

EDITORIAL

Optimizing transitional care for emerging adults with Type 1 diabetes: what needs to be done and by whom?

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“Many young people are lost to follow-up during the transition from pediatric to adult care and others struggle to establish and maintain a connection with their adult diabetes providers...”

The issue of transition from pediatric to adult care represents a major clinical concern in diabetes care [1,2]. Although the evidence suggests that this is a critical developmental period in the lives of young people with diabetes, in terms of their future health, health behaviors and general psychosocial functioning [3], there is a dearth of clinical programs and research focused on transition issues [4]. Many young people are lost to follow-up during the transition from pediatric to adult care and others struggle to establish and maintain a connection with their adult diabetes providers, like they experienced with their pediatric healthcare teams [5]. Much is at stake during the developmental period corresponding with transition such as increased risk of cigarette smoking, unprotected sexual behavior and illicit drug and alcohol experimentation [3,6]. The evidence suggests that young adults with chronic illnesses, such as diabetes, are more likely to be delayed in achieving autonomy and psychosexual and overall social development [7]. These difficulties make transition more problematic and difficult compared to otherwise healthy peers [8].

Several studies have outlined problems with the transition of youth with diabetes and other chronic illnesses [9]. Kipps *et al.* observed a marked decline in clinic attendance around transition [10]. Pacaud *et al.*

observed a lapse of greater than 6 months between the last pediatric visit and first adult visit for 31% of their population, with 11% completely lost to follow-up [5]. Pacaud *et al.* reported that in their study, 46% of adolescents with diabetes who transitioned to adult care reported problems [5]. Participants reported that the transition was abrupt and in adult settings there was less guidance about healthcare decisions, reduced access to adult physicians, longer periods between appointments and less coordination between care professionals (e.g., dietitian, primary care provider and psychologist).

Raymond and associates examined the beliefs and behaviors of pediatric patients and their families regarding transition from pediatric to adult care prior to transition [11]. Their data indicated approximately 72% of parents and 75% of patients reported that they had not talked about the eventual need to transition. Approximately 92% of parents and 86% of patients reported that they had not received transition information from their pediatric provider and 90% of parents and pediatric patients reported that they did not have a transition plan. Approximately half of respondents reported that it was the family's responsibility to organize the transition process, while an almost equal number reported that it was the physician's responsibility. Both



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pediatric patients and their parents felt that discussions about transition should begin at 16.5–17 years of age, patients should begin seeing the doctor alone at 17.5 years, and transfer of care should occur at approximately 18 years of age. While these findings are not surprising to anyone working clinically with this population, it is discouraging that families of youths with diabetes have not done more to prepare for the eventual transition from pediatric to adult care.

Duke and associates examined retrospectively the transition experience of 18–28-year-olds who were diagnosed with diabetes as children [12]. The primary reason patients reported for changing from pediatric to adult care, and the most common method of finding an adult diabetes physician, was the recommendation of their pediatric physician. Approximately 58% of patients reported being fine during the transition process. However, 28% reported being worried and apprehensive, while 11% reported ambivalence. The time lapse between the last pediatric visit and first adult care visit was reported to be 1 year or longer by 23%, with 15.4% reporting a greater than 2-year lapse between their last pediatric appointment and first adult diabetes appointment. The most commonly reported age range at time of transition was 17–19 years (53%). Analysis of topics discussed during transition indicated that healthcare providers addressed prescriptions with emerging adults at relatively high rates (83%). However, other important topics such as family planning (33%), social support (38%) and insurance (38%) were less frequently discussed. Topics young adults most frequently indicated they wished were discussed during transition included: the use of diabetes technology, introducing diabetes to others and advocacy.

Our clinical experience, coupled with the extant research suggests that there are multiple and often complex reasons why transition has not been consistently and successfully accomplished in most clinical settings. First, it is clear that both healthcare providers and patients are ill-prepared for transition. One problem is probably a lack of connection between pediatric and adult care providers, coupled with a paucity of empirically derived information about how to best transition youths from pediatric to adult healthcare [13]. The settings are typically very different, with pediatric diabetes care more often being family-centered and interdisciplinary. By contrast, adult diabetes care is more often delivered using a patient-centered multidisciplinary care model. These fundamental

differences in healthcare delivery contribute to the difficulty in accomplishing a smooth and seamless transition. Second, pediatric patients have often established long-term personal relationships with their pediatric providers. Patients, their families and healthcare providers may have significant ambivalence regarding ending the relationship at the time when transition should occur. Third, the developmental demands during this period are complex and often involve simultaneously managing any number of life-altering experiences and decisions. Examples include graduating from high school, making college decisions, establishing intimate relationships, independent living, examining or pursuing career options, and more [8]. These normative demands occur simultaneously with the need to optimize attention to medical care, while the medical system decreases the available support for the young adult. Thus, the risk of inadequate attention to medical care is increased during this critical period. Finally, the transition period between adolescence and young adulthood is marked by some of the worst metabolic control an individual with diabetes is likely to experience in his/her life [14]. Clearly, most of the health risks associated with diabetes are behavioral in origin and thus are partly preventable. Transitioning healthcare services during a period of stress, inadequate health behaviors and suboptimal diabetes control, increases the risks a young person with diabetes will drop out of treatment to avoid clinic visits that are viewed as punitive or negative.

Although key components of transition programs have been outlined, few programs have been developed based on what youth and their parents have identified as important. McGill outlined key components and goals of a transition program [15]. They included self-advocacy with the healthcare team, independent healthcare behaviors, sexual health, education and vocation planning, informed decisions about illicit drug and alcohol use and increased social support. Reiss and Gibson prescribed three primary goals of transitioning pediatric patients to adult care [16]. First, they prescribed the development of family-centered, community-based, coordinated and culturally competent systems for adults as they exist for children. Second, they suggested that healthcare professionals should be informed and trained regarding transition issues. Third, they advocated the use of real-world approaches that can be used effectively by providers and payers.

Finally, the Society of Adolescent Medicine indicated that regardless of the transition model

used there are key principles that should be followed [17]. The summary highlighted the importance of viewing transition from pediatric to adult care as a process, not an event [17]. The transition process should begin at the time of diagnosis and involve the entire family. Other key principles included the need for healthcare providers to prepare themselves for transition, involving the adolescents in the decision-making process and the proper coordination of services. Likewise, several have outlined the need for transitions to be grounded in development psychology, which includes a proper individual assessment, building relationships among patients and healthcare providers, involving the entire family, identifying barriers to transition and establishing specific goals and a treatment plan for transition [1,18,19].

In summary, there are multiple challenges to optimizing the transition of youth with diabetes from pediatric to adult care. Transition occurs during a developmental period in a young person's life when there are many other nondiabetes-related life changes and stressors occurring. Research has demonstrated that many youths with diabetes and their providers are ill prepared for transition, healthcare systems often do not

support transition and specialized transition care can be costly and difficult to implement. While many seem to expect the youth and their family to lead the transition process, it is the pediatric and adult providers who are better equipped to take the lead in transitioning youths with diabetes to adult care. One innovative approach to optimizing transition might include increasing healthcare provider awareness regarding the transition process and related issues and training them in how to best assist their patients and families with the transition to adult care. Such a strategy would be a pragmatic, sustainable and generalizable approach that does not further burden patients or their families often during this critical time in their lives.

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