In Brief

This article outlines barriers to successful transition from pediatric to adult care for patients with type 1 diabetes, describes evolving models for transition care in this population, and highlights multiple online transition resources for diabetes team providers.

Adolescent Transition: Challenges and Resources for the Diabetes Team

Paula Lynne Jameson, MSN, ARNP, FNP-BC, CDE

Background

Health care transition has been 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.”¹ The 2002 consensus statement on health care transition of the American Academy of Pediatrics, American Academy of Family Physicians, American College of Physicians, and American Society of Internal Medicine mandated that “all adolescents with special healthcare needs should have a written healthcare transition plan by the age of 14 years.”²

In general, studies across various pediatric patient populations have found transition care to be suboptimal. For example, in an analysis of data from the 2000–2001 National Survey of Children with Special Health Care Needs, Scal and Ireland³ found that only about half of the parents of 4,332 children aged 14–17 years had discussed transition needs with their child’s provider, and only 16.4% had developed a plan to address these needs.

Although there is a paucity of data on diabetes transition practices in the United States, review of the literature and the author’s 2009 survey of members of the Pediatric Specialty Practice Group of the American Association of Diabetes Educators (AADE) indicate that many U.S. pediatric endocrine practices struggle with developing workable, effective models for suc-
cessful transition. Of the 176 AADE members surveyed, only 4 of the mere 9 respondents indicated that they had implemented a structured transition program. A 2007 survey by the International Society for Pediatric and Adolescent Diabetes (ISPAD) indicated that, among the 92 responding members representing 36 countries, ~50% had structured transition programs. However, only one of the five respondents from the United States indicated having a transition program and described it as “partial,” further highlighting the need for progress in this area in the United States.

Barriers to Effective Diabetes Health Care Transition in the United States

Most transition research in diabetes has been conducted in Canada and Europe, where transition is generally mandated at a specific age. At present, the structure of the U.S. health care system poses challenges to transition care. Significant challenges include limited reimbursement for transition services, limited access to adult providers experienced with salient developmental issues, and difficulties obtaining insurance coverage for young adults.

At the level of the patient-provider relationship, several modifiable barriers to successful transition have been identified. For example, young adults and families have reported negative experiences when age was used as an arbitrary trigger for transition. Also, longstanding relationships among patients, parents, and providers have been reported to hinder establishment of trust with the new adult diabetes team, as is the case with other chronic conditions of childhood. Finally, a lack of shared institutional databases or electronic medical records between pediatric and adult providers also limits provider communication and transition of care.

Along similar lines, and including many of the concepts described above, the Committee on Disability in America has identified multiple barriers to health care transition for adolescents with special health care needs. These include 1) involvement of multiple service delivery systems with no organized system overall for care coordination, 2) inadequate communication among health care professionals, and 3) language and cultural barriers.

In addition to these issues, review of the diabetes literature and the AADE pediatric educators’ survey have identified other key barriers, such as a relative lack of multidisciplinary diabetes teams in the adult care setting compared to the pediatric setting, lack of a standardized diabetes transition curriculum, and limited opportunity for communication between pediatric and adult providers or organization of combined pediatric/adult diabetes clinics to promote patient comfort with the transition.

From young adults’ perspective, competing priorities and busy life demands are major barriers to the establishment of reliable adult diabetes care.

Making Strides

Despite the many challenges, diabetes care teams around the world are making some progress with innovative and exciting programs and tools to help adolescents move through this potentially difficult time. As noted above, a significant proportion of transition research and program development is evolving in other health care systems, where transition age is mandated and programs are financially supported.

Various approaches to meeting the clinical, educational, and networking needs for transitioning adolescents with diabetes have been initiated with success. Sometimes these approaches have been suggested by the patients themselves. Educational formats include individualized instruction at clinic visits over time, residential holiday weekends, day-long workshops for transitioning teens, shorter group educational events, 2- to 4-hour panel presentations for adolescents and families featuring a variety of experts, discussion forums, and social events. Evening clinics are preferred by young adults and have been initiated to improve clinic attendance. Media used to reach out to older teens include newsletters, comprehensive Web sites, e-mail, telephone calls, and text messaging.

Joint ventures between pediatric and adult services have included young adult clinics, shared visits with pediatric and adult services clinics, and periodic meetings of pediatric and adult staff to discuss common patients.

Transition Program Tools

To equip young adults and their families for transition and the probable transfer of care, diabetes care and education services must prepare themselves for the task. One essential tool is a diabetes-specific transition curriculum that outlines the essential information that needs to be shared with patients and family. The curriculum and educational process should also facilitate transfer of information and skills from family caregivers to adolescents. This process should begin

Table 1. Diabetes-Specific Transition Topics

- Mastering Your Diabetes Medication Regimen
- Managing Your Diabetes Medication and Supplies
- Managing Your Own Health Care
- Financing Diabetes Care
- Preparing for Life After High School: Career or School
- Heading Off to College or Other Secondary School
- Roommates/Living Alone
- Diabetes and Employment
- Traveling by Car or Air
- A1C
- Meal Planning on Your Own
- When You Are Sick
- Social Risk-Taking and Diabetes
- Hypoglycemia
- Complications and How to Avoid Them
- Sex-Specific Reproductive Health Issues
- Changing Diabetes Care Teams
- Resources for Transitioning Teens
early, with many programs beginning “transition talk” around the age of 12 years for most patients. Six key competency areas include self-advocacy, independent health care behavior, sexual health, psychological support, education and vocational planning, and health and lifestyle. The author’s institution (Nemours Children’s Clinic—Orlando) has developed a curriculum and associated patient/family transition guide for internal use. Specific topics outlined in those documents are listed in Table 1.

Providing patient/family checklists and assigning “homework” (e.g., having a young patient call the pharmacy for a prescription refill before the next visit) may help patients and their families meet transition goals in a timely manner. Using a variety of media may encourage and enhance learning. Providing lists of local adult diabetes services/education resources and lists of diabetes centers available to students near a state’s major colleges and universities can help link patients and families to the receiving diabetes team. Contact information for the Student Disabilities Offices at public colleges and universities can also help.

The documentation process for the topics and skills covered should enable all team members to participate and address curriculum components with patients and families at an opportune time. Electronic medical record systems often have automatic “pop-up” capability that could trigger age-appropriate transition checklists accessible by all staff participating in the visit. This feature can ease the burden on any one member of the diabetes team. Furthermore, this documentation could populate encounter notes being shared with the adult diabetes team and primary care providers.

Transition experts now recommend that the pediatric team, assisted by patients and parents, complete transition summaries that are sent to the receiving services before transfer of care. These summaries could include the problem list and pertinent medical history, recent laboratory findings, medication names and dosing schedules, information on self-monitoring, recent diabetes education history, and research participation.

Recent studies and reviews support the use of a transition coordinator in diabetes. It is not yet clear whether that role should be clinical, administrative, or divided, and that issue may depend on the setting. Using a member of the pediatric diabetes education team who could help identify and address self-care deficits may work best in some settings. Using a diabetes-trained administrative assistant might be effective if the role is primarily coordination of care and services.

An expanding array of transition resources is becoming available. The National Diabetes Education Program has recently developed an online transition tool that includes a transition planning checklist for the diabetes care team, a clinical summary for the new health care team as outlined above, and a hyperlinked resource list for patients, parents, and providers. The ISPAD has recently articulated its recommendations for transition in its 2009 Clinical Practice Guidelines.

Other useful and accessible online resources, including a sample care map for a combined pediatric and adult clinic, are listed in Table 2.

Table 2. Links to Online Transition Tools*

<table>
<thead>
<tr>
<th>Tool/Resource</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sample diabetes transition care pathway</td>
<td><a href="http://www.fitforthefuture.northstaffs.nhs.uk">www.fitforthefuture.northstaffs.nhs.uk</a></td>
</tr>
<tr>
<td>National Diabetes Education Program online tools</td>
<td><a href="http://www.YourDiabetesInfo.org/transitions">www.YourDiabetesInfo.org/transitions</a></td>
</tr>
<tr>
<td>Sweet: the diabetes transition program at Mater Children’s Hospital, in Brisbane, Australia (interactive learning resources for patients, models, checklists, and forms for health care professionals)</td>
<td><a href="http://www.sweet.org.au">http://www.sweet.org.au</a></td>
</tr>
<tr>
<td>Adolescent Health Transition Project: Diabetes Mellitus (tools for teens and parents, including online video of April 2009 Diabetes Teen Transition Panel)</td>
<td><a href="http://depts.washington.edu/healthtr/diabetes/index.html">http://depts.washington.edu/healthtr/diabetes/index.html</a></td>
</tr>
</tbody>
</table>

*All tools accessed 28 August 2010

References


2. American Academy of Pediatrics, American Academy of Family Physicians, American College of Physicians, American Society of Internal Medicine: A consensus statement on the development of transition care for patients with diabetes remains in the early stages, particularly in the United States. Evidence-based data are limited, and many questions remain. The tools highlighted above are an important start, but their efficacy remains to be determined in future investigations. Importantly, as new transition programs develop, solid evaluation measures will be imperative. However, appropriate outcome measures are unclear. Possible measures include frequency of adult diabetes clinic attendance; A1C; intermediate outcomes such as frequency of self-monitoring of blood glucose; and patient-related outcomes such as satisfaction, health-related quality of life, or problem areas in diabetes. In addition, transition programs must address the importance of communication and collaboration among all stakeholders, including patients, family members, the pediatric diabetes team, and adult diabetes care providers.

8Scal PB, Ireland M: Addressing transition to adult health care for adolescents with special health care needs. *Pediatrics* 115:1607–1612, 2005


Paula Lynne Jameson, MSN, ARNP, FNP-BC, CDE, is the diabetes program coordinator and an endocrine nurse practitioner at the Nemours Children’s Clinic in Orlando, Fla.