnerable period in the life of an emerging adult with T1DM. Furthermore, one study looking at perceptions of emerging adults with T1DM about the transition period showed stress and anxiety regarding the matter, including lack of transition preparation by pediatric providers, vulnerability during the college years, and desire for more transition counseling, including preparation on the differences between pediatric and adult diabetes care, peer support for transition, and possibly adult clinic orientation opportunities (9).

Nearly 167,000 children had T1DM in 2009 according to the Center for Disease Control (CDC), with 18,000 youth under the age of 20 years being diagnosed annually (10). According to the SEARCH for Diabetes in Youth Study, T1DM prevalence increased between 2001 and 2009, with estimated prevalence in 2009 of 1.93 per 1,000 (95% CI, 1.88–1.97) (11). Adolescents and young adults with T1DM face many challenges throughout emerging adulthood (generally defined as the period between 18–30 years of age). Young adults with T1DM struggle with managing a chronic illness in addition to balancing work and school, living independently, and organizing finances and health insurance, often for the first time apart from their parents. The American Diabetes Association (ADA) Standards of Medical Care for 2017 recommends that health care providers and families should start preparing teens with diabetes to transition by early to mid-adolescence or at least for one year prior to the anticipated transfer to adult diabetes care (12).

Behavioral and economic factors affecting transition

There are several barriers obstructing the successful transition from pediatric to adult medical care. These barriers include reduced clinic visit frequency (13–16), increased HbA1c levels in some studies (17) but no change

in others (18-20), increased hospitalizations (20) and emergency department visits (21) among young adults with T1DM. Creating a systematic approach to transitioning emerging adults is essential to providing quality diabetes care and preventing development of acute and chronic complications of diabetes. The ADA Standards of Medical Care for 2017 recommends screening for diabetes-related distress, depression, anxiety, and eating disorders so they can be addressed (22).

Mental health disorders

Furthermore, mental health concerns are more common among young adults with diabetes than those without diabetes which is an important, yet often under-evaluated barrier (23,24). Adolescents with T1DM have increased rates of psychiatric disorder, as high as 47% at age 20 with an average duration of diabetes of 10 years in one study (24). Specifically, major depressive disorder was the most common disorder, while conduct disorder and generalized anxiety disorder were less common. A recent study found much higher prevalence of psychosocial illness among adolescents with T1DM compared to adolescents without diabetes (55.95% *vs.* 20%; $P < 0.0001$) (23), and in this population there was increased prevalence of psychosocial illness in patients with worse glycemic control ($HbA1c > 7.5\%$, $P = 0.014$) (23). Screening for mental health disorders including depression, anxiety, diabetes distress, and disordered eating, should be a routine part of diabetes care visits due to the increased prevalence of these conditions among young adults with diabetes and the effect of these mental health conditions on diabetes care and management. In addition to screening for diabetes related distress, it is important to provide support for emerging adults with T1DM whom experience ordinary stressors of young adulthood (school, family, social life) which they share with their non-diabetic counterparts, in addition to stress related to coping with and managing diabetes (25). Depression and anxiety have been identified as risk factor for decreased adherence to diabetes care, higher HbA1c (26), and increased morbidity and mortality in patients with diabetes (27).

Substance use

Similar to emerging adults without diabetes, substance use is common among adolescents and young adults with T1DM (28). High-risk alcohol use was found in 12.9% of

14–19-year old subjects with T1DM in Brazil. There was no significant gender difference among this age group, while higher rates of high-risk alcohol use were seen in older age groups with males having greater high-risk use than females (29). Emerging adults with T1DM should be counseled of effects of alcohol on glucose and risk for hypoglycemia unawareness and delayed hypoglycemia (30,31). Among patients with diabetes, tobacco use is an independent modifiable risk factor for both development and progression of cardiovascular disease, including stroke and myocardial infarction, neuropathy, microalbuminuria and renal impairment (32). Illicit drug use has been found to be a risk factor for non-adherence (33) and diabetic ketoacidosis (DKA) (33,34). There is limited literature on illicit drug use among T1DM young adults. One anonymous survey study among subjects aged 16–30 years in the United Kingdom found that 29% of respondents admitted to some kind of illicit drug use, with marijuana use most prevalent followed by cocaine, amphetamine, and ecstasy use (35). Importantly, street drug use can impact diabetes management and in this study 28% admitted to being aware that the drug use could affect their diabetes management, including reported cases of severe hypoglycemia and DKA. When evaluate a patient with poor glycemic control, alcohol and illicit drug use should be inquired about (35). Data on adolescents with diabetes mellitus in the United States reports a similar prevalence of recreational drug use (up to 25% of patients aged 12–20 years) (36). There is one published case report of a 41-year old man in Turkey with T1DM and pulmonary mucormycosis infection stemming from chronic tobacco and heroin inhalational use (37).

Disordered eating and insulin restriction

There is increased frequency of disordered eating and insulin restriction among adolescents and young adults with T1DM compared to their peers without diabetes. Disordered eating is defined as intentional purging such as vomiting, use of laxatives, preoccupation with weight, dissatisfaction with body image, intrusive thoughts about weight loss and food. Disordered eating and frank eating disorders are more common among young adults with diabetes compared to young adults without diabetes (38,39). Furthermore, among patients with T1DM, intentionally withholding insulin can be a form of purging. Up to 1/3 of females with T1DM and 1 in 6 males with T1DM report disordered eating, while up to 3% of females with T1DM reported intentionally restricting insulin to lose weight.

Disordered eating and insulin restriction may be more common among patients with longer durations and earlier diagnoses of diabetes than those diagnosed later in life (38), which increases the risk of development of complications of diabetes over time among this patient population. A German study found that usual eating disorder screening tools are less sensitive for detecting eating disorders among adolescents with T1DM compared to a diabetes specific screening tool which specifically asks about intentional withholding of insulin (39). Several studies have shown higher A1c values among adolescents and young adults with T1DM compared to those patients with T1DM who do not report disordered eating (38,40). Furthermore, BMI has not been found to be statistically different among those young adults with T1DM who report disordered eating and those who do not (40). Factors that predict eating disorders among adolescents with T1DM include desire for a lower weight, increased anxiety and lower diabetes related quality of life (41).

As discussed, there is a higher prevalence of psychologic challenges face young adults with diabetes including diabetes distress, depression, anxiety, and fear in general. Furthermore, the alcohol and tobacco use among the T1DM population has been found in several studies to be similar to that of young adults without T1DM (42,43). High risk behavior such as alcohol, drug, and tobacco use further complicate the transitional period. Similarly, young adults with T1DM are just as likely to engage in sexual behavior which many pediatric providers may not feel comfortable addressing.

Sexual health and preconception planning

Preconception planning is an important topic to be stressed to adolescents and young woman with T1DM. The ADA recommends preconception planning be discussed with all women with T1DM starting at puberty (preconception care of women with diabetes) (44). Among teens with diabetes, less than 50% had discussed contraception with a health care professional, and nearly 1/3 did not feel comfortable addressing the topic on their own (45). Nearly 2/3 of emerging adults with diabetes aged 16–20 years reported that they were not aware of the need for preconception planning and 75% were not aware of the maternal and fetal risks of hyperglycemia (46).

Diabetes complications

The transition period is a vulnerable time for young adults

with diabetes for many reasons including gaps in medical care, associated mental health and substance use disorders, and occasionally the start of chronic complications of diabetes. A large study by Dabelea and colleagues of over 1,700 adolescents and young adults with T1DM diagnosed prior to the age of 20 (average age 17.9 years) in the United States found that 32% had evidence of at least one early diabetes-related complication or comorbidity including nephropathy, retinopathy, arterial stiffness, neuropathy, hypertension, and cardiovascular autonomic neuropathy (47). A study in the United Kingdom of adolescents and young adults with T1DM aged 16–25 showed decreased rates of screening for diabetes complications and increased rates of diabetes complications in the transition group (48). Teens and young adults with T1DM may be missing clinic appointments and opportunities for complications screening and prevention.

Economic instability and healthcare coverage

Lack of financial resources and access to adequate health care coverage continues to be one of the most significant barriers to health care transition for the emerging adult population. Changes in legal status and living situation that often occur in early adulthood impact the ability to secure and maintain insurance. Young adults living the United States have been found to be two times more likely to be uninsured than any other cohort in the population (49). Although insurance coverage accessibility has increased in recent years with the passage of the Affordable Care Act (ACA), many young adults will experience a period in which they are un- or under-insured (49,50).

Medicaid eligibility varies and remains limited in some states, especially for those who are working. Not all individuals are eligible or offered health insurance through their employers. Those individuals who may have the option of enrolling in employer-sponsored health insurance may not be able to afford monthly premiums.

Individuals who may be eligible for insurance coverage through the ACA may have difficulty navigating the application process or may find the coverage plans too expensive (51). Lastly, the cost of insulin has steadily risen over the last five years and some of the most commonly used insulin brands have increased in wholesale price by more than 160%. Many insurance plans have high deductibles increasing out of pocket costs to consumers in addition to the monthly premiums (52).

With emerging adulthood often comes financial

independence from parents. Young adults may not have the financial support or insurance coverage through their parents that they had when they were younger. Due to high out of pocket costs and co-pays, some individuals may be forced to switch to less optimal modes of insulin or may be less adherent to diabetes care to make medications last (53). Lack of adequate insurance has also been found to be associated with increased emergency department use and lack of routine care (54).

Transition program overview

Due to the strong need for a proactive approach to transition at our institution, we started with a transition program for our T1DM patients in 2014 by liaising one of the adult endocrinologists in the academic medical center. This was conceptualized based on challenges elaborated above that are faced by these young adults. A quality improvement approach to implementation was utilized and required the multi-disciplinary team to meet bi-weekly over a 6-month period. An imperative aspect of this process was obtaining “buy-in” from all disciplines of the diabetes team to provide support in the varying aspects involved in the preparation for transition. Studies have shown that pediatric provider attitudes and confidence toward adult medical care can impact transition outcomes (55-57). During the planning period, literature from Got Transition/Center for Health Care Transition Improvement and the U.S. Department of Health and Human Services’ National Diabetes Education Program Transition Check list was reviewed (58). Specifically, planning meetings focused on the Six Core Elements of Health Care Transition 2.0 as outlined by Got Transition which is consistent with the American Academy of Pediatrics/American Association of Family Practitioners/American College of Physicians (AAP/AAFP/ACP) Clinical Report on Health Care Transition (59). The Endocrine Society resources on diabetes transition were also used in the planning process (60).

The multi-disciplinary team created a transition policy outlining the goal of successfully transitioning patients to an adult endocrinology provider between the ages of 18 to 22. This policy has been maintained throughout the life of the transition program. The policy included the following provisions: The provider team will discuss the endocrinology transition policy with patients and families beginning at age 14. At age 16, providers begin documenting discussion of specific transition topics on a transition checklist within the electronic medical record

(EMR). The flow sheet included a suggested timeline and transition topics for providers to review. Upon completion, the provider can note the date, topic discussed, and any comments regarding the discussion. The flow sheet included a section to refer the patient into the transition clinic when the provider deemed the patient was approaching readiness to transition. Next, the diabetes transition program coordinator was notified and contacted the patient to schedule an appointment within the transition clinic.

Patients involved in transition program had their care coordinated by a team of providers including an adult endocrinologist from a large academic medical center, a transition coordinator, diabetes nurse educators, registered dietitians, and social workers who specialize in young adults with diabetes. The purpose of the clinic was for diabetes team members to assist teens and young adults to transition successfully from pediatric to adult diabetes care with the goal of patients being confident and prepared for the transition. Enrollment criteria for the transition clinic were that patients are 18 years or older, had been diagnosed with diabetes for at least 12 months, and had been linked with a pediatric endocrinologist. The age of 18 was identified due to the legal age of consent and the fact that there are many patients 18 years of age and older seen by pediatric endocrinologists at our institution. It was expected that the patient had at least two visits with the transition team prior to full transfer of care to an adult provider. Following the last transition visit, our diabetes care coordinator assisted with the transfer of care.

Over the course of the patient’s time within the transition clinic, the transition clinic social worker completed a full psychosocial assessment to identify patient strengths and challenges. The social worker also identified the level of need for decision-making supports for youth with intellectual challenges and made referrals to legal resources. A packet of educational handouts and resources was provided to each patient and reviewed during clinic visits. The packet included information on topics such as medical alert identification, diabetes and reproductive health, healthy relationships, foot care, mental health, insurance, diabetes in the work place, alcohol use, managing diabetes prescriptions and supplies, to advanced directives. The patient also completed the Transition Readiness Assessment for Young Adult derived from the Got Transition.org website (59). Goals and prioritized actions were identified in collaboration with the young adult, the transition team, and often parents/caregivers. The social worker also placed significant emphasis on education and planning surrounding insurance obtainment

and maintenance as well as access to diabetes prescriptions and supplies. A financial counselor employed by the hospital was consulted to assist with Medicaid and Hospital Assistance applications when needed. Mental health including eating disorder and substance use resources were given and referrals were made for individuals who identified a need for additional support.

Patients met with the transition program adult endocrinologist who came weekly to the pediatric setting for the transition clinic. Patients experienced visits with an adult endocrinologist and were often requested to meet with the provider alone if parents or guardians were present. This was an important part of the program to highlight as previous research has found that patients prefer to meet the adult endocrinologist and adult team members prior to the transition (61,62). Many patients chose to continue to follow with the transition endocrinologist into her adult practice thus providing the first few visits within the same pediatric system that the patient is familiar. A small portion of patients requested to transition to a provider within the vicinity of their home. The adult endocrinologist provided anticipatory guidance, transition education, and identified any diabetes management and education needs which needed addressed before the transition to the adult care setting. Transition dietitians and diabetes nurse educators were consulted as needed.

The transition coordinator met with patients to identify a plan for transition to adult care by the review of adult provider options that were within the location preferences of the patient and accepted the patient's insurance plan. Once an adult provider was identified, the transition coordinator sent referrals and records to the adult endocrinologist office as well as primary care providers and other specialists, such as gynecologists or ophthalmologists, as needed. The transition coordinator communicated with the referral source and kept record of the initial scheduled appointment. The transition coordinator made attempts to follow-up with the patient and referral source to ensure that the patient had successfully established care in the adult setting. If barriers to attending the appointment were identified, the transition social worker was consulted to assist with mitigating barriers such as transportation difficulties and change in insurance status.

Transition program patient characteristics

Since the transition clinic was established at a large free standing children's hospital, unpublished data has been and

continues to be collected. Thus far, we have seen 128 unique patients; of those 114 have the diagnosis of T1DM with the remaining 14 having type 2 diabetes mellitus. Of which 63 patients are male and 51 have been female. The average age of the patients in the transition clinic is 21.8 ± 1.6 years. On average, these patients attended the clinic for 3–4 visits prior to transitioning to adult care. The clinic had a 21% no-show rate to scheduled appointments. Of note, the attendance metrics may have been skewed due to a small number of patients who did not show frequently to clinic appointments or attended the clinic for six or more visits prior to transition due to the need for additional transition education and support. We found that characteristics among this emerging adult cohort are consistent with that in the literature. Although patients are closely followed by the transition clinic team, clinic appointment attendance continues to be a challenge and illustrates that perhaps transition education needs to begin at a younger age and have an increased focus within the pediatric clinic prior to enrollment in the transition clinic.

According to the ADA, the recommended target A1c level is less than 7% for adults with diabetes (63). The average A1c among patients with T1DM seen in the transition clinic was $9.2\% \pm 2.3\%$. This aligns with previous research completed through the T1D Exchange which found the average A1c among adolescents and young adults to be 9% (64) and highlights the importance of continued research on mitigating barriers to diabetes self-care among this population.

Summary of experiential learning

The two-year period since the establishment of the T1DM young adult transition program has provided confirmatory information as well as new perspectives regarding the transition from the pediatric to adult care setting.

- ❖ Consistent with previous literature, emerging adults with T1DM have varying competing demands and priorities, including starting a family, changes of insurance from their family to workforce, gaps in care due to this loss of insurance, and difficulty with finances to cover copays and supplies. Loss of insurance coverage delayed transition for some patients as well as caused some patients to 'boomerang' back to pediatric care prior to attending their first appointment outside of the pediatric establishment. Furthermore, young adults are often beginning undergraduate programs or jobs in which taking time off is difficult. These priorities and stresses are not

unique to the individual with T1DM. During this time, concerns arise about diabetes care in general, fear of hypoglycemia, and diagnosis or progression of long-term complications of diabetes (5).

- ❖ Emerging adults with T1DM often move and change living situations frequently. Their contact information at the diabetes care team provider office is not updated leading to gaps in medical care. This patient population tends to have a higher no-show rate or cancellation rate for appointments than other ages with T1DM. This often leads to running out of insulin and testing supplies and at times leading to unnecessary emergency department visits or hospitalizations for DKA. This was reflected within the “show rate” of the patients in our transition clinic program.
- ❖ There is a large overlap of psychosocial disease among young adults with T1DM. A team based approach with social work, psychology, counseling, psychiatry, and primary care in addition to the pediatric and adult diabetes care team is extremely beneficial.
- ❖ Assessing transition readiness with a questionnaire, such as the TRAQ (65) or the Transition Readiness Assessment for Young Adult derived from the Got Transition.org website (59) can be helpful as is assessing transition-specific diabetes skills using the provider assessment of patient skill set checklist provided by the Endocrine Society (66).
- ❖ Bringing part of the adult diabetes care team to the pediatric center has been helpful to allow the young adult to meet the adult provider in the familiar pediatric setting.
- ❖ We have developed a strong relationship with several adult primary care physicians to help facilitate health maintenance among this population. Many young adults seen in the clinic were still linked with their pediatrician or had not been seen by a primary care provider in a significant amount of time, requiring frequent linkage and referral to community primary care providers. Many of these young adults need preventative care, including up to date vaccinations, health maintenance screenings, discussion of contraception, and treatment for common mental health concerns.
- ❖ Emerging adults with T1DM often have questions about common concerns including alcohol and drug use, pregnancy planning, sexual dysfunction, and risk of type 1 diabetes in their offspring. They may often not even bring these topics up for discussion unless asked directly. However, once the subject is brought up, they often discuss these personal concerns eagerly and ask questions especially if they have not received education on such topics previously.
- ❖ Young adults with T1DM have varying degrees of independent care and familial involvement in their diabetes management. We have found that it is helpful to have accompanying parents or caregivers leave the room for parts of the visit. We encourage the emerging adult to start making appointments, refill prescriptions, and order diabetes supplies on their own. Straightforward and repeated education on how to do these basic tasks is necessary before transition to the adult medical setting.
- ❖ We have observed that it is extremely crucial to explain expectations for adult diabetes care clearly. Adult medical offices will often not discuss health information with a parent unless the patient signs a form allowing this. Similarly, many adult settings have strict attendance policies that could result in discharge of the patient from the adult practice and may differ from the often more ‘lax’ pediatric setting policies. It is helpful to establish a transition policy, thus encouraging providers, patients, and caregivers to begin thinking about and discussing the transition to adult care as well as beginning the gradual shift of responsibility. Transition education should begin in early adolescence so expectations for the process and skills needed for transition are clear. Structured and repeated education may be required.
- ❖ Consistent and robust administrative assistant support in addition to a transition coordinator is needed to track data, provide referrals, and provide timely follow-up following the patient’s last appointment in the pediatric practice.
- ❖ Only patients who decided to transition to the adult endocrinologist imbedded within the transition clinic could meet the adult provider prior to transition to adult care, thus not providing the same level of continuity of care for those individuals with their own adult provider compared to individuals that transitioned to the transition program adult provider.

Recommendations for future practice

Some practical and useful recommendations that may be initiated are listed below:

- ❖ Consider education programs for pediatric and adult diabetes providers on transitions of care.
- ❖ Consider meeting adult diabetes providers in your

community. It is helpful to provide a handoff of a transitioning patient's medical records. The Endocrine Society has a template clinical summary that can be completed to provide a synopsis of a transitioning patient's diabetes care (66).

- ❖ In order to prevent gaps in diabetes care, consider following up with the emerging adult after the transfer of care to ensure he or she scheduled an appointment, attended the visit, and plans to continue to see the adult diabetes provider.
- ❖ Collaborate with successful transition programs for other chronic diseases to learn from other practices and experiences.

The transition period from pediatric to adult medical care is a vulnerable time for emerging adults with chronic medical conditions. The transition period is challenging for patients as well as medical providers. Our experience in transitioning adolescents and young adults with T1DM both highlights the continued challenges facing the emerging adult population as well as provides some insight into beneficial methods and useful resources. The emerging adult population has unique needs that need to be met to achieve the best outcomes. Awareness and early initiation of a well-structured process for transition for ultimate transfer of care to an adult diabetes care team is essential. Longitudinal research is needed to determine how best to care for adolescents and young adults with chronic illnesses to further identify best practices and formulate guidelines for transition to adult medical care.

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Footnote

Conflicts of Interest: The authors have no conflicts of interest to declare.

References

1. Nathan DM. The diabetes control and complications trial/epidemiology of diabetes interventions and complications study at 30 years: overview. *Diabetes Care* 2014;37:9-16.
2. Wafa S, Nakhla M. Improving the Transition from Pediatric to Adult Diabetes Healthcare: A Literature Review. *Can J Diabetes* 2015;39:520-8.
3. Chu PY, Maslow GR, von Isenburg M, et al. Systematic Review of the Impact of Transition Interventions for Adolescents With Chronic Illness on Transfer From Pediatric to Adult Healthcare. *J Pediatr Nurs* 2015;30:e19-27.
4. Rachas A, Lefevre D, Meyer L, et al. Evaluating Continuity During Transfer to Adult Care: A Systematic Review. *Pediatrics* 2016;138:e20160256.
5. Peters A, Laffel L. Diabetes care for emerging adults: recommendations for transition from pediatric to adult diabetes care systems: a position statement of the American Diabetes Association, with representation by the American College of Osteopathic Family Physicians, the American Academy of Pediatrics, the American Association of Clinical Endocrinologists, the American Osteopathic Association, the Centers for Disease Control and Prevention, Children with Diabetes, The Endocrine Society, the International Society for Pediatric and Adolescent Diabetes, Juvenile Diabetes Research Foundation International, the National Diabetes Education Program, and the Pediatric Endocrine Society (formerly Lawson Wilkins Pediatric Endocrine Society). *Diabetes Care* 2011;34:2477-85.
6. Marathe PH, Gao HX, Close KL. American Diabetes Association Standards of Medical Care in Diabetes 2017. *J Diabetes* 2017;9:320-4.
7. Nakhla M, Bell LE, Wafa S, et al. Improving the transition from pediatric to adult diabetes care: the pediatric care provider's perspective in Quebec, Canada. *BMJ Open Diabetes Res Care* 2017;5:e000390.
8. Sonneveld HM, Strating MM, van Staa AL, et al. Gaps in transitional care: what are the perceptions of adolescents, parents and providers? *Child Care Health Dev* 2013;39:69-80.
9. Garvey KC, Beste MG, Luff D, et al. Experiences of health care transition voiced by young adults with type 1 diabetes: a qualitative study. *Adolesc Health Med Ther* 2014;5:191-8.
10. Center for Disease Control Diabetes Report Card. 2014. Available online: <https://www.cdc.gov/diabetes/pdfs/library/diabetesreportcard2014.pdf>
11. Dabelea D, Mayer-Davis EJ, Saydah S, et al. Prevalence of type 1 and type 2 diabetes among children and adolescents from 2001 to 2009. *JAMA* 2014;311:1778-86.
12. Standards of Medical Care in Diabetes-2017: Summary of Revisions. *Diabetes Care* 2017;40:S4-5.
13. Channon S, Smith V, Alcolado J, et al. Current methods of transfer of young people with type 1 diabetes to adult services. *Diabet Med* 2003;20:1034.
14. Garvey KC, Markowitz JT, Laffel LM. Transition to Adult

- Care for Youth with Type 1 Diabetes. *Current Diabetes Reports* 2012;12:533-41.
15. Garvey KC, Wolpert HA, Laffel LM, et al. Health care transition in young adults with type 1 diabetes: barriers to timely establishment of adult diabetes care. *Endocr Pract* 2013;19:946-52.
 16. Stanczyk J, Chobot A, Polanska J, et al. Patients with type 1 diabetes transition from pediatric to adult care in Poland—an example from Silesia. *International Journal of Diabetes in Developing Countries* 2014;34:224-8.
 17. Lotstein DS, Seid M, Klingensmith G, et al. Transition from pediatric to adult care for youth diagnosed with type 1 diabetes in adolescence. *Pediatrics* 2013;131:e1062-70.
 18. Kipps S, Bahu T, Ong K, et al. Current methods of transfer of young people with Type 1 diabetes to adult services. *Diabet Med* 2002;19:649-54.
 19. Lane JT, Ferguson A, Hall J, et al. Glycemic control over 3 years in a young adult clinic for patients with type 1 diabetes. *Diabetes Res Clin Pract* 2007;78:385-91.
 20. Nakhla M, Daneman D, To T, et al. Transition to adult care for youths with diabetes mellitus: findings from a Universal Health Care System. *Pediatrics* 2009;124:e1134-41.
 21. Pyatak EA, Sequeira PA, Whittemore R, et al. Challenges contributing to disrupted transition from paediatric to adult diabetes care in young adults with type 1 diabetes. *Diabet Med* 2014;31:1615-24.
 22. Association AD. Standards of Medical Care in Diabetes. *Diabetes Care* 2017;40:S4-S5.
 23. Khandelwal S, Sengar GS, Sharma M, et al. Psychosocial Illness in Children with Type 1 Diabetes Mellitus: Prevalence, Pattern and Risk Factors. *J Clin Diagn Res* 2016;10:SC05-SC08.
 24. Kovacs M, Goldston D, Obrosky DS, et al. Psychiatric disorders in youths with IDDM: rates and risk factors. *Diabetes Care* 1997;20:36-44.
 25. Chao AM, Minges KE, Park C, et al. General Life and Diabetes-Related Stressors in Early Adolescents With Type 1 Diabetes. *J Pediatr Health Care* 2016;30:133-42.
 26. Herzer M, Hood KK. Anxiety symptoms in adolescents with type 1 diabetes: association with blood glucose monitoring and glycemic control. *J Pediatr Psychol* 2010;35:415-25.
 27. Lustman PJ, Anderson RJ, Freedland KE, et al. Depression and poor glycemic control: a meta-analytic review of the literature. *Diabetes Care* 2000;23:934-42.
 28. Martinez-Aguayo A, Aranedo JC, Fernandez D, et al. Tobacco, alcohol, and illicit drug use in adolescents with diabetes mellitus. *Pediatr Diabetes* 2007;8:265-71.
 29. Knychala MA, Jorge ML, Muniz CK, et al. High-risk alcohol use and anxiety and depression symptoms in adolescents and adults with type 1 diabetes mellitus: a cross-sectional study. *Diabetol Metab Syndr* 2015;7:24.
 30. Kerr D, Macdonald IA, Heller SR, et al. Alcohol causes hypoglycaemic unawareness in healthy volunteers and patients with Type 1 (insulin-dependent) diabetes. *Diabetologia* 1990;33:216-21.
 31. Lange J, Arends J, Willms B. Alcohol-induced hypoglycemia in type I diabetic patients. *Med Klin (Munich)* 1991;86:551-4.
 32. Haire-Joshu D, Glasgow RE, Tibbs TL. Smoking and diabetes. *Diabetes Care* 1999;22:1887-98.
 33. Umpierrez GE, Kelly JP, Navarrete JE, et al. Hyperglycemic crises in urban blacks. *Arch Intern Med* 1997;157:669-75.
 34. Warner EA, Greene GS, Buchsbaum MS, et al. Diabetic ketoacidosis associated with cocaine use. *Arch Intern Med* 1998;158:1799-802.
 35. Ng RS, Darko DA, Hillson RM. Street drug use among young patients with Type 1 diabetes in the UK. *Diabet Med* 2004;21:295-6.
 36. Glasgow AM, Tynan D, Schwartz R, et al. Alcohol and drug use in teenagers with diabetes mellitus. *J Adolesc Health* 1991;12:11-4.
 37. Kebapci N, Efe B, Alataş F, et al. Pulmonary multinodular mucormycosis in Type 1 diabetic patient with diabetic ketoacidosis. *Journal of Endocrinological Investigation* 2007;30:247-52.
 38. Bächle C, Stahl-Pehe A, Rosenbauer J. Disordered eating and insulin restriction in youths receiving intensified insulin treatment: Results from a nationwide population-based study. *International Journal of Eating Disorders* 2016;49:191-6.
 39. Hevelke LK, Albrecht C, Busse-Widmann P, et al. Prevalence of Disturbed Eating Behavior in Children and Adolescents with Type 1 Diabetes: Assessment and Comparison to Healthy Peers--Results of a Multicenter Questionnaire-based Study. *Psychother Psychosom Med Psychol* 2016;66:128-35.
 40. Quinn SM, Ambrosino JM, Doyle EA, et al. Utility of psychological screening of young adults with type 1 diabetes transitioning to adult providers. *Endocr Pract* 2016;22:1104-10.
 41. Gonçalves S, Barros V, Rui Gomes A. Eating-Disordered Behaviour in Adolescents with Type 1 Diabetes. *Canadian Journal of Diabetes* 2016;40:152-7.
 42. Reynolds K, Liese AD, Anderson AM, et al. Prevalence of tobacco use and association between cardiometabolic risk

- factors and cigarette smoking in youth with type 1 or type 2 diabetes mellitus. *J Pediatr* 2011;158:594-601.e1.
43. Scott LJ, Warram JH, Hanna LS, et al. A Nonlinear Effect of Hyperglycemia and Current Cigarette Smoking Are Major Determinants of the Onset of Microalbuminuria in Type 1 Diabetes. *Diabetes* 2001;50:2842-9.
 44. Kendrick JM. Preconception care of women with diabetes. *Journal of Perinatal & Neonatal Nursing* 2004;18:14-25.
 45. Schwarz EB, Sobota M, Charron-Prochownik D. Perceived access to contraception among adolescents with diabetes: barriers to preventing pregnancy complications. *Diabetes Educ* 2010;36:489-94.
 46. Charron-Prochownik D, Sereika SM, Wang SL, et al. Reproductive health and preconception counseling awareness in adolescents with diabetes: what they don't know can hurt them. *Diabetes Educ* 2006;32:235-42.
 47. Dabelea D, Stafford JM, Mayer-Davis EJ, et al. Association of Type 1 Diabetes vs Type 2 Diabetes Diagnosed During Childhood and Adolescence With Complications During Teenage Years and Young Adulthood. *JAMA* 2017;317:825-35.
 48. Wills CJ, Scott A, Swift PG, et al. Retrospective review of care and outcomes in young adults with type 1 diabetes. *BMJ* 2003;327:260-1.
 49. Adams SH, Newacheck PW, Park MJ, et al. Health insurance across vulnerable ages: patterns and disparities from adolescence to the early 30s. *Pediatrics* 2007;119:e1033-9.
 50. Irwin CE Jr. Young adults are worse off than adolescents. *J Adolesc Health* 2010;46:405-6.
 51. The Kaiser Commission on Medicaid and the Uninsured. Key Facts about the Uninsured Population 2016. Available online: <http://files.kff.org/attachment/Fact-Sheet-Key-Facts-about-the-Uninsured-Population>
 52. Tsai A. The rising cost of insulin: why the price of this lifesaving drug is reaching new heights. *Diabetes Forecast* 2016;69:32-7.
 53. McBrien KA, Naugler C, Ivers N, et al. Barriers to care in patients with diabetes and poor glycemic control—A cross-sectional survey. *PLoS One* 2017;12:e0176135.
 54. Callahan ST, Cooper WO. Changes in Ambulatory Health Care Use During the Transition to Young Adulthood. *J Adolesc Health* 2010;46:407-13.
 55. Telfair J, Alexander LR, Loosier PS, et al. Providers' perspectives and beliefs regarding transition to adult care for adolescents with sickle cell disease. *J Health Care Poor Underserved* 2004;15:443-61.
 56. Ishizaki Y, Maru M, Higashino H, et al. The transition of adult patients with childhood-onset chronic diseases from pediatric to adult healthcare systems: a survey of the perceptions of Japanese pediatricians and child health nurses. *Biopsychosoc Med* 2012;6:8.
 57. Iannelli-Madigan G. Transitioning the adolescent with type 1 diabetes mellitus. *J Pediatr Nurs* 2012;27:602-4.
 58. The National Institute of Diabetes and Digestive and Kidney Diseases. Pediatric to Adult Diabetes Care: Transition Planning Checklist. 2014. Available online: <https://www.niddk.nih.gov/>, accessed June 7 2017.
 59. The National Alliance to Advance Adolescent Health. Got Transition Six Core Elements of Health Care Transition. 2014-2017. Available online: <http://www.gottransition.org/>
 60. Endocrine Society. Managing the Transition of Care for Patients with Type 1 Diabetes. 2017. Available online: <http://www.endocrinetransitions.org/type-1-diabetes/>, accessed 8/5/2017.
 61. Moons P, Pinxten S, Dedroog D, et al. Expectations and experiences of adolescents with congenital heart disease on being transferred from pediatric cardiology to an adult congenital heart disease program. *J Adolesc Health* 2009;44:316-22.
 62. Tuchman LK, Slap GB, Britto MT. Transition to adult care: experiences and expectations of adolescents with a chronic illness. *Child Care Health Dev* 2008;34:557-63.
 63. American Diabetes Association. Glycemic Targets. *Diabetes Care* 2017;40:S48-56.
 64. Miller KM, Foster NC, Beck RW, et al. Current state of type 1 diabetes treatment in the U.S.: updated data from the T1D Exchange clinic registry. *Diabetes Care* 2015;38:971-8.
 65. Sawicki GS, Lukens-Bull K, Yin X, et al. Measuring the transition readiness of youth with special healthcare needs: validation of the TRAQ—Transition Readiness Assessment Questionnaire. *J Pediatr Psychol* 2011;36:160-71.
 66. Society E. Managing the Transition of Care for Patients with Type 1 Diabetes: Provider Assessment of Patient Skillset. 2017. Available online: <http://www.endocrinetransitions.org/type-1-diabetes/>, accessed 08/05/2017.

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