

Type 1 diabetes: addressing the transition from pediatric to adult-oriented health care

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Abstract: Adolescents and young adults with type 1 diabetes are at risk for poor health outcomes, including poor glycemic control, acute and chronic complications, and emergency department admissions. During this developmental period, adolescent and young adult patients also experience significant changes in living situation, education, and/or health care delivery, including transferring from pediatric to adult health care. In recent years, professional and advocacy organizations have proposed expert guidelines to improve the process of preparation for and transition to adult-oriented health care. However, challenges remain and evidence-based practices for preparing youth for adult health care are still emerging. Qualitative research suggests that adolescent and young adult patients rely on health care providers to guide them through the transition process and appreciate a gradual approach to preparing for adult-oriented health care, keeping parents in supportive roles into young adulthood. Patients also benefit from specific referrals and contact information for adult care providers. Promising models of transition care include provision of transition navigators, attendance at a young adult bridge clinic, or joint visits with pediatric and adult care providers. However, much of this research is in its early stages, and more rigorous trials need to be conducted to evaluate health outcomes during transition into adult health care. The purpose of this review is to provide an overview of the transition process, patient and health care provider perceptions of transition care, and emerging evidence of successful models of care for engagement in adult-oriented health care. Recommendations and resources for health care providers are also presented.

Keywords: type 1 diabetes, transition to adult care, health care delivery, adolescents, young adults

Introduction

Type 1 diabetes is one of the most common chronic illnesses in childhood, affecting more than one out of every 500 youth.¹ As the modal age of diagnosis of type 1 diabetes is in middle childhood,² a growing number of adolescents and young adults are affected by type 1 diabetes, and they must simultaneously manage diabetes and navigate a complex health care system during a developmental period known for instability and uncertainty in education, employment, living situation, family and intimate relationships, and health care delivery.³ Recent policy statements and related efforts have attempted to increase support for youth during this challenging developmental period, primarily by improving the transition from pediatric to adult-oriented health care.^{4,5} However, challenges remain, and adolescents and young adults are at risk for poor glycemic control and other adverse health outcomes.⁶⁻⁹ Research suggests that only 20%–30% of late adolescents and young adults meet current recommendations

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for glycemic control.^{10,11} In addition, a significant percentage of adolescents and young adults experience acute and chronic complications,^{12–16} making continuous access to high-quality medical care exceedingly important for this age group.

This review provides a comprehensive, up-to-date overview of research on the transition to adult-oriented health care for youth with type 1 diabetes, highlighting patient and health care provider identification of transition needs, relevant risk factors that may influence outcomes related to transition, and current models of care that may facilitate successful transition to adult diabetes care. Additionally, we offer recommendations and resources for providers working with this age group and potential avenues for future intervention.

Challenges to diabetes management in adolescents and young adults

Management of type 1 diabetes during adolescence and young adulthood requires careful consideration of a number of physiologic, developmental, and health care system issues. This period is characterized by increasing independence and assumption of responsibility for most tasks of daily living, including disease care.³ In addition to potential adherence challenges related to decreased parental involvement in diabetes management, achievement of optimal metabolic control is also complicated by adolescent hormonal changes, leading to temporary increases in insulin resistance and related insulin requirements to maintain euglycemia.¹⁷ Longitudinal research suggests that hemoglobin A1c (A1c) levels begin to rise at age 10, concurrent with the onset of puberty and bodily growth. Although A1c values are variable depending on psychosocial, socioeconomic, and individual considerations,¹⁸ representative research suggests that youth with type 1 diabetes reach a peak mean A1c level of 8.9% between ages 16 and 18, before A1c gradually declines to 8.2% by age 26.¹⁹ As the American Diabetes Association recommends maintenance of A1c levels <7.5% for adolescents and <7.0% for adults with type 1 diabetes, these values are suboptimal.²⁰

Thus, health care providers working with this age group must frequently fine-tune diabetes management. Efforts to improve glycemic control may be stymied by physiologic factors as well as those mentioned earlier, which may be beyond a patient's control. Laboratory assessments recommended for adolescent and young adult patients with type 1 diabetes include quarterly appointments with a pediatric endocrinologist or diabetologist, with evaluation of A1c, downloaded blood glucose data, body mass index, and blood pressure at each visit. In addition, recommended

annual laboratory assessments include a lipid panel, level of thyroid-stimulating hormone, celiac panel (total immunoglobulin A [IgA], serum tissue transglutaminase IgA, and endomysial IgA), urine microalbumin-to-creatinine ratio, and creatinine clearance/estimated glomerular filtration rate. Evaluation every 1–2 years by an ophthalmologist 5 years after initial diagnosis of diabetes is also recommended.²⁰

Maintenance of a consistent relationship with a diabetes care provider across adolescence and young adulthood is required to provide the frequent monitoring necessary to minimize diabetes-related complications. The transition from pediatric to adult-oriented health care has the potential to disrupt clinical care and may further contribute to suboptimal glycemic control for adolescents and young adults.

Transition from pediatric to adult-oriented health care

Transition to adult-oriented health care is a key developmental task for adolescents and young adults with type 1 diabetes. Transition refers to the complex, planned process of preparing for and executing the move from pediatric to adult health care.²¹ Transfer refers to the discrete point in time when a patient initiates care in the adult health care system. Transition is a multiyear process, ideally beginning early in adolescence, designed to develop and enhance effective knowledge, self-management, and advocacy in order to ensure adequate readiness for meeting the demands of adult-oriented health care and to facilitate access to continuous health care into adulthood.^{5,21} Patients, parents, health care providers, and other supportive persons all contribute to the transition process, and transition activities occur both in pediatric and adult medical care.

There are a number of fundamental differences between pediatric and adult health care systems.²² Pediatric diabetes care is often family based, offering patients and parents access to an integrated team of physicians, nurse educators, dietitians, social workers, and psychologists.²³ In contrast, the adult-oriented health care system typically has less availability of multidisciplinary care, particularly social and behavioral health.²⁴ Clinic visits are often shorter, with greater emphasis on objective medical indicators and physical symptoms (eg, weight, blood pressure, and A1c) and less input from parents and other support partners.^{25–27} Preparing youth for the entrance into the adult care setting can minimize disruption and promote continuous engagement in high-quality diabetes care.

Preparation for adult-oriented health care often involves frequent, structured assessment of transition readiness – or the skills and behaviors thought to be important in adult-oriented health care – and the creation and implementation of transition plans to address specific deficits in these skills, knowledge, and behaviors prior to transfer.^{5,28} A number of measures exist to assess transition readiness in youth with special health care needs. Most validated transition questionnaires assess general transition readiness skills (eg, Transition Readiness Assessment Questionnaire [TRAQ]²⁹; Self-Management and Transition to Adulthood with Rx = Treatment [STARx] Questionnaire³⁰). Professional organizations, such as the National Diabetes Education Program and the Endocrine Society, also have created diabetes-specific checklists (<http://ndep.nih.gov/transitions/index.aspx>) designed to assess key patient skills that may promote successful transition as well as patient concerns and diabetes-specific worries that may affect transition (www.endocrinetransitions.org). A recent systematic review found that measures of general transition readiness are promising

but require additional testing and validation, particularly connecting measures of transition readiness with the previous experienced outcomes in adult medical care.³¹

Transition plans target the key tasks and goals that should be completed before entering adult-oriented health care, as well as informing interventions or other strategies for meeting these goals.³² The ongoing processes of assessing transition readiness and providing targeted intervention guided by evolving transition plans help to prepare youth for successful entrance into adult health care.^{28,33} An example of specific diabetes management skills that should be achieved prior to transition to adult health care is presented in Figure 1.

Transition time line for youth with diabetes

Most youth with type 1 diabetes transition to adult medical care during the early young-adult period between the ages of 18 years and 22 years. Research suggests that the median age of transition is 19.5–20 years.^{9,34} Representative research of transition to adult care for US youth enrolled in

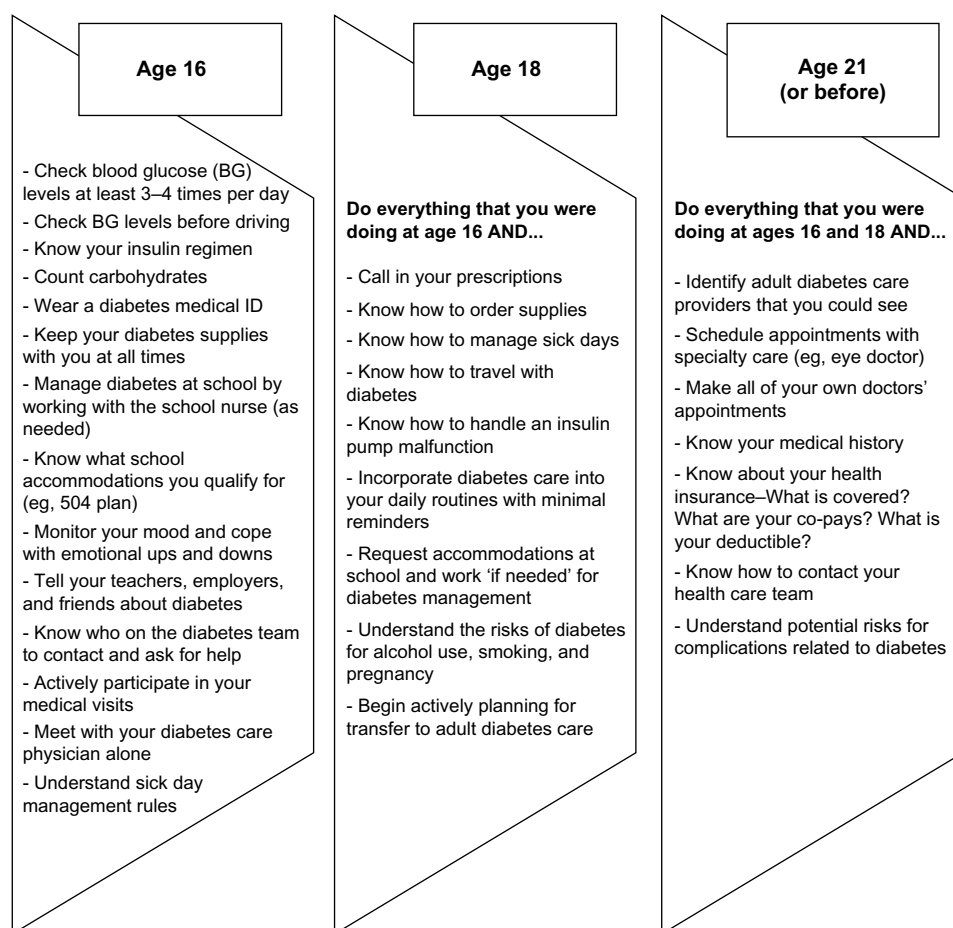


Figure 1 Sample diabetes skills and knowledge to be addressed before transfer to adult-oriented health care.

the SEARCH for Diabetes in Youth study³⁴ found that 53% of youth aged 18–20 years remained in pediatric care, but only 23% of youth were still in pediatric care at age 21 and older. In international samples, transition may occur closer to age 17 or 18 due to differences in health care systems and procedures.^{23,35,36} One representative study³⁷ of 36 countries found that 76% of centers reported patient transfer to adult diabetes care occurring at age 18. The age of transition may be important, particularly in clinics with more flexible age limits for transfer, as youth who transition earlier are at risk for worse health outcomes, including poor glycemic control and gaps in medical care.^{9,34,38}

Young adults in adult diabetes care may access health care in a variety of settings, including adult endocrinology clinics, primary care, family medicine, university-based health clinics, or in targeted young adult clinics designed to bridge pediatric and adult care.^{6,8,39} Most adults with type 1 diabetes see endocrinologists for their care, and research suggests that engagement in specialty care instead of primary care protects youth against negative outcomes in adult care and provides access to more diabetes-specific services (eg, certified diabetes educators, dietitians).^{8,40}

Components of successful transition

In 2011, the American Diabetes Association,⁴ along with representation from other leading health organizations caring for youth with diabetes, published a position statement on the care needs of late adolescents and young adults with diabetes. This comprehensive statement reviewed key considerations for caring for emerging adults and potential best practices in transitioning youth from pediatric to adult medical care. Considering the limited literature on outcomes of clinical transition programs, many of the recommendations were based on expert consensus. Specifically, this position statement recommended the following: 1) initiating transition preparation at least 1 year prior to the planned transfer date and likely earlier in adolescence if possible; 2) working with patients and parents to facilitate a gradual shift of diabetes management responsibility from shared management by patient and parent to more independent management by the patient; 3) providing practical education on differences between the pediatric and adult health care systems and specific referrals for adult care providers as appropriate; 4) assisting youth in compiling medical record documentation in preparation for adult care; 5) acknowledging developmental and psychosocial challenges that may affect transition; and 6) screening for complications commonly seen in older adolescents and

young adults with diabetes, including microvascular and macrovascular complications, disordered eating, depression, and substance abuse concerns.⁴

Around the same time, the American Academy of Pediatrics, American Academy of Family Physicians, and American College of Physicians⁵ also published broad guidelines on preparing youth for adult-oriented health care. These recommendations were similar to those put forth by the American Diabetes Association but advocated for transition preparation to begin early in adolescence, potentially by ages 12–13 if possible.⁵ The combination of these two positions statements has influenced the provision of health care and informed potentially successful models for transition to adult medical care. Unfortunately, it is unclear what recommendations have been put into practice. For example, Hilliard et al⁴¹ found that at age 16, most patients had yet to discuss transition with their health care providers. Similarly, Garvey et al⁴² sent a survey to young adults with type 1 diabetes aged 22–30 years after transition to adult medical care and found that <15% of the sample reported receiving written information related to transition or having a transition-specific visit before leaving pediatric care.

Patient perspectives on health care transition

The experiences of young adults with successful or unsuccessful transitions can inform best practices in transition to adult-oriented health care. Some adolescents and young adults report feeling prepared for the transition to and expectations related to adult diabetes care,⁸ whereas other patients may struggle to initiate or engage in adult-oriented health care. Pyatak et al⁴³ interviewed 20 young adults who had had a lapse in medical care for >1 year and identified factors that contributed to their disrupted transition, including lack of preparation in the pediatric care setting, difficulties with insurance, difficulty identifying appropriate adult care providers, and psychosocial challenges such as life stressors or competing priorities to diabetes care. These barriers have been identified in other samples as well. Garvey et al⁷ found that lack of a specific adult provider referral or contact information was the most frequently endorsed barrier to establishing adult care. Balfe et al^{44,45} interviewed 35 young adults with diabetes aged 23–30 years about their experiences with diabetes management, including dealing with the health care system. Common complaints about the adult-oriented health care system included a lack of multidisciplinary diabetes care services, time constraints for routine appointments, difficulties with communication and continuity of care, and difficulty scheduling appointments.

Qualitative data suggest that families rely on health care providers to initiate conversations about adult diabetes care and how to manage expectations related to transfer. While patients and families often feel comfortable managing the shift in responsibility for daily diabetes-related tasks, they are not as familiar with aspects of the health care system that require navigation and attention in adulthood.⁴¹ Patients and parents generally report that talking with health care providers at regular clinic visits and receiving family-based supports are particularly helpful in the transition process.⁴⁶ Additionally, young adult patients have identified services that may improve the transition process, including provision of targeted referrals to adult diabetes care providers, discussion of transition services earlier in pediatric care, assistance with logistics of transfer to adult care, increasing attention to differences between pediatric and adult care, and increased opportunities to connect with other young adults with type 1 diabetes.^{41,47,48} Services for transitioning patients to adult-oriented health care should continue to include parents as key aspects of the patient's support team rather than excluding them from the process.^{41,48} It is important to note that once young adults are firmly established in adult diabetes care, they often report a positive experience, including feeling more involved in their own medical care and enjoying the independence encouraged by adult providers.⁴⁸ However, some young adults in adult medical care report dissatisfaction with adult providers' knowledge of type 1 diabetes and insufficient time with providers during medical appointments.⁴⁹

Patients and parents have also requested more written resources related to transition⁸; however, the utilization of these resources varies. For example, one study offering transition classes and a comprehensive binder of materials found that only 50% of eligible parent/adolescent dyads attended the transition class or used the education materials. Furthermore, only 25% of adolescents found the written materials to be very helpful.⁴⁶ It is likely that transition services are best received when they are integrated into routine clinical care and are built upon interactions and relationships with health care providers.

Transition outcomes and related risk factors

Systematic reviews have examined the impact of transition on diabetes-related outcomes, and evidence suggests that there is a decrease in annual diabetes care visits after transferring to adult care.^{6,38} In addition to a lower number of yearly clinic visits, $\geq 25\%$ of young adults report a significant gap in medical care (>6 months) when transferring out of

pediatric care.^{8,50} There is also some evidence to indicate that the timing of transition influences outcomes in adult care. Transition to adult-oriented health care at younger ages has been associated with poorer glycemic control⁹ and late adolescents who remain in pediatric care into early young adulthood demonstrate better glycemic control and fewer hospitalizations as compared to those who transfer to adult care.^{34,51} However, evidence on the impact of transition on glycemic control is inconsistent, and one recent review³⁸ found that young adults generally maintained stable or even improved glycemic control after the transfer to adult medical care. This is similar to large cohort studies that report a general improvement in glycemic control in the mid-20s.¹⁹ As discussed earlier, this improvement may be due to a number of factors, including physiology.

Risk factors that may contribute to poor outcomes in adult health care have been identified through prospective and retrospective studies. Gaps in medical care in young adulthood may be related to 1) health care system issues, such as lapses in insurance or difficulties in finding an adult care provider, or 2) issues unique to the young adult, such as competing life priorities or an unstable living situation.⁷ Mistry et al⁵² evaluated clinic attendance in adult care in a prospective group of young adults referred to a Diabetes Transition Clinic. Overall, nearly one third of participants had a gap in care of at least 1 year after their last transition clinic appointment. Risk factors associated with failure to successfully transition included longer duration of diabetes, use of a conventional two-to-three-injection insulin regimen, worse glycemic control prior to transfer ($A1c > 9.0\%$), poor attendance in pediatric care, and low communication with care providers in the transition clinic.⁵² Young adults with lower family income or who live in areas with poorer access to adult care physicians are also at risk for poor health outcomes posttransfer to adult medical care.^{9,53} Addressing barriers to successful transition prior to the transfer to adult care may decrease gaps in care and increase engagement in adult-oriented health care, as identification of even one significant barrier to transition has been related to a >4 -fold increase in risk for poor attendance.⁷

Evidence-based models of transition care delivery

Much of the expert opinion on components of a successful transition has focused on preparation on the pediatric side, including the skills, attitudes, and knowledge that contribute to overall transition readiness. Less research has explored what outcomes constitute a successful transition in adult medical care. Pierce

and Wysocki⁵⁴ recently modified a validated theoretical model of transition to identify key outcomes of transition, including biomedical (eg, A1c, acute complications, emergency room visits, and inpatient hospitalizations); behavioral (adherence, engagement in care, reduced gaps in care); and emotional (quality of life, depression, and care satisfaction) outcomes. Others have argued that attendance in adult care should be the primary outcome variable for adult care.^{6,38,55}

Models of care delivery for transition-aged youth vary by program. In addition to the standard model of a discrete move from pediatric to adult-oriented health care, some programs include an interim level of care by young adult providers as a bridge between pediatric and adult care, a joint pediatric–adult clinic where young adults meet with both care providers in the same setting, or additional supports through patient navigators or educational groups.^{35,36,49,56,57} Some youth temporarily transfer diabetes care to student health centers while attending college; however, research suggests that only 50% of universities report adequate resources to manage type 1 diabetes.⁵⁸ Comprehensive programs promoting successful transition to adult-oriented care often utilize detailed transition protocols with checklists for transition steps, formal transition-related materials for youth, and targeted interventions to improve self-management.⁵⁹ Regardless of the method, most agree that a structured, planned transition to adult-oriented health care with adequate communication among providers is necessary to promote engagement in adult medical care.⁶⁰ Best practices for providers working with transition-aged youth are included in Table 1, and select programs with outcome data are reviewed below.

Young adults have requested participation in a structured young adult transition clinic or joint visits with a pediatric

and adult care provider to increase engagement in adult care.⁶¹ Simply meeting an adult care provider prior to transfer has been associated with increased satisfaction.⁶² Egan et al⁵⁷ piloted a program for 29 young adults with type 1 diabetes transitioning to adult-oriented health care. Participating young adult patients had one to two joint appointments with a pediatric and an adult health care provider prior to transfer to adult care and access to a transition coordinator to assist with appointment scheduling. All participants were seen at least twice in the first year of adult care and diabetes distress decreased over the same period, suggesting that joint appointments were successful in maintaining engagement in medical care across the transition period.⁵⁷ Another program offered young adults (n=53; mean age =22 years) care in a structured transition clinic staffed by pediatric and adult endocrinologists and a transition coordinator. The joint clinic was highly attended, with 68% of participants attending three visits per year. Notably, of the participants with a previous lapse of >6 months between visits, nearly half met the recommended number of visits (three visits per year) during their first year in the joint clinic. A1c also decreased for attendees, suggesting that this targeted model of care was successful in improving glycemic control.⁶³ If possible, it may be helpful to minimize the amount of change experienced during transition, including referring young adults for adult care in the same health care system/location as their pediatric care.⁶² Provision of continuity with the health care team or provider across the transition from pediatric to adult care also has been associated with decreased risk for diabetes-related hospitalization.⁵³

Some transition programs have aimed to provide targeted education and resources for young adults moving to adult

Table 1 Best practices for health care providers working with transition-aged youth

| | |
|---|---|
| For pediatric health care providers | Provide personalized referral to specific adult health care provider based on individualized knowledge of the patient or assist with identifying providers participating within a patient's insurance network ^{47,48} Initiate discussion about transition early, lead expectation-setting for transition and the adult medical setting, and time the transition based on individual readiness ^{41,56,57} |
| Transition process | Communicate with intended adult health care provider before transition and with patient afterward for follow-up ⁴⁸ Employ a transition coordinator to remind, facilitate, and rebook appointments when necessary; follow-up on any missed appointments; ensure transfer of information from pediatric to adult providers ^{56,57,63,64,68} Multidisciplinary "joint" (involving members of both the pediatric and adult health care teams) appointments ranging from one visit to up to 2 years before seeing solely adult providers, especially for those with history of infrequent clinic attendance ^{57,63} |
| For adult health care providers | Consider setting up an introductory meeting with new adult patients before transition ⁴¹ Provide orientation to clinic practices and take time to develop personal rapport and relationship with patients ⁴⁷ |
| For any providers serving adolescents and young adults with type 1 diabetes | Encourage collaboration in doctor–patient relationship and promote the patient's autonomy and gradual assumption of personal responsibility as developmentally appropriate ⁴⁸ As appropriate, involve parents as an important source of support and continually needed resource ^{41,46,48} Adequately address concerns specific to this age group (ie, risky behaviors, dietary patterns, changes in living situation, insurance status, and health effects of stress) ^{43,56} |

care. One comprehensive program, Let's Empower and Prepare (LEAP),⁵⁶ provided a structured transition program to young adults to facilitate the transition to adult medical care. Intervention participants (n=51) received structured individual and group education targeted to young adult issues, access to transition coordinators and a dedicated young adult clinic, and membership in a private online community to discuss transition issues. A convenience sample control group received standard care. Results indicated that 78% of young adults in the intervention group successfully attended at least one adult care visit in the specialized young adult clinic created for this study. Intervention group participants also experienced an improvement in A1c (0.4%) as compared to a worsening in A1c for the control group (0.4%), suggesting that the resources provided in the intervention were successful in improving diabetes care.⁵⁶ Another program⁴⁹ offered a monthly support group designed to increase peer-to-peer social support for young adults aged 18–30 years with type 1 diabetes. Ten of the 15 group participants demonstrated an improvement in A1c from pre- to postgroup participation. Transition to adult care was a topic of discussion in the group, along with strategies for managing daily diabetes care and related emotional burden.⁴⁹

Few randomized controlled trials have rigorously evaluated outcomes of transition programs. Steinbeck et al⁶⁴ recruited 26 young adults during the transition to adult-oriented health care and randomly assigned them to receive either telephone support after leaving pediatric care or standard care. Results indicated that the provision of support posttransfer did not contribute to transition outcomes, including attendance in adult care and glycemic control; however, at 1 year, 88% of all participants were established in adult care.⁶⁴ Another randomized controlled trial⁶⁵ utilized technology to improve disease self-management in youth with chronic illness, including type 1 diabetes. Participants randomized to the intervention group received a 2-month Web- and text-message-based program designed to improve disease management skills prior to transition to adult care. The intervention group showed improved disease management and communication with health care providers as compared to the control group; however, this study did not examine outcomes over the transition to adult care.⁶⁵

Resources for working with transition-aged youth with diabetes

There are a number of high-quality, freely available resources designed to promote successful transition to adult-oriented health care for patients and their families, as well as health

care providers. Although the majority of these resources have not been rigorously evaluated, these are based on expert consensus, and research is beginning to evaluate specific components of transition programs that may be efficacious. Health care providers are encouraged to utilize these resources when working with transition-aged youth and to connect patients with targeted resources as necessary, based on patient needs and goals.

Got Transition, one of the largest sources of information about transition, represents a cooperative agreement between the Maternal and Child Health Bureau and the National Alliance to Advance Adolescent Health. While not specific to type 1 diabetes, Got Transition offers resources and tools for health care providers, patients, and families preparing for entrance into adult-oriented health care. The cornerstone of Got Transition's work concerns the Six Core Elements of Health Care Transition, reflecting best practices for the transition process. The Six Core Elements of Health Care Transition include the following: Transition Policy, Transition Tracking and Monitoring, Transition Readiness, Transition Planning, Transfer of Care, and Transfer Completion (www.gottransition.org). These elements have been implemented in clinical practice, resulting in individual- and practice-level improvements in key areas that promote successful transition to adult-oriented health care.^{33,66} A number of diabetes-specific resources for transition have also been developed for use by providers in routine clinical care, including resources from the Pediatric Endocrine Society, Endocrine Society, and National Diabetes Education Program (NDEP). Furthermore, patient advocacy organizations such as JDRE, formerly known as the Juvenile Diabetes Research Foundation, and the College Diabetes Network also have extensive resources geared toward young adult patients and their families. Table 2 highlights select online resources.

Future directions

The transition from pediatric to adult-oriented health care has been an important topic of research and clinical care in recent years and many suggestions exist for improving this process. It is recommended that pediatric and adult endocrinology practices take an inventory of their current resources and approaches for transition and identify ways to incorporate additional supports for adolescents and young adults with type 1 diabetes. Resources such as Got Transition offer practice-level assessments that can be a starting point to identify areas for growth and improvement. Transition is not a discrete event that can be parceled out of comprehensive care for youth with diabetes. Much of the research supports transition as a gradual,

Table 2 Sample resources to assist with the transition from pediatric to adult-oriented health care

| Organization | Web site | Target audience | Resources |
|-------------------------------------|---|---|--|
| Got Transition | www.gottransition.org | Health care providers, patients, families | Information on best practices for general transition to adult-oriented health care; answers to frequently asked questions about transition |
| Pediatric Endocrine Society | https://www.pedsendo.org/patients_families/transition_toolkit/index.cfm | Health care providers | Toolkit to assist pediatric providers with planning for, structuring, and facilitating patient transition to adult-oriented endocrinology care |
| Endocrine Society | https://www.endocrine.org/education-and-practice-management/quality-improvement-resources/clinical-practice-resources/transition-of-care | Health care providers | Tools to implement in clinical practice with young adult patients preparing for and receiving care in the adult health care system |
| National Diabetes Education Program | http://ndep.nih.gov/transitions | Health care providers, patients, families | Transition planning checklist and clinical summary template for providers, links to information on health care and daily diabetes management for patients and families; includes in-person and online support groups |
| JDRF | http://typeonenation.org/resources/newly-diagnosed/t1d-toolkits/ | Adult patients | Toolkits for adults with type 1 diabetes, with information about diabetes management |
| College Diabetes Network | https://collegediabetesnetwork.org/ | Young adult patients | Resources for diabetes management during young adulthood, including diabetes at college, navigating health insurance, and addressing diabetes in personal relationships |

Abbreviation: JDRF, Juvenile Diabetes Research Foundation.

integrated process built upon ongoing interactions with trusted health care providers, starting in early to mid-adolescence. Pediatric health care providers are in a unique position to encourage key diabetes management skills and behaviors that can contribute to improved health well into adulthood.

Future research should more rigorously evaluate promising models of transition education and care for youth with diabetes in order to develop a robust collection of evidence-based practices in this area. Sophisticated trial designs, such as randomized controlled trials, and long-term follow-up into adult medical care are needed. Furthermore, it is necessary to define and evaluate specific outcomes in adult-oriented health care to determine how “successful” transition can be measured and to identify key risk factors that may predispose youth to transition-related challenges, such as income, insurance status, and availability of specialty adult-oriented health care providers. Changes to the health care landscape ushered in by the Affordable Care Act,⁶⁷ such as the ability to remain on a parent’s insurance until age 26, may influence transition timing and procedures and promote more successful diabetes management during this period.

Conclusion

Late adolescence and young adulthood represent risky developmental periods characterized by poor glycemic control and related acute and chronic complications. The transition from pediatric to adult-oriented health care can present many

challenges for patients, families, and health care providers, as well as exacerbating health concerns during this developmental period. Consistent engagement in high-quality diabetes care throughout young adulthood promotes health and well-being for youth and potentially prevents some of the complications experienced. However, identification of best practices to support successful transition to adult-oriented health care is in its early stage, and more research is needed to identify universal components of effective transition programs. Furthermore, models of adult care delivery may need to be modified to best meet the needs of young adult patients with type 1 diabetes. Health care providers can support the transition process by ongoing, integrated attention to developmental and health care system-related issues during preparation for adult-oriented health care and upon entrance into the adult-oriented health care system.

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