

Health Care Transition in Adolescents and Young Adults With Diabetes

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In the past 30 years, health care transition in adolescents with chronic diseases has become a significant challenge for health care providers. Advances in medical care have given physicians the ability to prolong life in children who previously had limited life expectancies. Approximately 90% of individuals born with a disability in the United States will reach 20 years of age, and more than one-third of youth in the United States have some form of chronic illness.¹ Each year, more than half a million children with disabilities and chronic illness transition from adolescence into adulthood.² Approximately 15,000 youth are diagnosed with type 1 diabetes in the United States each year.³ Although type 1 diabetes accounts for the majority of childhood diabetes, the incidence of type 2 diabetes is growing, with an estimated incidence of nearly 12 cases per 100,000 person-years in youth ages 15–19 years.³

Children with chronic diseases present unique challenges to patients, families, physicians, and the health care system. Well-organized health care transitions are needed to ensure high-quality care. The purpose of this review is to provide an overview of health care transition in adolescents with diabetes and provide recommendations for health care providers to improve transition from pediatric to adult-oriented health care services.

Transitions in Health Care

Health care transition is defined as the “purposeful, planned movement of adolescents and young adults with chronic physical and medical conditions from child-centered to adult-oriented health care systems.”⁴ For young people with diabetes, health care transition includes the process by which providers, patients, and families develop increasing diabetes knowledge and self-management skills to prepare for transfer from pediatric to adult-oriented health services. Through this process, adolescents are prepared to assume responsibility for their care.⁵ Provider responsibilities and patient skills suggested for improvement in diabetes health care transition are outlined in Table 1.

Transition is influenced and complicated by multiple concurrent changes in physical and emotional development and social structure during adolescence. Ideally, health care transition does not occur in iso-

lation, but rather is embedded within larger, developmentally appropriate processes that foster independence through education and job training. Although health care transition often leads to transfer of care from pediatric to adult providers, patients of family practice physicians and combined internal medicine/pediatric physicians can undergo transition without transfer of care. To provide high-quality health care, improvement in both transition and transfer are needed.

Importance of Health Care Transition in Diabetes

Absent or ineffective health care transition for patients with diabetes may result in failure to transfer to adult-oriented systems of care and increase diabetes-related complications. Among adolescents with type 1 diabetes, 11–24% of patients fail to follow up in the adult health care system,^{6–8} and clinic attendance may be sporadic among those completing transfer of care.⁶ Young adults with type 1 diabetes who have less than one appointment per year after transferring to adult health care have higher A1C levels, increased hospitalizations, increased diabetes-related complications, and increased comorbidities.^{6–9} Longitudinal follow-up of young adults with type 1 diabetes after transition found that high rates of obesity, tobacco use, and alcohol use developed within 8 years of transfer of care. Nearly 20% of patients devel-

IN BRIEF

Improving health care transition in adolescents and young adults with diabetes is a challenge shared by both pediatric and adult practitioners. This article provides an overview of health care transitions, reviews selected approaches to transition, and provides recommendations for health care providers to facilitate and optimize transition in adolescents with diabetes.

Table 1. Health Care Transition Checklist for Adolescents With Diabetes

Role of the Health Care Team in Diabetes Transition

- Develop structured diabetes transition plans
- Identify and address individual patient needs
- Refer to necessary services to prepare for transition
- Assess support of family and social system for transition
- Prepare diabetes transfer summary
- Identify accepting provider in adult health care system
- Communicate with receiving health care team
- Provide continuous medical care and preventive care until transfer occurs
- Follow up with patient after transfer to adult system to ensure that care is established

Adolescent Skills Required for Diabetes Transition

Participation in Health Care Visits

- Participates in health care decisions
- Communicates clearly with providers and clinic staff
- Asks informed questions
- Attends clinic visits without a family member present in the exam room
- Vocalizes willingness and readiness for transfer of care
- Contacts medical system for questions and medication refills
- Schedules appointments
- Keeps follow-up appointments

Diabetes Knowledge

- Understands diabetes pathophysiology
- Understands effects of nutrition and exercise on diabetes
- Recognizes signs and symptoms of hypoglycemia and treats appropriately
- Understands carbohydrate counting, if applicable
- Knows indications to seek medical care

Diabetes Management Skills

- Knows medications, indications for use, and correct doses
- Demonstrates ability to perform self-monitoring of blood glucose
- Demonstrates ability to adjust insulin based on blood glucose and carbohydrate counting, if applicable
- Demonstrates effective diabetes control and avoids diabetes-related hospitalizations

Social Responsibility

- Demonstrates ability to arrange transportation for appointments
- Proactively plans for continuing insurance coverage
- Sets education and employment goals
- Understands impact of substance use, smoking, and pregnancy on diabetes
- Utilizes social work and case management for assistance with community resources

oped retinopathy or nephropathy during this period.¹⁰

The factors contributing to poor diabetes outcomes after transfer to adult-oriented systems remain

understudied and poorly defined. Adolescents with type 1 diabetes who lack continuity of care during transition have increased rates of hospitalization.¹¹ Patients who

attribute negative events to external causes, have negative body images, and perceive little control over their health are at greatest risk for poor compliance and outcomes during transition.¹² Health care transition often occurs concurrently with the development of adolescent independence. This period of “emerging adulthood” focuses on the development of personal identity, and seeking independence may take precedence over self-care. Gradually decreasing parental influence may result in worsening glycemic control.^{13,14}

The Process of Health Care Transition

Adolescents with chronic illness undergoing health care transition often have substantial unmet needs. In spite of diverse underlying medical conditions, these needs are more similar than different.¹⁵ In 2002, the Consensus Statement on Health Care Transitions for Young Adults With Special Health Care Needs² was approved. This policy outlines key aspects of health care transition, including care coordination, access to continuous care, delivery of developmentally appropriate preventive health services, development of provider skills, development of written transition plans and medical summaries, and access to continuous insurance coverage.²

At the time of health care transition, young adults with diabetes either 1) receive ongoing services from pediatric-trained providers; 2) receive “blended” health care from both pediatric and adult providers; 3) receive care from all adult providers; 4) receive continuous care from family practitioners or physicians trained in combined internal medicine and pediatrics, or 5) drop out of the health care system and fail to receive structured care.¹⁶

Transition models generally fall into one of three categories:

condition-focused, primary care–based, or adolescent-focused.^{17–19}

Condition-focused health care transition is structured around a chronic illness such as diabetes and coordinated by subspecialty providers. Primary care–based health care transition is generally coordinated by primary care providers (PCPs) and may be embedded within the larger construct of the “medical home” model, which focuses on care that is accessible, family-centered, continuous, comprehensive, coordinated, compassionate, and culturally effective.²⁰ In this instance, PCPs coordinate care between endocrinologists and other members of the health care team.^{17–19, 21} Adolescent-focused health care transition relies on providers trained in adolescent medicine to coordinate care.^{17,18}

Few objective data exist to determine which models best improve health or which approaches are best suited for particular patients.¹⁶ However, experience suggests that health care transition is a complex process that varies with each patient, system of care, and disease process such that a “one-size-fits-all” transition model is unlikely to address all aspects of care across diseases.²²

Role of PCPs in Health Care Transition

The level of involvement of PCPs in health care transition of adolescents with diabetes is determined by individual providers and available resources. As outlined in the American Academy of Pediatrics Medical Home Initiative,²⁰ PCPs are instrumental in organizing and facilitating all aspects of medical care by providing family-centered, continuous care and planning and organizing transition between providers and health systems.²⁰ Thus, PCPs play an important role in transition regardless of the transition model used or the structure of the health care system.

Providers trained in family practice or combined internal medicine and pediatrics and those practicing in rural areas may provide both primary care services and diabetes care when access to endocrinologists is limited. In such instances, health care transition is orchestrated by PCPs and occurs without transfer of care. Alternatively, PCPs may provide routine medical services and either co-manage diabetes with, or defer management to, specialists in endocrinology. In such cases, PCPs coordinate transition and communicate with endocrinology colleagues to ensure that transition needs are met. In this model, transfer of care may ultimately occur among both endocrinologists and PCPs. In large hospital systems and academic centers, PCPs may coordinate care within “medical homes” or comprehensive disease management teams in collaboration with endocrinologists, other subspecialists, dietitians, nurse managers, and care coordinators. In such systems, PCPs remain the center of patient care and should take primary responsibility for coordinating transition and facilitating transfer of care to adult-oriented systems.

Plan for Transition in Diabetes

Health care transition from pediatric to adult-oriented health services should be an individualized, collaborative process designed by adolescent patients, their family, and their health care team.²³ Early initiation and planning help prepare patients, families, and health care teams for transfer to adult services. The development of written transition plans can outline strategies for progressive development of diabetes-related knowledge, disease management strategies, and self-management skills. Transition plans set clear goals for patients and providers²⁴ and allow for periodic assessment of progress to determine

readiness for transfer. Ultimately, the timing of transfer to adult care should be determined by patient readiness rather than age. In actuality, however, adolescents are often transferred to adult-oriented health care systems as dictated by preexisting hospital policies, federal funding agencies, and mission statements based largely on age.²⁵

When transition occurs in an organized, timely manner, transfer to adult care can be coordinated by both transferring and receiving physicians. Structured transition programs that allow young adults to meet with new providers before transfer occurs have been shown to increase clinic attendance within the adult health care system and to increase patient satisfaction.²⁶ Transferring care during a period of disease stability allows providers to orient young adults to their new health care team rather than managing urgent diabetes-related issues.²⁷ Initial visits should be structured to include orientation to the new system of care. Availability of evening or weekend appointments that better accommodate work and school schedules may increase clinic attendance.^{28,29}

Educate Providers, Patients, and Families on Diabetes Transition Issues

There is currently a lack of adequately trained adult care providers who are capable of providing developmentally appropriate care for young adults with chronic medical conditions.^{16,25} Provider recognition of this knowledge gap impedes physicians’ willingness to transfer patients to adult health care systems.²⁵ Pediatricians, internists, and family practitioners may lack disease-specific knowledge and experience to care for young adults with diabetes. When there is a lack of access to diabetes specialists, PCPs often seek consultation from colleagues in medicine,

education, social work, and psychology to assist with transition. These providers, however, are less likely to use transition guidelines or continuing education programs.¹⁹

Clinical training programs and continuing medical education curricula are needed to educate providers on the importance of transition and deliver information on evidence-based diabetes management, secondary screenings, and management of diabetes-related comorbidities.^{16,25} Participation by pediatric and adult health care providers in shared education programs may narrow gaps in medical knowledge, identify and address barriers to health care transition and transfer, and help establish relationships among local pediatric and adult care providers to facilitate transition. Such training may help address patient and family concerns that adult health care providers lack the skills necessary to manage complex, childhood-onset illnesses.¹⁶

Although adult providers are often comfortable with the medical management of diabetes, the relationship of adolescents' diabetes to their emotional and social development may be poorly understood or underestimated. This is particularly important because diabetes control and progression are strongly influenced by family, peer groups, and living environment. Young adults with diabetes desire developmentally appropriate care and often feel out of place in adult health care systems.^{28,29} Provision of developmentally appropriate care may be particularly challenging for pediatricians and internists because young adults typically represent the age extremes in their respective practices. Health care providers, nurses, and clinical staff may need additional training to accommodate the developmental, emotional, and social needs of young adults.

Before transition, patients should be able to demonstrate competency in diabetes knowledge and self-management skills and participate actively in health care decisions.²⁵ Parents and caregivers of adolescents with diabetes may struggle to relinquish control of the day-to-day management of the illness.³⁰ Progressive involvement of adolescents in clinic visits, decision making, and self-care is important.

Providers should educate patients about diabetes and the impact of having a chronic, progressive disease on all aspects of life.³⁰ Some educational programs to build self-management skills in diabetes have been shown to improve glyce-mic control and increase diabetes management knowledge.¹³ However, adequate diabetes knowledge does not ensure diabetes control.³¹ PCPs should provide developmentally appropriate educational materials and programs for young adults as part of the transition process.^{13,24} Diabetes education programs accounting for literacy and numeracy³² have been shown to improve self-efficacy and diabetes control.³³ Incorporating materials that are sensitive to patients' numeracy and literacy level into routine clinical care and education programs may improve safety and quality of care³⁴ and should be considered in the health care transition process.

Adolescents with diabetes have also expressed a need for education about stress management, financial matters, sexual development and pregnancy, alcohol and drug use, new developments in diabetes research, and healthy cooking.²⁹ As part of routine preventive health services, PCPs should provide counseling and education on the risks associated with alcohol, tobacco, and drug use as they relate to diabetes management.³⁵ Appropriate counseling should also be pro-

vided about sexual health and the impact of diabetes on pregnancy.^{29,35} Particular emphasis should be placed on the importance of planning ahead for pregnancy so that peripartum and postpartum complications associated with poor glucose control and teratogenic medications such as ACE inhibitors may be avoided.^{35,36}

Residential weekend programs have been designed for adolescents with diabetes to increase independence through peer support, education, and friendship-building activities. In these programs, diabetes nurses, dietitians, and youth workers lead small groups in meal planning, meal preparation, and discussions about substance use, driving, and sexual health.³⁷ Such programs have received positive feedback from participants and may facilitate transition, although formal evaluation is lacking.

Ensure Continuity of Care

PCPs provide longitudinal patient care and are responsible for health promotion, disease prevention, health maintenance, counseling, patient education, and diagnosis and treatment of acute and chronic illnesses.³⁸ Health care providers, adolescents, and family members are often reluctant to end longstanding relationships that develop during the provision of longitudinal care. This may pose a substantial barrier to transition for patients with diabetes and result in young adults receiving ongoing care in pediatric systems.¹⁶ Acknowledgment of this phenomenon and utilization of defined transition plans may help alleviate this barrier.

When health care is transferred from pediatric to adult care providers, transferring physicians should help identify follow-up physicians, arrange appointments, and facilitate the transfer of medical records. The presence of both pediatric and adult

providers at the initial transfer visit may help promote continuity of care between providers and health care systems.¹³ Young adults with type 1 diabetes have identified discontinuity among physicians and clinical staff as an area of particular concern in the transition and transfer process.²⁸ The perception of fragmented care is magnified by the change from family-centered pediatric care to disease-focused adult care. Among adolescents, this leads to a fear of the unknown³⁰ and feelings of being “lost in the shuffle” during the transition process.²⁹

The lack of adequate, cost-effective, continuous insurance coverage poses a major obstacle to health care transition and access to health care for young adults.³⁹ During the transition process, providers should discuss employment, school plans, and options to maintain insurance coverage as patients “age out” of their parents’ coverage or traditional Medicaid coverage. Even if ongoing insurance coverage is available, many patients experience a decrease in coverage and benefits. If continuous insurance coverage is not attainable, providers should provide information about community resources and clinics capable of providing low-cost health services for uninsured patients. Social workers and case managers may be particularly helpful in this process. Proactive transition planning can help establish a safety net to prevent the loss of health care services during transition.

Coordinate Care

Adolescents participating in structured transition programs are more likely to establish care in the adult health care system³⁰ and may have better clinical outcomes.^{40,41} Coordination of health care services and community resources requires a high level of collaboration and com-

munication among the health care team, community agencies, patients, and family members.^{17,22,42} Young adults with diabetes may receive services from endocrinologists, dietitians, diabetes educators, case managers, social workers, exercise therapists, and other health care professionals.

During health care transition and transfer, PCPs are responsible for coordinating individualized services for each patient. Large primary care practices, academic medical centers, and pediatric health care clinics often utilize multidisciplinary teams to meet patient needs. However, the limited availability of such teams in adult health care systems may pose another significant barrier to transition. After transfer to adult care, young adults and family members have described having to create a “patchwork quilt” of health care services to meet their health care needs.¹⁶ This may result in more frequent visits, delayed care, and poor health care communication between services and medical teams.²²

Utilization of structured diabetes transition plans may help PCPs identify patient needs and recognize their own limitations to meet those needs. Knowledge of local community resources and establishment of referral patterns and relationships with specific dietitians, diabetes educators, exercise therapists, social workers, and community agencies improve coordination and communication such that comprehensive patient needs are more likely to be addressed during transition.

Transition coordinators act as liaisons between pediatric and adult health care systems and have been utilized to provide continuity of care during the transition process.^{17,23,24, 43,44} Transition coordinators help young adults navigate complex health care systems and may assist in arranging appoint-

ments, sending reminder notices, and providing after-hours phone support.⁴¹ This approach has led to increased clinic attendance, improved glycemic control, and decreased diabetic ketoacidosis admissions for patients with type 1 diabetes.^{41,45} For example, the Maestro Project in Canada uses a care coordinator to identify barriers to care, maintain regular telephone and e-mail contact with patients, conduct drop-in groups, maintain a program Web site and monthly newsletter, and conduct educational events. Implementation of this program resulted in a 30% reduction in dropout from diabetes care during a 2-year period.⁴⁶

Involve Parents in Health Care Transition

In addition to coordinating care for adolescents with diabetes, PCPs should facilitate communication between adolescents and parents. During transition, provider communication evolves from parent-focused to adolescent-focused. As responsibility for diabetes care evolves from parental management to shared parent-child management to adolescent management with parental oversight to independent young adult management, clear communication of roles, expectations, and responsibilities for diabetes care is necessary. This allows adolescents to develop greater responsibility for their diabetes care and participate in decision making. However, parents, who are often highly involved in the diabetes care of their children, may feel left out and struggle to relinquish responsibilities for disease management.²⁵ When this occurs, adolescent autonomy, self-care, and personal responsibility are undermined, and adolescents fail to develop rapport and communication skills with clinicians. Furthermore, persistent parental control during transition compromises patient

privacy and may limit discussion of adolescent-sensitive issues.²² Establishment of transition plans and clinical boundaries by providers, with the interests of the adolescents in mind, may facilitate step-wise decreases in parental oversight and avoid power struggles between adolescents and their parents.

Although excessive parental involvement may impede the development of skills necessary for diabetes transition, parental guidance and involvement in the transition process appears to improve diabetes management.¹⁸ The appropriate balance of adolescent and parental diabetes management and decision making evolves over time, and the relative balance is specific to adolescents' stage in transition. Parental involvement may be particularly important in type 2 diabetes, where dietary choices, physical activity levels, obesity, and development of type 2 diabetes appear to cluster within families.⁴⁷ Thus, adolescents' ability to make changes may be limited by behaviors modeled within their family, family support, and resource limitations. Treatment strategies for adolescents with type 2 diabetes will likely require lifestyle modifications and disease interventions directed at the family level.⁴⁷

Communicate With Patients and the Health Care Team

PCPs should establish and maintain clear communication between adolescents and members of the diabetes health care team. Utilization of transition notes in addition to concise medical summaries may enhance provider communication and outline diabetes skills developed and mastered during the transition process. Such documents may include information about diabetes self-management skills, social and family

dynamics, and strategies for achieving enhanced patient activation.²⁵

Technology-based communication strategies such as telephone care^{48,49} may increase patient-provider interaction and achieve better disease outcomes in young adults. Adolescents and young adults with diabetes have also expressed interest in e-mail and phone text messaging to enhance disease management.^{28,29} Utilization of such communication modalities for disease management in adolescents with diabetes may increase patients' contact with the medical system without increasing their frequency of office visits. This may help address patient and family concerns of decreased contact with and difficulty accessing the adult health care system.³⁰

Recently, an Internet-based problem-solving tool for adolescents with type 1 diabetes was shown to increase self-management skills by using a combination of online multimedia presentations, social networking, and e-mail.⁵⁰ The development of user-friendly Web sites, newsletters, and social networking links may also enhance education and awareness of community resources.²⁴ Web-based discussion forums and social networking enhance peer interaction among adolescents with diabetes²⁹ and may help alleviate feelings of abandonment by the health care team during transition and transfer of care. Utilization of group visits during the transition process may enhance peer support and provide novel opportunities for diabetes education, problem solving, and disease management.

Implementation of Transition Recommendations

Despite well-outlined recommendations and guidelines to facilitate transition, the use of organized, structured transition programs to

transition adolescents with diabetes from pediatric to adult care remains sporadic. In a recent survey of the International Society for Pediatric and Adolescent Diabetes, only 50% of respondents had structured transition programs, and the transition approaches varied widely, including telephone calls or letters to notify patients of transition, joint clinics with pediatric and adult providers, and group transfers. Of the institutions with transition strategies, only 35% evaluated their programs.⁵¹

Few published studies have combined multiple transition recommendations into programs and evaluated outcomes. A recently published study described a transition program for adolescents with type 1 diabetes that included a transition coordinator, transfer summary, transition appointment involving the PCP and both pediatric and adult endocrinologists, and participation of the pediatrician in the initial appointment in the adult health care system. This program led to improved glycemic control, improved clinic attendance, earlier follow-up in the adult health care system, and greater patient satisfaction. In this pilot program, patients were given the option to return to pediatric care after their initial appointment in the adult health care system; only 1 of 30 patients returned to the pediatric system.⁴⁰

Future Directions

Development of comprehensive health care transition programs in diabetes will require systematic changes in health care, and PCPs are well positioned to lead the way through the delivery of longitudinal, patient-centered care. The chronic care model⁵² provides an evidence-based approach to quality improvement and disease management by outlining principles for systems-based changes in health care delivery. The delivery of

high-quality medical care requires a clinical infrastructure capable of providing continuous relationships with a health care team, individualization of care according to patient needs and values, anticipation of patient needs, cooperation among clinicians, and evidence-based care. Such goals are best met with cooperation between activated patients and well-prepared, proactive health care teams.⁵²

Although the challenges of caring for adolescents with chronic diseases are unique, examination of successful disease management programs in adults with type 2 diabetes^{53–55} may significantly inform the design, implementation, and evaluation of diabetes transition programs. Focusing on adolescents' overall health and understanding their social networks, goals, beliefs, and expectations of glycemic control will be instrumental in improving their transition from pediatric to adult diabetes care.⁵⁶

Conclusions

Health care providers can take a leading role in the health care transition of adolescents and young adults with diabetes. The level of physician involvement in the transition process will likely be determined by provider skills and available resources.

After assessing individual patient needs, providers should recognize their own limitations and the limitations of their clinical staff in providing services required for the transition process. Providers can develop and execute diabetes transition plans to teach progressive self-management skills and develop support systems using a combination of office and community resources.

Although the essential components, optimal organization, and best approaches to transition are unknown, the principles outlined in this article should provide a useful guide for health care providers

planning for health care transition. The publication of articles about both successful and unsuccessful approaches to health care transition is needed to determine the effectiveness of existing programs and inform the design and evaluation of future transition efforts.

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