



A Practice in Maturation: Current Perspectives on the Transition from Pediatric to Adult Care for Young Adults with Diabetes

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Abstract

Purpose of Review This review of available literature and resources highlights the challenges in transition from pediatric to adult care for young adults with diabetes, summarizes practical recommendations for facilitating the process, and identifies areas for improvement in current transition practice.

Recent Findings Observational studies highlight suboptimal transition preparation counseling, gaps between pediatric and adult care, and increased post-transition hemoglobin A1c and acute care utilization. Studies showing improved outcomes with later age at transition allows for an extended focus on transition preparation with an eye toward developmental maturity. Interventional studies suggest varying benefits of transition coordinators and support programs.

Summary The period of transition from pediatric to adult care is a time of in which patients are at high risk for adverse outcomes and loss to follow-up; however, careful attention to planning the process and tracking patient readiness along with skilled care coordination can contribute to transition success. The durability of interventional models, as well as generalizability to varied clinical settings, must be further tested.

Keywords Diabetes · Transition of care · Young adult · Emerging adult

Introduction

As adolescents with diabetes move into young adulthood, they must assume responsibility for day-to-day diabetes self-management as well as the logistical aspects of diabetes care. At the same time, patients in this population must eventually transition from pediatric to adult diabetes care providers. In the setting of decreased parental support and competing life demands, the pediatric to adult care transition can increase the risk of fragmentation of care and adverse clinical outcomes.

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Over the last decade, the transition from pediatric to adult care for young adults with diabetes has been widely recognized as a critical moment in the healthcare experience that can have longstanding consequences for future health.

Observational studies have demonstrated that young adults at the age of transition remain vulnerable to emergency care, hospitalization, complications, and worsening glycemic control. In addition, whereas the majority of work on transition of care in diabetes has been focused on the type 1 diabetes population, young adults with type 2 diabetes remain a population in need and perhaps even more susceptible to health consequences of interrupted care [1••].

The goal of health care transition is to provide developmentally appropriate health services in an uninterrupted manner. Consensus recommendations from the American Academy of Pediatrics (AAP), the American Diabetes Association (ADA), and the International Society of Pediatric and Adolescent Diabetes (ISPAD) highlight the importance of transition preparation and well-coordinated transfer from pediatric to adult care settings [2–4]. However, despite the years elapsed since initial publication of transition guidelines, substantial gaps remain between expert recommendation and implementation in practice.

As a result, it is incumbent on healthcare providers and health services researchers working in this area to create, hone, and evaluate methods for ensuring successful transitions from pediatric to adult care that are adaptable to diverse care settings. The purpose of this review is to summarize the challenges in caring for young adults with diabetes making the transition from pediatric to adult care, to explore practical recommendations for purposeful transition and potential interventions, and to identify opportunities for further maturation in the practice of transition.

Developmental Context and Adverse Young Adult Outcomes

The period of transition from pediatric to adult care occurs during a vulnerable and critical time in development. Seminal literature in psychology by J.J. Arnett describes the ages from 18 to 30 years as a period of “emerging adulthood” characterized by change, exploration, and the development of behavioral patterns that lay the foundation for future adulthood. According to Arnett’s framework, which is valuable in contextualizing the experience of young adults with diabetes, early emerging adulthood (ages 18–24 years) is characterized by competing educational, social, and economic demands and difficulty accepting responsibility; in this phase, there is a considerable mismatch between developmental maturity and the expectations of health care providers. In the later emerging adulthood phase (ages 25–30 years), individuals assume more traditional adult roles and are more optimally ready to self-manage all aspects of care; however, transition to the adult care setting often occurs before this stage [5, 6].

Given the challenge of managing diabetes amidst the competing demands of early adulthood, it is not surprising that glycemic control outcomes are suboptimal. In a 2015 report from the US Type 1 Diabetes Exchange Clinic Registry, 13% of 2867 young adults (18–25 years) in US T1D Exchange met the ADA hemoglobin A1c target < 7%, with peak hemoglobin A1c > 9% at age 19 years; further, glycemic control trajectories were worse in a recently published update [7, 8]. In addition, longitudinal analyses from SEARCH cohorts indicated that poor glycemic control in adolescence is a strong predictor of poor glycemic control in adulthood for both type 1 diabetes and type 2 diabetes [10, 9]. This highlights the critical importance of interventions to improve glycemic control and increase patient engagement and adherence prior to transition.

Importantly, transition of care also occurs during the period in which many young adults are vulnerable to the early microvascular and macrovascular complications of diabetes, including microalbuminuria, neuropathy, and early pathologic changes associated with coronary artery disease [3, 10]. A

2017 study of young adults with diabetes diagnosed before the age of 20 found that 72% of those with type 2 diabetes and 32% of those with type 1 diabetes had evidence of at least one diabetes-related complication or comorbidity [10]. Young adults with type 2 diabetes are at high risk for developing additional conditions associated with obesity such as hepatic steatosis, sleep apnea, hypertension, dyslipidemia, PCOS, and orthopedic complications [11].

In addition, diabetes management, diabetes-related distress, increased life demands and personal stress, and the known increase in risk-taking behavior in emerging adulthood all increase susceptibility to comorbid mental health diagnoses that interfere with glycemic control such as depression, anxiety, eating disorders, and substance abuse [12–16]. A recent systemic literature review of DKA prevalence in adults highlighted that young adults aged 18–25 were at highest risk of DKA. In fact, when reported instances of DKA were stratified by age, young adults in this age range demonstrated an increased risk of DKA nearly 2.5 times that of elderly adults (> 65 years), with an overall trend suggesting declining rates of DKA with increasing age in adulthood [17]. Adding to the urgency of continuity of care, young women during this period are at high risk for pregnancy and pregnancy-related complications and adverse outcomes [3, 18].

In terms of utilization, studies have demonstrated declining diabetes clinic attendance rates after transition to adult care [19, 20]. Gaps greater than 6 months between pediatric and adult care have been noted in several studies to occur in as much as 21–34% of cases, with gaps occurring less frequently in patients who had regular pediatric visits in the year prior to transition [21, 22, 23, 24]. In terms of inpatient visits, a large Canadian analysis showed a significant increase in diabetes-related hospitalizations in the 2 years after transition to adult care [25].

Given the vulnerability of young adults at the time of transition, careful attention to fostering commitment to continuity diabetes care in young adult patients is of utmost importance to both pediatric and adult providers across transfer.

Barriers to Effective Transition and Areas for Improvement

Multiple studies have sought to address barriers to effective transition to adult care. One of the first papers by Reiss et al. in 2002 revealed key challenges associated with transition of care from the perspective of patients, caregivers, and providers amongst a general population with chronic illness including loss of life-long relationship with pediatric providers, insurance changes, fear that care quality will decline with adult providers, and unease over the role to be played by patient families/caregivers in adult care [26]. Qualitative studies of patients with diabetes and their families echo these themes,

particularly regarding attachment between pediatric providers and patients, and identify additional concerns about the different culture in adult practices [27, 28]. Patients and their families have expressed perceptions of a less friendly atmosphere in adult care, as well as increased focus on glycemic control and microvascular complications and increased exposure to older adults with diabetes complications (e.g., in the waiting room) [24, 27, 29]. Providers agree that this cultural difference between adult systems and pediatrics may be a potential challenge in the transition process [30, 31]. In addition, in survey analyses, both pediatric and adult providers have endorsed logistic difficulties with transition care coordination involving the transfer of medical records and communication between transferring pediatric and receiving adult providers [30–32].

Lack of consensus on the appropriate timing of referral to adult care further complicates provider ability to facilitate purposeful transition. A number of countries have a mandated transition age of 18 years. In the USA, there is currently no universally enforced transition age and available data suggest a mean age of transition between 19 and 21 years [9, 24]. Studies looking at outcomes such as glycemic control suggest that young adults may experience better control when cared for in pediatric settings through later emerging adulthood, perhaps related to developmental maturity. An analysis of data from 185 patients with type 1 diabetes in the SEARCH for Diabetes in Youth study found a 2.5 higher odds of poor glycemic control in the 57% of young adults who transitioned to adult care during the study period versus those that remained in pediatric care [9]. Helgeson reported similar findings in a study of 118 young adults in their last year of high school and 1 year later, in which those who remained in pediatric care displayed better glycemic control [33]. Data from the SEARCH for Diabetes in Youth study assessing a type 2 population aged 18–25 found a 4.5 higher odds of worsening glycemic control in the 57% of 185 participants analyzed who moved from adult care. Interestingly, the 17% of patients who were lost to care after pediatric care, mostly due to lack of health insurance, had a similarly 4.6 higher odds of worse glycemic control controlling for sociodemographics and baseline characteristics [1••]. In all of these studies, worse baseline glycemic control again portended worse follow-up control.

The reason why glycemic control may worsen from transition to pediatric care remains unclear; possible factors include natural disease progression (particularly in the case of type 2 diabetes), loss of insurance, failure to keep up with the demands of diabetes amongst a challenging period of development and growth, possible benefit of the team-based approach more typical of pediatric practices, or increased familial involvement/support in pediatric care. Fine tuning the right time for transition is a potential area for intervention in improving the transition process. An individualized approach is indicated, tailored to the developmental needs of the patient, but delay of transition until the early twenties may be

appropriate for many patients. Finally, transition preparation counseling is a critical area for improvement. Multiple studies suggest that some of the failure in transition care to date may be attributable to deficits in planning. Surveys of patients and providers have identified these deficiencies as lack of clear adult provider recommendations, absence of physician hand-off or transfer of records, insufficient discussion between patient and provider in promoting increased independence and in logistical preparations for actual transfer, and failure to track patients who do not complete transfer to adult care [19, 24, 28, 34, 35]. Consistent with these reports, two surveys of young adults assessing their transition of care experience showed that young adults who perceived better transition preparation were less likely to report a gap > 6 months in care and were more likely to feel satisfied with the transition process [25, 26].

The Process of Transition: Practical Roadmap for Improvement

The widely accepted definition for healthcare transition includes “the planned, purposeful movement of young adults from child-centered to adult-oriented health-care systems” [36]. Indeed, the process of transition requires a great degree of organization, coordination, and thoughtfulness for young adults with diabetes. Throughout this process, providers must keep in mind the competing demands on young adults with diabetes, create a clear role for families/sources of support, and be sensitive to the difficulty of leaving a trusted relationship with what is often a longstanding pediatric provider.

In addition to the aforementioned expert consensus guidelines from the AAP, ADA, and ISPAD, The US “Got Transition” initiative (www.gottransition.org/) provides recommendations and downloadable resources for transition of care focused around six core practice elements. These elements were developed for a general population but are easily applicable to transition of care in diabetes: establishing a clear transition policy, tracking progress in transition preparation, assessing transition readiness, planning for adult care, transferring, and integrating patients into adult practices [37•].

First, pediatric programs and practices should develop a clear transition policy following buy-in from providers, administrators, and patients/families based upon available resources, adequate time for transition planning, and keeping in mind patient developmental maturity. Regardless of when transition is recommended, professional societies agree that setting expectations is key in transition, and transition policies should be disseminated in early adolescence even as young as ages 12–14 to set the stage for future conversation. Subsequently, during adolescence, self-care and transition preparation skills should be intermittently assessed and progress tracked. The Endocrine Society has excellent resources

on their website, specific to type 1 diabetes, which providers and programs can use to assess and track patient mastery of skills related to diabetes management, healthcare logistics, and emergency care (<https://www.endocrine.org/guidelines-and-clinical-practice/transitions>) [38]. Providers should also establish a formal plan, ideally written, for patients and families highlighting the roles and responsibilities of patients, caregivers, and providers in preparing young adults for independence and transition. To this end, Got Transition recommends a transition registry with careful tracking of plan progression [37]. Some groups advocate a recognition of transition by creating a “graduation” from pediatric care certificate or other small ritual marking this rite of passage [28].

Once a young adult has been prepared adequately for transition, the actual process of transfer should take place. Again, while there is no formally agreed upon age for transition, as previously discussed, patients may benefit from transition in later emerging adulthood once they have more established patterns of behavior and independence. Also, since available evidence suggests an association between pre-existing glycemic control and future glycemic control, patients may not be ready for transfer during a period of significant glycemic turbulence [9]. Transfer should include a coordinated referral to a specific medical provider wherever possible, chosen with attention to personality fit, insurance issues, and geographic location. A complete medical summary should accompany the patient to adult care, samples of which are available through the Endocrine Society and Got Transition [37, 38]. Patients and providers also agree that direct pediatric to adult provider communication is ideal [30–32]. In particular, feedback from adult providers on whether transition has occurred will help identify any patients that have been lost to follow-up to reintegrate them into care [37]. This can also be monitored through a transition registry.

In addition to these more generalized recommendations, dedicated transition guidelines specific to type 1 diabetes transition have been published by the American Diabetes Association and the UK National Health Service [3, 39].

Overview of Transition Intervention Models

While guidelines on transition are in large part derived by expert consensus, a number of transition interventions for young adults with diabetes have been undertaken and analyzed to inform transition practice.

In April 2019, Spaic et al. published the first multicenter, randomized control trial of a transition of care intervention in Ontario, Canada. A total of 205 patients randomly assigned to an intervention and control group were seen for a total of three visits in pediatric care and three visits in adult care over 18 months and then observed without intervention for an

additional 12 months. The intervention group ($n = 104$) received assistance from a Certified Diabetes Educator serving as a “Transition Coordinator” for the first 18 months, including direct care coordination between pediatric and adult programs; communication with patients between visits via text, email, and phone (on average 17.6 contacts including reminders, insulin titration and sick day management between visits); accompaniment to visits; and facilitation of referrals to ancillary services such as mental health or nutrition. Patients in the intervention group also received written information about their new adult physician and clinic. The primary outcome was the proportion of patients who did not attend at least one of the two expected visits in the post-intervention 12-month follow-up visit. Secondary outcomes included mean HgbA1c, diabetes-related acute care utilization, patient satisfaction, and diabetes distress. Results during the intervention showed a significant increase in the number of visits attended (4.1 vs. 3.6; with 49% vs 26% perfect attendance), with improvement in satisfaction and reduced diabetes distress, but there was only a trend toward improvement in HgbA1c change from baseline. However, in the 12-month post-intervention follow-up period, there was no difference in the primary outcome of loss to follow-up and significant differences in secondary outcomes were not maintained [40]. The lack of sustained benefit, even with this intensive intervention featuring specialized nurse coordinators, underscores the challenges of the transition-age patient population. In the USA, a single-center, prospective, nonrandomized study assigned 81 young adults to usual care or enrollment in the “Let’s Empower and Prepare (LEAP)” program. LEAP is a structured diabetes program incorporating multiple components such as diabetes education, group classes, case management, and assignment to a young adult clinic. The results of this study suggested improved glycemic control and overall well-being and decreased hypoglycemia in the intervention versus control group, although the intended primary outcome of follow-up visits could not be ascertained due to data collection limitations [41].

In a randomized control trial at the Royal Children’s Hospital in Melbourne, Australia, 120 participants with DM1 aged 17–19 transitioning to one of eight adult providers in the city were randomly assigned to an intervention group versus usual care control. The intervention involved coordination of care through direct patient contact via telephone/text messages and appointment facilitation by a physician. The study showed no significant difference in the primary outcome of clinic attendance in the 12 months after transition to adult care; however, there was a significant difference in the secondary outcome of clinic attendance in the 12–24 months after transition (2.5 visits in the intervention versus 1.4 visits in the control group), with no effect on glycemic control [42].

The “Maestro Project” in Canada successfully used a systems navigator to ensure adherence to follow-up and

reengagement of patients previously lost to follow-up [34]. Other non-randomized studies of dedicated transition planning and care coordination suggest positive effects on glyce-mic control [34, 43–46].

A study of fifteen 18–30-year-old participants offered a monthly support group over 5 months at the Joslin Diabetes Center found that this intervention contributed to trends to-ward improved HgbA1c from baseline and decreased self-reports of diabetes burden [47]. Published models of clinical transition innovation in diabetes include dedicated young adult clinics and combined pediatric-adult visits prior to tran-sition with varying outcomes, perhaps related to disparities in the programs themselves or the patient populations [45, 48–51]. Whereas many transition interventions take place in

pediatric health systems, a retrospective report of on an adult-based transition program at the University of Pennsylvania revealed promising data on adherence to care and program satisfaction [52]. This model is certainly of interest, as much of the current transition research in diabetes has been under-taken from the perspective of pediatric care. To date, there have been no rigorous randomized control trials to validate the preferred transition of care model, which may also vary based on location and availability of services.

It is important to note that to date, there are no randomized transition intervention studies specifically addressing type 2 diabetes in the published literature. However, a retrospective cohort study analyzing encounter frequency of 26,496 adult patients with uncontrolled, mostly type 2 diabetes found that

Table 1 A summary of barriers to transition of care and potential interventions

Barriers to transition	Potential Interventions
Loss of relationship with pediatric provider	<ul style="list-style-type: none"> - Ensure adequate transition preparation to ensure not a sudden loss - Consider “graduation” certificate gifted from pediatric provider to adult provider or other small rite of passage ritual - Refer to a directed adult provider matched in preferred location, expertise, personality - Consider “warm hand off” if possible from pediatric to adult provider
Inadequate transition preparation	<p>Suggestions for pediatric programs:</p> <ul style="list-style-type: none"> - Set transition policy to share with patients in early adolescence - Create a transition registry or spreadsheet to track young adult progress - Assess transition readiness at least annually starting in mid-adolescence - Counsel patient to take-over aspects of diabetes management if previously managed by family members (i.e., get refills, schedule appointments) - Educate patients on self-care and diabetes emergency management - Prepare a written transition plan with patients and families - Draft a medical summary to be shared with adult providers - Make specific referral recommendations
Unclear role of family members/caregivers in adult care	<ul style="list-style-type: none"> - Set clear expectations of patient and family roles - Encourage involvement of support systems where possible
Insurance issues	<ul style="list-style-type: none"> - Ensure patient has appropriate insurance to be seen at suggested preferred adult provider, consider referral to hospital financial services if available
Perception of less-friendly attitude in adult care	<ul style="list-style-type: none"> - Set expectations with patients during the preparation process - Optimize of environment for young adults - Consider adult provider introductions - Involve care coordinator where resources allow - Allot a longer initial transition visit to “get to know patient” beyond medical history - Work to focus on whole patient rather than “numbers”
Transfer of medical records	<ul style="list-style-type: none"> - Create a medical summary to be transferred directly between providers, consider giving copy to patient to provide to adult provider as well - Ensure direct communication between pediatric and adult providers - Involve a care coordinator where resources allow
Decline in glycemic control prior to transition	<ul style="list-style-type: none"> - Delay transition of care until patient stabilized and underlying issues related to worsening of control can be addressed
High prevalence of mental health comorbidities	<ul style="list-style-type: none"> - Ensure screening for comorbid depression, anxiety, substance abuse - Co-manage with mental health providers where resources available - Consider use of “peer support” methods for young adults with diabetes
Prolonged gaps in outpatient care	<ul style="list-style-type: none"> - Create a transition registry to track patients - Feedback should be given from adult to pediatric providers when a scheduled transition patient successfully enters care or fails to transition
Competing demands of education, work, social life, and diabetes control	<ul style="list-style-type: none"> - Delay transition until patient able to best manage competing demands and in a stable position, i.e., until after college - Involve support of family, partner, friend in transition and adult care

patients with encounter frequency of 2 weeks to 1 month had a significantly faster time to achieving hemoglobin A1c targets, a fact that may be applied to future interventions should resources allow and further confirming the importance of engagement and regular visits in outpatient care [53].

Overall, intervention studies on transition of care for patients with diabetes have a number of limitations including lack of randomization, lack of generalizability, and often limited periods of follow-up. The vast number of observational studies suggest a trend toward improved outcomes, particularly with care coordination and direct patient support. Of note, while transition coordinators do appear to confer some degree of benefit in randomized and nonrandomized studies, the added cost of a care coordinator raises concerns about generalizability. A focus on a cost-effective, reproducible interventions across healthcare systems is warranted. Table 1 provides a summary of transition of care recommendations based upon review of the literature and professional guidelines.

Conclusion

The transition from pediatric to adult care for young adults with diabetes is a period in which patients are at high risk for the development of diabetes-related complications, worsening glycemic control, and loss to follow-up likely related to difficulty of balancing competing demands of emerging adulthood and diabetes management, as well as natural disease progression. However, it is also a time where healthcare providers have the opportunity to set young adults up for a lifetime of positive health behaviors and relationships with the healthcare system.

Transition care challenges as demonstrated in published literature include deficits in transition preparation counseling, gaps between pediatric and adult care and decreased follow-up rates, and increases in post-transition hemoglobin A1c and acute care utilization rates. Evaluations of the patient experience demonstrate that patients and providers would benefit from a thoughtful, purposeful, and empathetic transition process that fosters patient independence while setting clear expectations for the role of providers, patients, and loved ones. The transition to adult care should not be abrupt, but should follow a coordinated process of preparation and adjustment. Guiding patients to a specific adult provider or program can greatly diminish the fear of leaving a beloved longstanding pediatric provider. Logistic details such as clear written transfer summaries, direct provider to provider communication, and tracking patients to ensure transition has occurred can all work toward ensuring success of continued engagement in adult care. Intervention studies suggest that, where resources allow, the use of care coordination can enhance these processes and the patient experience. Further randomized studies may help to address additional models for transition

care that will be of most benefit to patients and accessible across a variety of health care systems and practice settings.

Overall, supporting patients through the transition from pediatric to adult care is a challenge wherein effort can lead to big rewards in patient outcomes. As we mature our practice in caring for patients, we likewise help our patients become self-efficacious adults.

Compliance with Ethical Standards

Conflict of Interest Courtney N. Sandler and Katharine C. Garvey declare that they have no conflict of interest.

Human and Animal Rights and Informed Consent Ethical Approval

All studies performed with Dr. Garvey as the author involving human participants were in accordance with the ethical standards of the institutional and/or national research committee and with the 1964 Helsinki declaration and its later amendments or comparable ethical standards.

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- Of major importance

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