

Addressing the burdens of Type 1 diabetes in youth

Sureka Bollepalli¹, Laura B Smith¹, Amanda Vasquez¹, Henry Rodriguez¹
& Kendra Vehik²



Practice Points

- Type 1 diabetes (T1D) is an immune-mediated disorder that requires lifelong dependence on exogenous insulin therapy and imposes demands on patients and their families that impact virtually every aspect of day-to-day life.
- A lack of adequate glycemic control can lead to increased acute and chronic diabetes complications.
- Diabetes self-management education and medical nutrition therapy are essential components of diabetes management.
- Youth with T1D in the USA face additional burdens at school relating to the lack of appropriately trained staff, policies that prohibit staff assistance, limitations on adherence to the diabetes management plan and missed class time.
- Youth with T1D are at greater risk for psychological adjustment difficulties including depression, anxiety, disordered eating and family conflict related to diabetes management.
- It is essential to create a diabetes care plan that includes an insulin regimen, delivery system, blood glucose monitoring system and nutrition/activity plan that can meet an individual's needs and lifestyle.
- Multidisciplinary diabetes teams possess the expertise and experience necessary to assist patients in addressing the burdens associated with T1D and are up-to-date on current research, new medications/equipment, lifestyle challenges and psychosocial burdens.

¹Department of Pediatrics, University of South Florida Diabetes Center, 12901 Bruce B Downs Blvd, MDC 62, Tampa, FL 33612, USA

²Department of Pediatrics, Pediatrics Epidemiology Center, University of South Florida, College of Medicine, 3650 Spectrum Blvd STE 100, Tampa, FL 33612, USA

*Author for correspondence: Tel.: +1 813 974 8536; Fax: +1 813 974 3313; sbollepa@health.usf.edu

SUMMARY In this review, we will discuss the burdens of Type 1 diabetes (T1D) that are faced by youths in the USA, which impact virtually every aspect of day-to-day life. A multidisciplinary diabetes care team can effectively address the burdens of T1D in order to achieve adequate glycemic control and to minimize the risk of acute and chronic complications. The support of a multidisciplinary diabetes team possessing varying and complementary skills in collaboration with other healthcare providers can assist youth with T1D and their families in overcoming the multitude of potential obstacles. The development of an individualized diabetes care plan that accommodates the patient's lifestyle is essential for improving the quality of life, while allowing the patients to maximize their potential and achieve their life goals.

Addressing the burdens of Type 1 diabetes in youth

Type 1 diabetes (T1D) is an immune-mediated disorder characterized by progressive destruction of the pancreatic β -cells, leading to insulin deficiency and consequent hyperglycemia. It is a chronic illness that requires lifelong dependence on exogenous insulin therapy. As a result, T1D imposes demands on patients and their families that impact virtually every aspect of day-to-day life. Despite technological advances in insulin preparations, insulin delivery devices and blood glucose monitoring, the management of T1D in the USA remains a major burden. Maintaining adequate metabolic control to minimize the risk of diabetes-related complications while preserving quality of life and a flexible lifestyle continues to be a major challenge for youth with T1D.

In this review, we will emphasize the importance of multidisciplinary care to address the burdens of T1D in order to achieve adequate glycemic control and to minimize the risk of acute and chronic complications. The support of a multidisciplinary team possessing varying and complementary skills can assist youth with T1D and their families in overcoming a multitude of potential obstacles including concerns/issues at school/work, financial conflicts, psychological burdens of the disease, and choice of insulin regimen and method of insulin delivery. This facilitates the selection of a treatment plan that best accommodates the patient's lifestyle, which can dramatically improve quality of life, allowing the patient to maximize their potential and achieve their life goals. Advances in technology and research continue to improve treatment modalities with the intention of developing a cure. However, current treatment still requires commitment and ongoing daily efforts

from the patient and their support network to achieve optimal glycemic control and minimize diabetes-related complications.

Incidence of diabetes

There has been a significant rise in the incidence of T1D worldwide. The largest increase is occurring in younger individuals (<5 years of age) who will have the greatest lifetime burden associated with the disease. In Europe, there is a reported overall annual increase of 3.9% in the incidence of T1D and a possible doubling of the incidence rate in children <5 years of age by 2020 [1]. While the USA lagged behind the increasing incidence throughout the 1970s to the 1990s reported by Europe, recent reports show increasing US incidences similar to worldwide trends [2]. The SEARCH for Diabetes in Youth (SEARCH) study reported that the 2002–2005 incidence of T1D in non-Hispanic white youth aged ≤ 14 years was 27.5/100,000 per year [3], 14.1/100,000 in Hispanic youth [4], 15.7/100,000 in African–American youth [5] and 6.4–7.4/100,000 in Asian–Pacific Islander youth [6]. Such increasing rates have global consequences, including increasing hospitalizations, increasing micro- and macro-vascular complications, increasing medical care costs and reduced lifetime productivity. Complications associated with T1D, both acute and chronic, as well as mortality, vary geographically and ethnically. Those in the youngest age groups (0–4 years) have the highest rates of diabetic ketoacidosis (DKA; primary acute complication) with rates in the USA of almost 30% [7]. Reports have suggested that overall awareness of T1D and access to care are primarily responsible for the geographical variation [7]. By contrast, the global variation in the prevalence of long-term complications – primarily nephropathy

and retinopathy affecting adults – appears to be due to factors such as socioeconomic status (SES), access to healthcare, duration of diabetes and basic demographic characteristics including family structure [7]. While mortality from T1D is relatively low it is nonetheless twice that of the general diabetes-free population [7]. Poor glycemic control is the main culprit; however, SES plays a significant role in mortality as well. The Pittsburgh Epidemiology of Diabetes Complications Study (EDC) study recently reported that mortality in T1D is mediated by education as a marker of SES [8], whereas those with a college degree had lower rates of mortality. Additionally, the EDC showed that hemoglobin A1c (HbA1c), a marker of glycemic control, was inversely associated with income level [9]. Addressing the burden of this disease is complex and requires an approach that takes into account geographical and ethnic background, as well as SES.

Burdens of T1D

T1D is a demanding and burdensome disease that can result in multiorgan failure without continuous care. The day-to-day management is time consuming and involves meticulous balancing of insulin replacement with diet and exercise, and is a crucial element of ensuring better quality of life and a positive long-term outlook. Optimal therapy requires a youth with T1D and his/her family to monitor dietary intake, count carbohydrates, match insulin to carbohydrate intake, administer multiple daily injections (MDIs) or master insulin pump therapy, and monitor the blood glucose four or more times daily [10]. Adherence to this regimen can become overwhelming when also coping with the demands of school, work and family obligations. A lack of diabetes control and proper insulin therapy often promotes diabetes-related family conflict, poor school performance and/or increased interpersonal conflict [11], in addition to physiologic damage.

Exogenous insulin therapy is lifesaving for individuals with T1D and can decrease their long-term morbidity. However, the adverse effects of insulin are often barriers to adherence to prescribed insulin regimens. Exogenous insulin administration circumvents the normal physiological response to hypoglycemia, including counter-regulatory hormone release. Hypoglycemia can impair cognition, precipitate convulsions and lead to death. The risk of hypoglycemia is heightened in the younger age group (<5 years of age) [12] and for

those on intensive insulin therapy [13]. Therefore, iatrogenic hypoglycemia is a common obstacle to achieving a near-normal blood glucose control [14]. Also, since insulin is lipogenic, replacement with high doses of exogenous insulin therapy can exacerbate weight gain [13]. Weight gain contributes to an increased risk of cardiovascular disease and insulin resistance [15]. Further obstacles to achieving effective insulin therapy include fear of needles and of self-injection. Although intensive insulin therapy is recommended as early as possible to achieve near-normal glycemia, safety is the priority [16]. Consequently, glycemic targets are tailored to age [10]. Insulin analogs and delivery systems (i.e., insulin pumps) are designed to reduce the burden of manual administrations, reduce hypoglycemia and improve glycemic control; however, they can be cost-prohibitive based on medical insurance coverage.

The financial burden of diabetes in the USA can be immense and can further contribute to nonadherence and family stress if patients are unable to afford their diabetes medications or supplies. The total US annual medical expenditure for T1D is reported to be US\$6.9 billion with a per capita expenditure of \$6288 per year (hospitalizations and diabetes care supplies account for over 75% of the annual cost) [17]. The costs are additive and include medical visits and a multitude of diabetes supplies (blood glucose monitors, lancets, lancet devices, test strips, alcohol pads, glucagon kits, ketone test strips, glucose tablets, syringes/pen needles and insulin vials/pen devices). Insurance coverage is frequently a source of frustration and a barrier to acquiring optimal therapies. As a result, some patients settle for suboptimal insulin regimens that do not accommodate their lifestyle and personal needs. Increased morbidity associated with poor glycemic control exponentially adds to the financial burdens associated with T1D. Recent reports indicate that progression of diabetic nephropathy is associated with a 30–40% rise in annual baseline medical costs, at least some of which is typically borne by the patient [18]. Additionally, the nonmedical costs include stress and lost productivity. Therefore, support of a social worker and financial specialist is essential to maintaining optimal quality of life and reducing the financial burden on families with T1D.

The risks and complications from T1D range from acute to chronic and include an increased

likelihood of acquiring other associated autoimmune disorders. The autoimmune diseases that patients with T1D are at an increased risk of include celiac disease (1–16% of individuals with T1D), thyroid disease (17–30% of individuals with T1D), Addison's disease and pernicious anemia. Therefore, close monitoring for development of signs/symptoms of these associated disorders is imperative to improving patients' overall wellbeing [10].

The lack of adequate glycemic control can lead to increased acute diabetes complications, including emergency room visits and hospitalizations associated with hypoglycemia or DKA. Cerebral edema is a devastating complication of DKA and the leading cause of mortality among youth with T1D. Factors associated with an increased risk of these acute complications include poor glycemic control, intrafamily conflict, presence of psychological/behavioral problems, lower social competence and inadequate health insurance coverage. More specifically, adolescent girls are at the highest risk for DKA and the highest incidence of hypoglycemia is in the youngest children [19]. Despite the technological advances in diabetes care, youth with T1D remain at high risk for these acute complications, particularly those with poor glycemic control. The overall incidence rate of hospitalizations in youth with T1D has been reported to be more than three-times the rate in the general pediatric population [20]. These acute events contribute to absenteeism at school and work, impaired performance, and increased morbidity and risk of mortality [17].

Inadequate diabetes management can also impact the growth, as well as physical and psychological development of young children and adolescents. As the incidence of diabetes rises, the burden of increased morbidity and mortality associated with the micro- and macro-vascular complications also rises. While the goal of diabetes management is to achieve optimal metabolic control to minimize these complications, many patients are unable to achieve this. In 1993, the Diabetes Control and Complications Trial (DCCT) showed that the primary benefit of intensive insulin therapy was a significant decrease in the onset and progression of micro-vascular complications (Table 1) [21]. Subsequently, a 10-year follow-up of the DCCT cohort in the Epidemiology of Diabetes Interventions and Complications (EDIC) study showed a significant protective effect of prior intensive diabetes

therapy, compared with conventional therapy, on the progression of coronary artery calcification, diabetic nephropathy, impaired glomerular filtration rate, retinopathy and cardiac autonomic neuropathy. In fact, these protective effects persisted years after intensive therapy [22–26]. The development of diabetes-related complications can be seen even in youth. Up to 30% of adolescents with T1D have been reported to have significant difficulties following their medical regimen [27]. Early-onset diabetic nephropathy is evident in those with poor glycemic control with mean disease duration of 11.32 years [28]. However, adolescents with T1D were found to be as likely as adults to benefit from early intensive therapy to improve glycemic control and reduce the risks of complications [29]. The benefits of intensive insulin therapy do not diminish over time if HbA1c rises subsequently [30]. Therefore, the goal of all clinicians should be to achieve optimal metabolic control with a HbA1c goal of less than 7–8% as early in the disease process as possible [16]. This can be achieved with a diabetes care plan tailored to the individual's needs, which should be modified to fit the child's developmental stages as they emerge into adulthood.

Diabetes management is constant and must continue at school. Therefore, school personnel play an integral role in the student's diabetes care [27]. In the USA, some schools have limited or no availability of school nursing or other appropriately trained staff [31] and often school personnel lack an understanding of T1D and diabetes care [27]. In other instances, even when staff are available, school policies may prohibit staff from administering insulin/glucagon when necessary [32]. As a result, students are often required to manage their diabetes on their own and, for those who are not independent, parents must provide the care [33]. School policies have also been identified as potential barriers to proper management of diabetes at school. In the USA, these include the requirement to leave the classroom to check/treat blood glucose values, lack of additional time to complete tests and assignments and restrictions on having snacks or restroom breaks when necessary [32,34,35]. These policies can lead to a delay in treatment and missed class time/teacher instruction, which can place youth with T1D at risk for serious complications and pose additional educational risks [31,35]. A study carried out by Wagner and colleagues found that 72% of parents indicated that there was a

designated person – generally the school nurse – trained to handle diabetes-related emergencies at school. However, only 6% reported that there was a second trained person available in the event of an emergency. The same study found that 57% of students had no available help for after-school activities and that 97% of nurses felt that afterschool advisors should be more knowledgeable about diabetes care [32]. There are currently no laws in the USA that require private schools to meet the needs of students with special medical conditions; however, there are state and federal laws that protect students in public schools. The American Diabetes Association (ADA) states that “appropriate care at school is essential for the child’s immediate safety, long-term well-being and optimal academic performance” [36]. Therefore, families may need an advocate to help support and balance their child’s diabetes and educational needs at school.

Given the complexities of diabetes management and the constant vigilance that is required, it is not surprising that patients with T1D often experience emotional difficulties. While many youths adjust well to T1D, substantial numbers experience decreases in their health-related quality of life, suggesting that their disease negatively impacts their physical functioning and psychological well-being [37]. However, general measures of quality of life have shown that youths with T1D have similar levels compared with youths without T1D [38], suggesting that diabetes has a more focused impact on their functioning. Difficulties in psychological functioning are also common in youth with T1D. Cross-sectional studies have found that 10–20% of youths with T1D experience clinically significant depression [39,40], while 13–17% experience significant anxiety [41]. In recent years, there has been increasing focus on the occurrence of disordered eating in patients with T1D, most notably omitting or reducing insulin in order to lose weight. In fact, estimates suggest that as many as 10% of girls and 1.4% of boys with T1D engage in insulin omission to lose weight. Furthermore, while youth with T1D show less dieting behavior and body dissatisfaction than youth without T1D [42], almost half of females with T1D have reported disordered eating, which can include skipping meals and excessive exercising, as well as insulin omission [43]. Given these findings, a sizable percentage of youth with T1D are at risk of unhealthy eating behaviors. While psychological

Table 1. Risk reduction in patients on intensive insulin therapy* in the Diabetes Control and Complications Trial.

Microvascular complication	Reduction (%)
Severe nonproliferative diabetic retinopathy	47
Progression of retinopathy	63
Microalbuminuria	39
Macroalbuminuria	54
Neuropathy	60

*As compared to the Diabetes Control and Complications Trial conventional insulin therapy group. HbA1c values in the intensive therapy group were significantly lower than in the conventional therapy group ($p < 0.001$).

Data taken from [21].

difficulties certainly have a detrimental impact on a patient’s life, their diabetes care is often also negatively affected. Youth with T1D who have comorbid psychological conditions and/or poorer quality of life also tend to have poorer glycemic control [40,41]. It is not clear whether T1D, T1D with poor glycemic control, or psychological difficulties and quality-of-life deficits are causal in the negative cycle that yields difficulties in each of these areas; however, it is clear that these problems are common and typically co-occur.

It is also important to consider developmental issues and how T1D impacts youths’ functioning over time. While many youths with T1D experience a period of mild adjustment difficulties soon after diagnosis, there is some evidence that these difficulties resolve quickly in the first year after diagnosis [44]. Furthermore, in a 10-year follow-up of youths diagnosed with T1D in childhood, there were no notable differences in psychiatric symptoms or other psychosocial variables, such as educational attainment and employment, suggesting that youths with T1D generally function at the same level as their nonaffected peers. However, youths with T1D did show lower levels of self-esteem, which may lead to psychological difficulties in the future [45]. Conversely, other research has suggested that, over time, and particularly at points of transition or developmental changes (e.g., school entry, puberty and adolescence), patients with T1D are at an increased risk of psychological difficulties. It is not surprising that typical developmental changes, such as the increasing need for independence and autonomy in adolescence, are associated with declines in both psychological functioning [40] and diabetes management [46]. In part, as youth have T1D for longer periods of time, they may experience fatigue resulting from the daily care of a chronic,

time-consuming condition [47]. In particular, when a child or adolescent perceives that their disease is so burdensome – due to a lack of positive results or the ongoing daily demands among other factors – they may no longer feel able or willing to care for it properly. Experiencing fatigue with diabetes care leads to poor management and can also be associated with difficulties in psychological functioning.

In addition to the individual impact of T1D on youths, the disease can greatly impact the family. Many families experience increased conflict and arguing as a result of the prescribed daily diabetes tasks that may be difficult to implement. This type of diabetes-specific family conflict has been consistently linked to poor glycemic control and diabetes management in youths [48] as well as difficulties in psychological functioning in youth, such as symptoms of depression and anxiety [49]. Parents of youths with T1D can also have difficulty coping and often experience stress related to their child's diagnosis and ongoing treatment [50]. The occurrence of these diabetes-specific difficulties in parents has also been related to poorer parental psychological functioning [51] and poorer child psychological functioning [52], but not to diabetes management and glycemic control [53]. Furthermore, general life stress reported by parents has also been associated with poorer health outcomes in youths with T1D [54]. Overall, T1D may impact the youth's individual functioning, family interactions and/or parent functioning. When psychological or adjustment concerns arise in these areas, diabetes management, as well as general functioning, is negatively affected.

■ Addressing the burdens of T1D with multidisciplinary care

Youths diagnosed with T1D are confronted very early in life with responsibilities for their health. T1D treatment is demanding and the most challenging and time-consuming piece – maintaining adequate glycemic control – is also the most important in reducing immediate and long-term complications. As shown by the DCCT, intensive insulin therapy to improve glycemic control can minimize the risk of acute and long-term complications and can help reduce the financial burden and improve quality of life for those with the disease [21,55]. However, several reports indicate that only 33–34% of children with T1D achieve a target HbA1c of <8.1% [20,56]. Achieving optimal

glycemic control requires that the patient and their family successfully overcome the numerous challenges mentioned above. Multidisciplinary diabetes teams in the USA possess the expertise and experience necessary to assist patients in meeting these challenges and improving their glycemic control. These teams are experts in the disease and are up-to-date on current research, new medications/equipment, lifestyle challenges and psychosocial burdens.

Medical care

In the USA, all youth with T1D should be given a comprehensive diabetes evaluation as outlined in the ADA's Standards of medical care in diabetes – 2012 [10]. Monitoring diabetes self-care and measurement of glycemic control with quarterly HbA1c measurements (depending on the level of the patient's glycemic control) is a critical part of routine care. Screening for autoimmune disorders and assessing the risk for microvascular and macrovascular complications are also essential components of diabetes medical visits (Table 2). Attending quarterly clinic visits generally requires patients to miss school/work days. Distance frequently adds additional burdens of time and travel expense as many patients do not have local access to multidisciplinary teams. To combat this distance issue, some practitioners/hospitals have developed satellite clinics with ancillary services in more remote areas. More recently, telemedicine has been shown to be an effective strategy to deliver care in remote areas [57]. A combination of telemedicine visits/primary care visits once every 3 months with an annual face-to-face visit with a multidisciplinary team can dramatically improve the care provided to patients with T1D while reducing some of the burden of the disease.

■ Blood glucose monitoring devices

The ability to self-monitor blood glucose (SMBG) can reduce the burden by providing a level of control over T1D and improved quality of life. Home blood glucose monitoring devices have been available since the 1970s. Patients with T1D should monitor their blood glucose a minimum of four-times daily [10]. A number of studies have documented the association between increased SMBG frequency and improved glycemic control [58,59], with such benefits extended in younger patients with T1D [60,61]. In a pediatric population, the frequency of blood glucose monitoring

Table 2. Screening recommendations for youths with Type 1 diabetes.

Complication/comorbidity	Screening test	Frequency
Microalbuminuria	Random spot urine sample for albumin:creatinine ratio	Annually, once the child is 10 years of age and has had T1D for 5 years
Hypertension	Blood pressure measurement (appropriate size cuff must be used)	Every visit
Dyslipidemia	Fasting lipid profile	Family history of hypercholesterolemia or a cardiovascular event before age 55 years or if family history is unknown: >2 years of age Family history is negative: ≥10 years of age Diagnosed with T1D at or after puberty: after diagnosis once glucose control is established
Retinopathy	Dilated eye examination	First exam: ≥10 years of age and T1D for 3–5 years, then annual follow-up. Less frequent follow-up is acceptable if recommended by eye care professional
Celiac disease	Tissue transglutaminase or antiendomysial antibodies, IgA	Soon after diagnosis of T1D, repeat as needed for children with growth failure, failure to gain weight, weight loss, diarrhea, flatulence, abdominal pain or signs of malabsorption, or in children with frequent hypoglycemia or decline in glycemic control
Hypothyroidism	Thyroid peroxidase and thyroglobulin antibodies, TSH	Soon after diagnosis, repeat TSH every 1–2 years or sooner if patient develops symptoms of thyroid dysfunction, thyromegaly or an abnormal growth rate
Psychological concerns (e.g., depression, anxiety and eating disorders)	Standard clinical interview questions and/or psychological screening questionnaires (e.g., PSC-17 [91])	Every visit, particularly if glycemic control is suboptimal

PSC-17: 17-item Pediatric Symptom Checklist; T1D: Type 1 diabetes; TSH: Thyroid-stimulating hormone.
Adapted with permission from [10].

was inversely correlated with glycemic control, such that HbA1c levels decreased from a mean value of $9.1 \pm 0.34\%$ to $8.9 \pm 0.16\%$ to $8.0 \pm 0.31\%$ when SMBG frequency improved from once per day to three-times or five-times or more per day, respectively [20].

The advent of a continuous glucose monitoring system (CGMS) has added another facet to the management of T1D and monitoring of blood glucose. The CGMS measures interstitial glucose every 1–5 min for 72 h. The resulting profile is a more comprehensive indicator of glycemic excursions over a 24-h period. The use of a real-time CGMS minimizes the risk of nocturnal hypoglycemia [62] and glucose variability.

For patients, data obtained from SMBG and CGMSs can be extensive and overwhelming. However, the data can be viewed in an organized and meaningful manner with computer programs that provide statistical summaries of blood glucose values displayed in varied user-friendly formats including log books, graphs and percentages of results in and out of range. Using these computer-generated reports, patients have successfully decreased their HbA1c by 10% compared with handwritten logbooks and meters

without memories [63]. Analysis of the data by both the patient and their diabetes care provider at regular intervals can influence adjustments in the insulin regimen, diet and activity level to improve glycemic control [63,64]. Therefore, instructing patients to monitor blood glucose frequently, along with providing educational skills and tools to interpret the data obtained from SMBG and CGMSs and to make adjustments in the diabetes regimen, can enhance the benefit of such data.

■ Insulin therapy

Treatment of T1D requires the subcutaneous delivery of exogenous insulin. Insulins and their delivery have evolved since the discovery of insulin in 1921. Current intensive treatment of T1D requires the provision of sufficient basal insulin to maintain basal requirements over a 24-h period and appropriately deliver insulin boluses to match the glycemic effects of meals. There are an almost infinite number of potential insulin regimens that can accomplish this. Newer rapid-acting insulin analogs have allowed for more rapid onset, sharper peaks and shorter duration of action, which help decrease the rate

of postprandial hyperglycemia and nocturnal hypoglycemia. Formulations of long-acting insulin analogs allow for a more steady profile, with minimal to no peaks. A regime of two to three injections per day, using rapid- and intermediate-acting insulin, requires a more structured and consistent eating pattern with consistent carbohydrate intake. The option of MDIs, using mealtime rapid-acting insulin and a long-acting insulin analog to cover the basal insulin needs, requires multiple injections per day but it provides greater flexibility at mealtimes and provides for the ability to address inconsistent carbohydrate intake. Finding the insulin regimen and insulin delivery system that accommodates the patient's lifestyle and activities is extremely important in helping to minimize the burden of diabetes. There are a variety of delivery systems available today that have different levels of automation, ranging from more manual delivery, such as insulin pens, to continuous subcutaneous insulin infusions (CSII)/insulin pumps.

■ Insulin delivery systems

Many patients begin insulin therapy using insulin vials and a syringe but often transition to other insulin delivery systems. The introduction of insulin pen delivery devices for various insulin preparations in the mid-1980s has facilitated insulin administration, particularly outside of the home. Several studies indicate the advantages of insulin pens (ease of delivery, improved accuracy of dosing at lower insulin doses and audible click to ensure delivery) for improving adherence to the prescribed insulin regimens [65–67].

For patients who would like to minimize manual administration of insulin, CSII/insulin pumps are available to further ease the delivery of insulin. The technology of ambulatory insulin pumps has advanced dramatically since its development in the 1970s [68]. Advances in insulin pumps over the years include: smaller sizes; safety features/alarms (to prevent overdosing and recognize insulin delivery occlusions); wireless pump systems; waterproof devices; smaller increments of insulin delivery (0.01 units/h); altered patterns for insulin delivery based on content of meal; temporary settings to accommodate increased activity, illness and stress; and a large selection of catheters and infusion sets. Some studies indicate that insulin pumps are more effective than MDIs in improving glycemic control [69,70]. Insulin pumps permit patients to vary

basal rates throughout the day to accommodate diurnal changes in insulin requirements. Insulin pumps have been shown to improve postprandial hyperglycemia, decrease nocturnal hypoglycemia and decrease glucose variability [71]. Benefits of insulin pump therapy in the younger age groups have been shown in several studies. These include improved glycemic control, reduction in recurrent/nocturnal hypoglycemia and improvement in quality of life [72,73]. However, some randomized prospective studies indicate no significant difference in glycemic control with insulin pump therapy compared with multiple daily insulin injections [74–77]. Despite these studies showing no benefit in glycemic control, quality of life was shown to improve with insulin pump therapy in two of the studies [75,76].

For all insulin delivery systems, specialized patient education is a necessary component to ensure that the device is being appropriately used. For insulin pump therapy, more extensive education for both patients and caretakers regarding the use of the pump, troubleshooting pump errors, management of blood glucose variability and use of the advanced pump features is necessary for patients to obtain the maximal benefit of the delivery system.

Diabetes education

Understanding the importance of diet and exercise at an early age sets up healthy habits that improve quality of life and management of T1D. Adequate diabetes self-management education should be provided by a certified diabetes educator at diagnosis and at least annually to provide knowledge, as well as problem-solving skills, in all aspects of diabetes management [10]. Education, coupled with the technological advances of blood glucose monitoring systems and the various insulin delivery systems, is a necessary component of diabetes education in order to maximize the benefit of these advances in diabetes care. Therefore, all patients with T1D and their families must receive education on how to use blood glucose meters, administer insulin/glucagon, treat low and high blood glucose values and manage ketones.

A healthy diet is an essential component of every child's development to attain a healthy bodyweight, achieve their genetic height potential and maintain optimal metabolic control. Medical nutrition therapy (MNT) is a component of diabetes education. Education focusing on counting

carbohydrates and optimizing food choices at meals is extremely important. Matching the insulin dose to carbohydrate intake can maintain optimal glycemic control and prevent excess weight gain [78]. There are several web-based programs, handbooks and applications for smartphones available to assist patients with carbohydrate counting and calculating insulin dosages. A healthy diet with an appropriate distribution of fat, carbohydrates and protein (Idaho plate method) will limit the need for excess exogenous insulin and help maintain ideal bodyweight. Emphasis on high-fiber and low glycemic index foods can help reduce sharp rises in postprandial blood glucose levels [79,80]. MNT can also tailor nutrition plans for youths with other comorbidities, such as celiac disease/renal disease. Studies have shown that improvements in HbA1c are sustained for a period of 12 months or more with MNT three to 12 times per year [10]. The design of a meal plan for patients with T1D and their families must take into consideration their food preferences and lifestyles, as well as ethnic and socioeconomic background in order to promote long-term adherence [81].

As important as diet, physical activity is essential for maintaining a healthy, stable weight and achieving optimal glycemic control. The 1996 Surgeon General's Report reinforces the significance of physical activity in health promotion and disease prevention [82,83]. Exercise increases insulin sensitivity and uptake of glucose by the muscles, and reduces body fat [84]. It also improves cardiovascular function by improving risk factors for atherosclerosis. Increased physical activity can improve the lipoprotein profile, reduce blood pressure and improve cardiovascular fitness [83]. Therefore, it is important to encourage all youth with T1D to participate in all levels of activity, recreational or competitive. Diabetes camps [201–217] are available throughout the year in the USA to help promote independence and the importance of activity in a medically safe environment. Furthermore, athletes with T1D, such as Sam Fuld, outfielder for the Tampa Bay Rays, and Chris Dudley, former NY Knicks center, have helped raise the awareness of the importance of physical activity by organizing yearly weekend sports camps addressing the unique needs of athletes with T1D. However, the fear of hypoglycemia can prevent patients from engaging in physical activity. This can be addressed with education about the importance

of SMBG during activity, how to adjust insulin doses, meals, and snacks surrounding activity, and how to recognize and treat low blood glucose [84,85]. This level of education will allow every patient with T1D to continue a healthy level of activity and participate in athletic competition if they choose.

Continuing diabetes education, annually, throughout the patient's lifetime will provide them with the appropriate knowledge, skills and tools to manage their disease and enhance their self-satisfaction and glycemic control. To ensure all age-appropriate and relevant material is covered in the education classes on a yearly basis, it is helpful for the primary care providers and endocrinologists to highlight to the diabetes educator areas of concern. However, in the USA, providers can be assured that all basic concepts of diabetes management, according to the American Association of Diabetes Educators (AADE) guidelines, are reviewed annually within an AADE-certified education program.

Psychosocial care

To address the burdens of diabetes care at school, it is essential that each student in the USA have an individualized diabetes care plan in place. The plan must be developed with input from the patient, family and healthcare provider, and be directly communicated to the school personnel responsible for the student's care [31,36]. The care plan should include a list of diabetes care supplies to be provided by the family, physician orders for blood glucose monitoring and insulin/glucagon administration, a meal/snack plan, exercise guidelines, the student's access to diabetes supplies and the level of supervision necessary to carry out the plan. The plan should further address any necessary accommodations that will allow the child to maximize their success at school, for example, being allowed to evaluate and treat blood glucose in the classroom, having a private space to complete necessary diabetes tasks or having more time to complete tests and monitor blood glucose. The school staff must be trained to recognize symptoms that require immediate attention, such as hypoglycemia [31], and a nurse or trained professional should maintain current knowledge and skills to fully implement a student's diabetes care plan at school [86]. When appropriate, students with T1D should have permission to independently monitor and treat their diabetes while in school and should

not be limited to administering care only within the nurse office or another location outside the classroom [34,36].

In the USA, several laws are in place to protect students with T1D at school. Section 504 of the Rehabilitation Act of 1973 and The Individuals with Disabilities Education Act of 2004 are both federal laws that were designed to protect the rights of students by prohibiting discrimination based on a disability and mandating that children with disabilities, including those with chronic illness, have access to a free and appropriate public education [36]. The Americans with Disabilities Act requires schools to make reasonable accommodations for children with T1D and the ADA has recommended that schools make accommodations and have at least two available personnel trained in diabetes care [36]. The ADA provides advocacy assistance to families who have been unable to receive appropriate care and accommodations at school. At the University of South Florida Diabetes Center (FL, USA), a multidisciplinary team assists the family and school in developing the diabetes medical management plan of care. The team then maintains contact with families and school personnel to provide education and to ensure that individual diabetes care needs are being met, and that family and school personnel questions and concerns are addressed on an ongoing basis. It is important for healthcare providers to be aware of the student's rights so that they can advocate for their needs. Furthermore, it is essential to develop a partnership between the school and the family to establish a comprehensive plan to address the student's needs and to ensure a safe learning environment [27,87].

In addition, in order to provide patients with optimal therapy in a cost-effective manner, it is important for patients and providers to be attentive to the preferred diabetes supplies/medications offered through their insurance carrier so they can manage their diabetes in the most cost-effective manner. Prior authorizations can also be carried out in some instances to help obtain approval for nonpreferred medications/supplies. Intensive insulin therapy can be more expensive and require more resources but, in the long term, it can decrease the incidence of costly chronic complications; therefore, formal economic analyses indicate intensive therapy is a more cost-effective treatment for T1D [55]. In order to reduce long-term complications, optimal

therapy must be maintained through childhood and adolescence and into adulthood.

An additional component of optimal diabetes management is planning for and facilitating the transition from pediatric to adult care. An ideal transition is structured based on individual needs and requires the ongoing collaboration of the youth, family and the medical team. It is important to encourage youth with T1D to actively participate in their diabetes care and an appropriately planned transition can provide the education and support necessary to meet the goals of independent self-management [88]. Providers caring for youth with T1D should recognize changes in cognitive abilities and emotional maturation and provide education and support to promote independence to advance and eventually master diabetes care skills [12]. During the transition to adult care, it is important to address future plans associated with independent living and educational/vocational goals as this may impact insurance coverage as youth 'age out' of their parents' insurance plan or Medicaid coverage [89]. Youth and families should be given information about available resources to ensure continued access to health insurance. It is also important to address issues related to the establishment of healthy adult relationships, sexual functioning, pregnancy, and the effects of smoking, drugs and alcohol use, in general and related to diabetes management [90]. Finally, pediatric providers should partner with adult diabetes providers in the community and provide clear communication through an in-depth health summary to allow for smooth transition [88]. While youths become more independent in their care and decision making during the transition process, it is important to recognize family needs, as parents and caregivers must adjust to a new, less directive role in their child's diabetes management. A multidisciplinary team approach to transition can provide the necessary support and resources to ensure a successful transition to adult care.

When caring for youth with T1D it is also essential to regularly assess for potential adjustment difficulties, particularly if they have poor glycemic control. At a minimum, this should include asking briefly about the patient's emotional, behavioral and social functioning at each visit. Given the high rates of disordered eating behaviors in this population, providers should also inquire about eating habits and attempts to lose weight. A more in-depth assessment

can include providing standardized screening instruments to assess for common psychological disorders such as depression or anxiety. Scales such as the 17-item Pediatric Symptom Checklist (PSC-17) [91] have been shown to be specific and sensitive in identifying psychological difficulties [92] and are easy to administer and score. If psychological difficulties are suspected, a referral to a psychologist, licensed social worker or other mental health professional who specializes in diabetes or chronic health conditions is warranted. The benefits of initiating a timely referral for mental health services in youth with T1D include not only improvements in their psychosocial functioning, but also improved family relationships, and improved diabetes management and health outcomes [93].

For all youth with T1D, regardless of their level of adjustment, healthcare providers can address common difficulties through anticipatory guidance. For example, it is important to emphasize parental involvement in the diabetes regimen, even when youths are capable of completing the tasks independently. While even young children can learn to check blood glucose levels or administer insulin, ongoing parent supervision and support are needed – well into adolescence – if youths are to successfully manage the complexities of daily diabetes management. However, negative parental involvement, in the form of nagging, blaming and conflict about diabetes, can be as detrimental as a lack of parental involvement. Therefore, it is important to emphasize positive, supportive methods of parenting youths with T1D. It can be useful to encourage parents to openly discuss with their child/adolescent the ways in which they can help with the diabetes regimen. If significant family conflict related to diabetes is reported by families, a mental health referral is also warranted, as these issues may be difficult to address in a fast-paced healthcare setting.

Conclusion & future perspective

Over the last few decades in the USA, the awareness of diabetes has increased substantially, mainly due to the increasing prevalence of Type 2 diabetes. Confusion still remains in understanding the difference between the diabetes types, the associated treatment, acute needs, severity of complications and management burden. Medical advances and technology have drastically improved care and quality of life;

however, the burden pervades. The first step in addressing these burdens is increasing patient support through multidisciplinary diabetes teams that can provide medical management plans, education, nutritional advice, psychosocial resources and a support network to reduce the overwhelming nature of managing this disease.

Current studies for T1D are aimed at understanding the physiology of T1D and environmental exposures for prevention, identifying accelerating risk factors and clinical interventions to slow the disease and/or sustain organ function to reduce long-term complications. The Environmental Determinants of Diabetes in the Young study [94] is an international, multicenter, longitudinal study, following children at risk for diabetes starting at birth and comparing different populations with different geographical incidence, different lifestyles and environmental exposures, which will hopefully identify major environmental triggers of autoimmunity and T1D. TrialNet is a network of intervention studies, focused on prevention [95] through vaccine development, preservation of β -cell function [96], reduction of complications and, ultimately, curing the disease. Immunotherapies aimed at preventing β -cell destruction in T1D patients with residual c-peptide continue to be evaluated [97]. Whole-organ pancreas transplantation is effective in restoring and maintaining long-term glycemic control but it is associated with the risks of a major surgery and long-term immunosuppressive drug therapy. Islet cell transplantation, on the other hand, does not carry the risks of significant surgery/general anesthesia and the exocrine pancreas remains intact [98]. Islet cell transplantation may be associated with less progression of microvascular complications than intensive insulin therapy [99]. However, limitations to widespread use of islet cell transplantation include the risk of islet rejection and limited supply of islets for transplantation.

The ‘artificial pancreas’ is the next major development in managing T1D. Both insulin pump therapy and CGMSs have benefits but combining these two technologies truly has the potential to revolutionize the treatment of T1D. A closed-loop system with communication between the two devices approximates an artificial pancreas. Insulin can be delivered according to continuous glucose monitoring data, as directed by a control algorithm, rather than at preprogrammed rates. Investigators are now

moving from hospital-based to ambulatory studies and the hope is that these studies will support regulatory approval of these devices within the next decade. The potential benefits of a closed-loop system for youths are an improvement in glycemic control and a reduction in the risk of hypoglycemia [100], which may alter the patient's fear of glucose excursions (low and high) and therefore reduce the burden of living with T1D for patients and their families.

In summary, there are various insulin regimens, delivery systems and monitoring systems that can meet an individual's needs and lifestyle in the USA. A multidisciplinary team consisting of an endocrinologist, diabetes educator, registered dietitian, financial specialist, social worker and a mental health professional can assist patients and their families in developing

an optimal, individualized diabetes care plan and in coping with the disease and addressing the various burdens of T1D. The team's expertise can provide continuing support to keep patients and their families updated on the advances in diabetes care.

Since multidisciplinary diabetes centers are not always easily accessible, it is essential that all providers caring for youth with T1D screen for barriers that patients may encounter, are aware of community resources that are available to address their struggles and act as advocates for their patients [201–217]. Providers should understand the typical stages of physical and psychological development and how these may impact diabetes management [12]. Quarterly medical visits in conjunction with annual psychological and educational evaluations by providers with expertise

Box 1. Role of providers in a multidisciplinary diabetes team[†].

Medical (MD/DO/ARNP): every 3 months, yearly physician visit if managed by ARNP

- Explanation of physiology/complications of T1D, insulin therapy
- Physical examination/screening laboratories/HbA1c
- Review/analysis of blood glucose logs
- Initiation and continuing management of insulin therapy
- Provide refills of diabetes supplies

Diabetes education (ARNP/RD/CDE): yearly assessment and education or as needed

- Teach diabetes management concepts:
 - Monitoring blood glucose
 - Use of blood glucose meters
 - Calculating insulin doses
 - Administering insulin/glucagon
 - Management of hypoglycemia/hyperglycemia/ketones
 - Dietary/exercise guidelines
 - Review goals of treatment/expectations
- Medical nutrition therapy: counting carbohydrates, matching carbohydrates to insulin dose
- Diabetes and technology education: insulin pump therapy, continuous glucose monitoring systems

Social work: yearly assessment or as needed

- Psychosocial assessments and appropriate referrals
- Support/education/community resource referrals for patients and families
- Ensure access to insurance/medication coverage/follow-up care
- Communication/collaboration with schools and other community providers/agencies
- Events/diabetes camps
- Transition to independent adult care

Psychology/mental health: yearly assessment or as needed

- Psychological assessment
- Anticipatory guidance on parenting a child with diabetes
- Anticipatory guidance on family sharing of diabetes tasks/transition to adult care
- General and diabetes-specific coping skills
- Behavior plans for diabetes tasks when warranted
- Psychological interventions when warranted (individual and/or family-based)

[†]Based on the structure of the multidisciplinary diabetes team at the University of South Florida Diabetes Center (FL, USA). T1D: Type 1 diabetes.

in diabetes are recommended to optimize the patient's care plan (Box 1). Collaboration between healthcare providers and a multidisciplinary diabetes team can provide a level of support that is necessary throughout the patient's lifetime. Finally, as diabetes treatment and technologies advance, patients will benefit from the medical, emotional or behavioral, and educational support to implement and integrate these new advances into their lives.

References

Papers of special note have been highlighted as:

- of interest
- of considerable interest

- 1 Patterson CC, Dahlquist GG, Gyurus E, Green A, Soltesz G. Incidence trends for childhood Type 1 diabetes in Europe during 1989–2003 and predicted new cases 2005–2020: a multicentre prospective registration study. *Lancet* 373(9680), 2027–2033 (2009).
- Discusses possible reasons for the rise in incidence of Type 1 diabetes (T1D), including the role of viruses, gut microbiota, early-life feeding patterns, perinatal factors and childhood growth patterns.
- 2 Vehik K, Dabelea D. The changing epidemiology of Type 1 diabetes: why is it going through the roof? *Diabetes Metab. Res. Rev.* 27(1), 3–13 (2011).
- American Diabetes Association (ADA) position statement about clinical recommendations for diabetes care.
- 3 Bell RA, Mayer-Davis EJ, Beyer JW *et al.* Diabetes in non-Hispanic white youth: prevalence, incidence, and clinical characteristics: the SEARCH for Diabetes in Youth Study. *Diabetes Care* 32(Suppl. 2), S102–S111 (2009).
- Resource on current standards of care for youth with T1D.
- 4 Lawrence JM, Mayer-Davis EJ, Reynolds K *et al.* Diabetes in Hispanic American youth: prevalence, incidence, demographics, and clinical characteristics: the SEARCH for Diabetes in Youth Study. *Diabetes Care* 32(Suppl. 2), S123–S132 (2009).
- Intensive insulin therapy effectively delays the onset and slows the progression of microvascular complications in patients with T1D. The risk of severe hypoglycemia is a two- to three-fold increase.
- 5 Mayer-Davis EJ, Beyer J, Bell RA *et al.* Diabetes in African American youth: prevalence, incidence, and clinical characteristics: the SEARCH for Diabetes in Youth Study. *Diabetes Care* 32(Suppl. 2), S112–S122 (2009).
- Discusses diabetes management in school and day care settings.
- 6 Liu LL, Yi JP, Beyer J *et al.* Type 1 and Type 2 diabetes in Asian and Pacific Islander U.S. youth: the SEARCH for Diabetes in Youth Study. *Diabetes Care* 32(Suppl. 2), S133–S140 (2009).
- Youth with T1D exhibit a high incidence of depressive symptomatology, which is related to poorer diabetes-specific variables. Therefore, it is important to assess depressive symptoms, given that these difficulties not only impact the youths' overall functioning but are also related to poorer diabetes management.
- 7 Borchers AT, Uibo R, Gershwin ME. The geoepidemiology of Type 1 diabetes. *Autoimmun. Rev.* 9(5), A355–A365 (2010).
- Diabetes-specific family conflict between youths with T1D and their caregivers is common and is related to diabetes management variables, such as adherence behaviors and glycemic control. Interventions to improve glycemic control should consider the influence of family interactions, particularly diabetes-specific interactions.
- 8 Secrest AM, Costacou T, Gutelius B, Miller RG, Songer TJ, Orchard TJ. Association of socioeconomic status with mortality in Type 1 diabetes: the Pittsburgh Epidemiology of Diabetes Complications study. *Ann. Epidemiol.* 21(5), 367–373 (2011).
- On average, youths with T1D show a decline in functioning during the adolescent period, both psychologically and with respect to their diabetes management. Difficulties appearing in adolescence may be related to pubertal influences on diabetes as well as normative developmental issues, such as independence seeking. While functioning may improve as youths reach young adulthood, many youths with T1D with difficulties in adolescence continue to have difficulties over time.
- 9 Secrest AM, Costacou T, Gutelius B, Miller RG, Songer TJ, Orchard TJ. Associations between socioeconomic status and major complications in Type 1 diabetes: the Pittsburgh Epidemiology of Diabetes Complication (EDC) Study. *Ann. Epidemiol.* 21(5), 374–381 (2011).
- 10 American Diabetes Association. Executive summary. Standards of medical care in diabetes – 2012. *Diabetes Care* 35(Suppl. 1), S4–S10 (2012).
- 11 Markowitz JT, Volkening LK, Butler DA, Antisdell-Lomaglio J, Anderson BJ, Laffel LM. Re-examining a measure of diabetes-related burden in parents of young people with Type 1 diabetes: the Problem Areas in Diabetes Survey - Parent Revised version (PAID-PR). *Diabet. Med.* 29(4), 526–530 (2011).
- 12 Silverstein J, Klingensmith G, Copeland K *et al.* Care of children and adolescents with Type 1 diabetes: a statement of the American Diabetes Association. *Diabetes Care* 28(1), 186–212 (2005).
- 13 Adverse events and their association with treatment regimens in the diabetes control and complications trial. *Diabetes Care* 18(11), 1415–1427 (1995).
- 14 Cryer PE. Banting Lecture. Hypoglycemia: the limiting factor in the management of IDDM. *Diabetes* 43(11), 1378–1389 (1994).
- 15 Purnell JQ, Hokanson JE, Marcovina SM, Steffes MW, Cleary PA, Brunzell JD. Effect of excessive weight gain with intensive therapy of Type 1 diabetes on lipid levels and blood pressure: results from the DCCT. Diabetes Control and Complications Trial. *JAMA* 280(2), 140–146 (1998).

Financial & competing interests disclosure

The authors have no relevant affiliations or financial involvement with any organization or entity with a financial interest in or financial conflict with the subject matter or materials discussed in the manuscript. This includes employment, consultancies, honoraria, stock ownership or options, expert testimony, grants or patents received or pending, or royalties.

No writing assistance was utilized in the production of this manuscript.

- 16 White NH, Sun W, Cleary PA *et al.* Effect of prior intensive therapy in Type 1 diabetes on 10-year progression of retinopathy in the DCCT/EDIC: comparison of adults and adolescents. *Diabetes* 59(5), 1244–1253 (2010).
- 17 Tao B, Pietropaolo M, Atkinson M, Schatz D, Taylor D. Estimating the cost of Type 1 diabetes in the U.S.: a propensity score matching method. *PLoS ONE* 5(7), e11501 (2010).
- 18 Nichols GA, Vupputuri S, Lau H. Medical care costs associated with progression of diabetic nephropathy. *Diabetes Care* 34(11), 2374–2378 (2011).
- 19 Rewers A, Chase HP, Mackenzie T *et al.* Predictors of acute complications in children with Type 1 diabetes. *JAMA* 287(19), 2511–2518 (2002).
- 20 Levine BS, Anderson BJ, Butler DA, Antisdel JE, Brackett J, Laffel LM. Predictors of glycemic control and short-term adverse outcomes in youth with Type 1 diabetes. *J. Pediatr.* 139(2), 197–203 (2001).
- 21 The Diabetes Control and Complications Trial Research Group. The effect of intensive treatment of diabetes on the development and progression of long-term complications in insulin-dependent diabetes mellitus. *N. Engl. J. Med.* 329(14), 977–986 (1993).
- 22 The Diabetes Control and Complications Trial/Epidemiology of Diabetes Interventions and Complications Research Group. Retinopathy and nephropathy in patients with Type 1 diabetes four years after a trial of intensive therapy. *N. Engl. J. Med.* 342(6), 381–389 (2000).
- 23 Writing Team for the Diabetes Control and Complications Trial/Epidemiology of Diabetes Interventions and Complications Research Group. The Epidemiology of Diabetes Interventions and Complications (EDIC) study. Sustained effect of intensive treatment of Type 1 diabetes mellitus on development and progression of diabetic nephropathy. *JAMA* 290(16), 2159–2167 (2003).
- 24 Cleary PA, Orchard TJ, Genuth S *et al.* The effect of intensive glycemic treatment on coronary artery calcification in Type 1 diabetic participants of the Diabetes Control and Complications Trial/Epidemiology of Diabetes Interventions and Complications (DCCT/EDIC) Study. *Diabetes* 55(12), 3556–3565 (2006).
- 25 Pop-Busui R, Low PA, Waberski BH *et al.* Effects of prior intensive insulin therapy on cardiac autonomic nervous system function in Type 1 diabetes mellitus: the Diabetes Control and Complications Trial/Epidemiology of Diabetes Interventions and Complications study (DCCT/EDIC). *Circulation* 119(22), 2886–2893 (2009).
- 26 De Boer IH, Sun W, Cleary PA *et al.* Intensive diabetes therapy and glomerular filtration rate in Type 1 diabetes. *N. Engl. J. Med.* 365(25), 2366–2376 (2011).
- 27 Nabors L, Troillett A, Nash T, Masiulis B. School nurse perceptions of barriers and supports for children with diabetes. *J. School Health* 75(4), 119–124 (2005).
- 28 Salgado PP, Silva IN, Vieira EC, Simoes E, Silva AC. Risk factors for early onset of diabetic nephropathy in pediatric Type 1 diabetes. *J. Pediatr. Endocrinol. Metab.* 23(12), 1311–1320 (2010).
- 29 White NH, Cleary PA, Dahms W, Goldstein D, Malone J, Tamborlane WV. Beneficial effects of intensive therapy of diabetes during adolescence: outcomes after the conclusion of the Diabetes Control and Complications Trial (DCCT). *J. Pediatr.* 139(6), 804–812 (2001).
- 30 White NH, Sun W, Cleary PA *et al.* Prolonged effect of intensive therapy on the risk of retinopathy complications in patients with Type 1 diabetes mellitus. 10 years after the Diabetes Control and Complications Trial. *Arch. Ophthalmol.* 126(12), 1707–1715 (2008).
- 31 Hayes-Bohn R, Neumark-Sztainer D, Mellin A, Patterson J. Adolescent and parent assessment of diabetes mellitus management at school. *J. School Health* 74(5), 166–169 (2004).
- 32 Wagner J, Heapy A, James A, Abbott G. Brief report: glycemic control, quality of life, and school experiences among students with diabetes. *J. Pediatr. Psychol.* 31(8), 764–769 (2006).
- 33 Hains AA, Berlin KS, Davies WH, Smothers MK, Sato AF, Alemzadeh R. Attributions of adolescents with Type 1 diabetes related to performing diabetes care around friends and peers: the moderating role of friend support. *J. Pediatr. Psychol.* 32(5), 561–570 (2007).
- 34 Boden S, Lloyd CE, Gosden C, MacDougall C, Brown N, Matyka K. The concerns of school staff in caring for children with diabetes in primary school. *Pediatr. Diabetes* doi:10.1111/j.1399-5448.2011.00780.x (2011) (Epub ahead of print).
- 35 Schmitt AJ, Wodrich DL, Lazar S. Type 1 diabetes mellitus case decisions: health-related service considerations for school psychologists. *Psychol. Schools* 47(8), 803–816 (2010).
- 36 Clarke W, Deeb LC, Jameson P *et al.* Diabetes care in the school and day care setting. *Diabetes Care* 35(Suppl. 1), S76–S80 (2012).
- 37 Lawrence JM, Yi-Frazier JP, Black MH *et al.* Demographic and clinical correlates of diabetes-related quality of life among youth with Type 1 diabetes. *J. Pediatr.* doi:10.1016/j.jpeds.2012.01.016 (2012) (Epub ahead of print).
- 38 Laffel LM, Connell A, Vangsness L, Goebel-Fabbri A, Mansfield A, Anderson BJ. General quality of life in youth with Type 1 diabetes: relationship to patient management and diabetes-specific family conflict. *Diabetes Care* 26(11), 3067–3073 (2003).
- 39 Hood KK, Huestis S, Maher A, Butler D, Volkening L, Laffel LM. Depressive symptoms in children and adolescents with Type 1 diabetes: association with diabetes-specific characteristics. *Diabetes Care* 29(6), 1389–1391 (2006).
- 40 Whittemore R, Kanner S, Singleton S, Hamrin V, Chiu J, Grey M. Correlates of depressive symptoms in adolescents with Type 1 diabetes. *Pediatr. Diabetes* 3(3), 135–143 (2002).
- 41 Herzer M, Hood KK. Anxiety symptoms in adolescents with Type 1 diabetes: association with blood glucose monitoring and glycemic control. *J. Pediatr. Psychol.* 35(4), 415–425 (2010).
- 42 Ackard DM, Vik N, Neumark-Sztainer D, Schmitz KH, Hannan P, Jacobs DR Jr. Disordered eating and body dissatisfaction in adolescents with Type 1 diabetes and a population-based comparison sample: comparative prevalence and clinical implications. *Pediatr. Diabetes* 9(4 Pt 1), 312–319 (2008).
- 43 Colton PA, Olmsted MP, Daneman D, Rydall AC, Rodin GM. Five-year prevalence and persistence of disturbed eating behavior and eating disorders in girls with Type 1 diabetes. *Diabetes Care* 30(11), 2861–2862 (2007).
- 44 Northam E, Anderson P, Adler R, Werther G, Warne G. Psychosocial and family functioning in children with insulin-dependent diabetes at diagnosis and one year later. *J. Pediatr. Psychol.* 21(5), 699–717 (1996).
- 45 Jacobson AM, Hauser ST, Willett JB *et al.* Psychological adjustment to IDDM. 10-year follow-up of an onset cohort of child and adolescent patients. *Diabetes Care* 20(5), 811–818 (1997).
- 46 Bryden KS, Peveler RC, Stein A, Neil A, Mayou RA, Dunger DB. Clinical and

- psychological course of diabetes from adolescence to young adulthood: a longitudinal cohort study. *Diabetes Care* 24(9), 1536–1540 (2001).
- 47 Polonsky WH. Understanding and treating patients with diabetes burnout. In: *Practical Psychology for Diabetes Clinicians*. Anderson BJ, Rubin RR (Eds). American Diabetes Association, VA, USA, 219–228 (2002).
- 48 Duke DC, Geffken GR, Lewin AB, Williams LB, Storch EA, Silverstein JH. Glycemic control in youth with Type 1 diabetes: family predictors and mediators. *J. Pediatr. Psychol.* 33(7), 719–727 (2008).
- 49 Williams LB, Laffel LM, Hood KK. Diabetes-specific family conflict and psychological distress in paediatric Type 1 diabetes. *Diabet. Med.* 26(9), 908–914 (2009).
- 50 Streisand R, Swift E, Wickmark T, Chen R, Holmes CS. Pediatric parenting stress among parents of children with Type 1 diabetes: the role of self-efficacy, responsibility, and fear. *J. Pediatr. Psychol.* 30(6), 513–521 (2005).
- 51 Streisand R, Mackey ER, Elliot BM *et al.* Parental anxiety and depression associated with caring for a child newly diagnosed with Type 1 diabetes: opportunities for education and counseling. *Patient Educ. Couns.* 73(2), 333–338 (2008).
- 52 Lewin AB, Storch EA, Silverstein JH, Baumeister AL, Strawser MS, Geffken GR. Validation of the pediatric inventory for parents in mothers of children with Type 1 diabetes: an examination of parenting stress, anxiety, and childhood psychopathology. *Families Systems Health* 23(1), 56–65 (2005).
- 53 Monaghan M, Horn IB, Alvarez V, Cogen FR, Streisand R. Authoritative parenting, parenting stress, and self-care in pre-adolescents with Type 1 diabetes. *J. Clin. Psychol. Med. Settings* doi:10.1007/s10880-011-9284-x (2012) (Epub ahead of print).
- 54 Helgeson VS, Becker D, Escobar O, Siminerio L. Families with children with diabetes: implications of parent stress for parent and child health. *J. Pediatr. Psychol.* 37(4), 467–478 (2012).
- 55 Fioretto P, Mauer M, Brocco E *et al.* Lifetime benefits and costs of intensive therapy as practiced in the diabetes control and complications trial. The Diabetes Control and Complications Trial Research Group. *JAMA* 276(17), 1409–1415 (1996).
- 56 Mortensen HB, Hougaard P. Comparison of metabolic control in a cross-sectional study of 2,873 children and adolescents with IDDM from 18 countries. The Hvidovre Study Group on Childhood Diabetes. *Diabetes Care* 20(5), 714–720 (1997).
- 57 Krakoff LR. Management of cardiovascular risk factors is leaving the office: potential impact of telemedicine. *J. Clin. Hypertens. (Greenwich)* 13(11), 791–794 (2011).
- 58 Schutt M, Kern W, Krause U *et al.* Is the frequency of self-monitoring of blood glucose related to long-term metabolic control? Multicenter analysis including 24,500 patients from 191 centers in Germany and Austria. *Exp. Clin. Endocrinol. Diabetes* 114(7), 384–388 (2006).
- 59 Helgeson VS, Honcharuk E, Becker D, Escobar O, Siminerio L. A focus on blood glucose monitoring: relation to glycemic control and determinants of frequency. *Pediatr. Diabetes* 12(1), 25–30 (2011).
- 60 Ziegler R, Heidtmann B, Hilgard D, Hofer S, Rosenbauer J, Holl R. Frequency of SMBG correlates with HbA1c and acute complications in children and adolescents with Type 1 diabetes. *Pediatr. Diabetes* 12(1), 11–17 (2011).
- 61 Haller MJ, Stalvey MS, Silverstein JH. Predictors of control of diabetes: monitoring may be the key. *J. Pediatr.* 144(5), 660–661 (2004).
- 62 JDRF CGM Study Group. JDRF randomized clinical trial to assess the efficacy of real-time continuous glucose monitoring in the management of Type 1 diabetes: research design and methods. *Diabetes Technol. Ther.* 10(4), 310–321 (2008).
- 63 Strowig SM, Raskin P. Improved glycemic control in intensively treated Type 1 diabetic patients using blood glucose meters with storage capability and computer-assisted analyses. *Diabetes Care* 21(10), 1694–1698 (1998).
- 64 Laffel LM, Hsu WC, McGill JB, Meneghini L, Volkening LK. Continued use of an integrated meter with electronic logbook maintains improvements in glycemic control beyond a randomized, controlled trial. *Diabetes Technol. Ther.* 9(3), 254–264 (2007).
- 65 Korytkowski M, Bell D, Jacobsen C, Suwannasari R. A multicenter, randomized, open-label, comparative, two-period crossover trial of preference, efficacy, and safety profiles of a prefilled, disposable pen and conventional vial/syringe for insulin injection in patients with Type 1 or 2 diabetes mellitus. *Clin. Ther.* 25(11), 2836–2848 (2003).
- 66 Korytkowski M, Niskanen L, Asakura T. FlexPen: addressing issues of confidence and convenience in insulin delivery. *Clin. Ther.* 27(Suppl. B), S89–S100 (2005).
- 67 Luijff YM, Devries JH. Dosing accuracy of insulin pens versus conventional syringes and vials. *Diabetes Technol. Ther.* 12(Suppl. 1), S73–S77 (2010).
- 68 Pickup JC, Keen H, Parsons JA, Alberti KG. Continuous subcutaneous insulin infusion: an approach to achieving normoglycaemia. *Br. Med. J.* 1(6107), 204–207 (1978).
- 69 Pickup J, Mattock M, Kerry S. Glycaemic control with continuous subcutaneous insulin infusion compared with intensive insulin injections in patients with Type 1 diabetes: meta-analysis of randomised controlled trials. *BMJ* 324(7339), 705 (2002).
- 70 Weissberg-Benchell J, Antisdel-Lomaglio J, Seshadri R. Insulin pump therapy: a meta-analysis. *Diabetes Care* 26(4), 1079–1087 (2003).
- 71 Bruttomesso D, Crazzolara D, Maran A *et al.* In Type 1 diabetic patients with good glycaemic control, blood glucose variability is lower during continuous subcutaneous insulin infusion than during multiple daily injections with insulin glargine. *Diabet. Med.* 25(3), 326–332 (2008).
- 72 Mack-Fogg JE, Orlowski CC, Jospe N. Continuous subcutaneous insulin infusion in toddlers and children with Type 1 diabetes mellitus is safe and effective. *Pediatr. Diabetes* 6(1), 17–21 (2005).
- 73 Ahern JA, Boland EA, Doane R *et al.* Insulin pump therapy in pediatrics. a therapeutic alternative to safely lower HbA1c levels across all age groups. *Pediatr. Diabetes* 3(1), 10–15 (2002).
- 74 Wilson DM, Buckingham BA, Kunselman EL, Sullivan MM, Paguntalan HU, Gitelman SE. A two-center randomized controlled feasibility trial of insulin pump therapy in young children with diabetes. *Diabetes Care* 28(1), 15–19 (2005).
- 75 Dimeglio LA, Pottorff TM, Boyd SR, France L, Fineberg N, Eugster EA. A randomized, controlled study of insulin pump therapy in diabetic preschoolers. *J. Pediatr.* 145(3), 380–384 (2004).
- 76 Fox LA, Buckloh LM, Smith SD, Wysocki T, Mauras N. A randomized controlled trial of insulin pump therapy in young children with Type 1 diabetes. *Diabetes Care* 28(6), 1277–1281 (2005).
- 77 Nabhan ZM, Kreher NC, Greene DM, Eugster EA, Kronenberger W, Dimeglio LA. A randomized prospective study of insulin pump vs. insulin injection therapy in very young children with Type 1 diabetes: 12-month glycemic, BMI, and neurocognitive outcomes. *Pediatr. Diabetes* 10(3), 202–208 (2009).

- 78 Brown RJ, Wijewickrama RC, Harlan DM, Rother KI. Uncoupling intensive insulin therapy from weight gain and hypoglycemia in Type 1 diabetes. *Diabetes Technol. Ther.* 13(4), 457–460 (2011).
- 79 Nansel TR, Gellar L, McGill A. Effect of varying glycemic index meals on blood glucose control assessed with continuous glucose monitoring in youth with Type 1 diabetes on basal–bolus insulin regimens. *Diabetes Care* 31(4), 695–697 (2008).
- 80 Rovner AJ, Nansel TR, Gellar L. The effect of a low-glycemic diet vs a standard diet on blood glucose levels and macronutrient intake in children with Type 1 diabetes. *J. Am. Diet. Assoc.* 109(2), 303–307 (2009).
- 81 Chait A. Dietary management of diabetes mellitus. *ASDC J. Dent. Child* 51(6), 455–457 (1984).
- 82 US Department of Health and Human Services. *Physical Activity and Health: a Report of the Surgeon General*. CDC, National Center for Chronic Disease Prevention and Health Promotion, US Government Printing Office, Washington, DC, USA (1996).
- 83 Zinman B, Ruderman N, Campaigne B, Devlin J, Schneider S. Physical activity/exercise and diabetes. *Diabetes Care* 27(Suppl. 1), S58–S62 (2004).
- 84 Zisser H, Gong P, Kelley CM, Seidman JS, Riddell MC. Exercise and diabetes. *Int. J. Clin. Pract. Suppl.* 170, 71–75 (2011).
- 85 Dube MC, Lavoie C, Galibois I, Weisnagel SJ. Nutritional strategies to prevent hypoglycemia at exercise in diabetic adolescents. *Med. Sci. Sports Exerc.* doi:10.1249/MSS.0b013e3182500a35 (2012).
- 86 Bobo N, Wyckoff L, Patrick K *et al.* A collaborative approach to diabetes management. The choice made for Colorado schools. *J. Sch. Nurs.* 27(4), 269–281 (2011).
- 87 Erickson CDP, Splett PL, Mullett SS, Heiman MB. The healthy learner model for student chronic condition management – Part I. *J. Sch. Nurs.* 22(6), 310–318 (2006).
- 88 Cooley WC, Sagerman PJ. Supporting the health care transition from adolescence to adulthood in the medical home. *Pediatrics* 128(1), 182–200 (2011).
- 89 Bowen ME, Henske JA, Potter A. Health care transition in adolescents and young adults with diabetes. *Clinical Diabetes* 28(3), 99–106 (2010).
- 90 Peters A, Laffel L. Diabetes care for emerging adults: recommendations for transition from pediatric to adult diabetes care systems: a position statement of the American Diabetes Association, with representation by the American College of Osteopathic Family Physicians, the American Academy of Pediatrics, the American Association of Clinical Endocrinologists, the American Osteopathic Association, the Centers for Disease Control and Prevention, Children with Diabetes, the Endocrine Society, the International Society for Pediatric and Adolescent Diabetes, Juvenile Diabetes Research Foundation International, the National Diabetes Education Program, and the Pediatric Endocrine Society (formerly Lawson Wilkins Pediatric Endocrine Society). *Diabetes Care* 34(11), 2477–2485 (2011).
- 91 Gardner W, Murphy M, Childs G *et al.* The PSC-17. A brief pediatric symptom checklist with psychosocial problem subscales. A report from PROS and ASPN. *Ambulatory Child Health* 5(3), 225–236 (1999).
- 92 Gardner W, Lucas A, Kolko DJ, Campo JV. Comparison of the PSC-17 and alternative mental health screens in an at-risk primary care sample. *J. Am. Acad. Child Adolesc. Psychiatry* 46(5), 611–618 (2007).
- 93 Gelfand K, Geffken G, Lewin A *et al.* An initial evaluation of the design of pediatric psychology consultation service with children with diabetes. *J. Child Health Care* 8(2), 113–123 (2004).
- 94 TEDDY Study Group. The Environmental Determinants of Diabetes in the Young (TEDDY) Study. *Ann. NY Acad. Sci.* 1150, 1–13 (2008).
- 95 Wherrett DK, Bundy B, Becker DJ *et al.* Antigen-based therapy with glutamic acid decarboxylase (GAD) vaccine in patients with recent-onset Type 1 diabetes: a randomised double-blind trial. *Lancet* 378(9788), 319–327 (2011).
- 96 Gallagher MP, Goland RS, Greenbaum CJ. Making progress: preserving beta cells in Type 1 diabetes. *Ann. NY Acad. Sci.* 1243, 119–134 (2011).
- 97 Michels AW, Eisenbarth GS. Immune intervention in Type 1 diabetes. *Semin. Immunol.* 23(3), 214–219 (2011).
- 98 Ichii H, Ricordi C. Current status of islet cell transplantation. *J. Hepatobiliary Pancreat. Surg.* 16(2), 101–112 (2009).
- 99 Thompson DM, Meloche M, Ao Z *et al.* Reduced progression of diabetic microvascular complications with islet cell transplantation compared with intensive medical therapy. *Transplantation* 91(3), 373–378 (2011).
- 100 Bruttomesso D, Farret A, Costa S *et al.* Closed-loop artificial pancreas using subcutaneous glucose sensing and insulin delivery and a model predictive control algorithm: preliminary studies in Padova and Montpellier. *J. Diabetes Sci. Technol.* 3(5), 1014–1021 (2009).

■ Websites

- 201 American Diabetes Association (ADA). www.diabetes.org
- 202 Juvenile Diabetes Research Foundation (JDRF). www.jdrf.org
- 203 American Dietetic Association. www.eatright.org
- 204 Children with Diabetes. www.childrenwithdiabetes.org
- 205 DiabetesHealth. www.diabeteshealth.com
- 206 Diabetes Life. www.dlife.com
- 207 Diabetes Camps. www.diabetescamps.org
- 208 2-1-1 Information and Referral Search. www.211.org
- 209 Patient Assistance Program Center. www.rxassist.org
- 210 National Diabetes Education Program. www.ndep.nih.gov
- 211 National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK). www.niddk.nih.gov
- 212 National Diabetes Information Clearinghouse (NDIC). www.diabetes.niddk.nih.gov
- 213 CDC Diabetes Public Health Resource. www.cdc.gov/diabetes
- 214 Social Security Administration. www.socialsecurity.org
- 215 Section 504 of the Rehabilitation Act. www.hhs.gov/ocr/civilrights/resources/factsheets/504.pdf
- 216 Individuals with Disabilities in Education Act (IDEA). <http://idea.ed.gov>
- 217 State Laws and Policies from the ADA. www.diabetes.org/living-with-diabetes/parents-and-kids/diabetes-care-at-school/legal-protections/state-laws-and-policies.html