Diabetes mellitus (type 1) has long been identified as one of the most common chronic, lifelong illnesses developing in childhood. In the United States, type 2 diabetes and metabolic syndrome are increasing in children and adolescents at an alarming rate. Type 1 diabetes mellitus (T1DM) has also been called insulin-dependent diabetes mellitus (IDDM) and juvenile onset diabetes mellitus. The hallmark feature of T1DM is the underproduction or lack of production of insulin by the beta cells of the pancreas. This lack of insulin is felt to be due to the destruction of the beta cells. The hallmark feature of type 2 diabetes is “insulin resistance.” In type 2 diabetes, the pancreatic beta cells still make insulin, but cells become “resistant” to insulin and are unable to take up circulating glucose. Thus, high levels of circulating insulin and glucose are found in type 2 diabetes. Risk factors for type 2 diabetes include being overweight (Table 1). The incidence of overweight children and adolescents (above the 95th percentile for weight) has been increasing during the last few decades, with 17.1% of all children and adolescents being defined as overweight in 2003 and 2004. Risk factors for children and adolescents becoming overweight and who are at risk for metabolic syndrome or type 2 diabetes

**KEYWORDS**
- Diabetes mellitus
- Children
- Adolescents
- Psychosocial functioning
- Cognitive functioning
- Mental health

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have included the increased use of atypical antipsychotics, most notably olanzapine and clozapine.\textsuperscript{6–9}

The incidence of T1DM varies with geography, age, gender, family history, and race. Risk for developing T1DM in childhood seems to increase with distance from the equator.\textsuperscript{10} In the United States, the highest incidence of T1DM is found in non-Hispanic white children, 23.6 per 100,000 annually.\textsuperscript{11} Childhood-onset T1DM has a bimodal presentation for age of onset, with the first peak between ages 4 and 6 years and the second peak in early adolescence.\textsuperscript{12}

Development of childhood-onset IDDM occurs with the destruction of the beta cells in the pancreas. The destruction is most often felt to be mediated by an autoimmune response but can also be seen in association with cystic fibrosis. In addition, there is noted genetic susceptibility as the risk for T1DM increases for first-degree relatives.\textsuperscript{13} Thus, for genetically susceptible individuals, it is postulated that environmental exposures (proposed agents including: viral infections, immunizations, diet, vitamin D deficiency and perinatal factors) trigger an immune response, leading to the destruction of the beta cells of the pancreas. There is also an associated increased risk for celiac disease for children with T1DM. Some children and families struggle with the dietary restrictions of T1DM and the gluten-free dietary requirements for celiac disease.

The treatment regimen for T1DM includes close monitoring of blood glucose level by “finger sticks,” monitoring of urine for glycosuria, diet modifications, and multiple injections of insulin per day. Some treatment centers advocate “tight” control, with blood glucose levels monitored as frequently as every 4 hours and decisions on insulin dose made as predicated by the blood glucose level. Other programs may have as “loose” a program as twice a day injections and twice a day monitoring of blood and urine glucose levels. But in the developing child with variable times of exercise, school lunches, birthday parties ensuring healthy blood glucose levels can be a challenge to the child, the family, and the care providers. Often in later adolescence, the individual with T1DM may opt (or be recommended by the treatment provider) to receive treatment from an insulin pump (subcutaneous continuous infusion of insulin). The insulin pump delivers continuous basal insulin with boluses associated with meals. Use of the insulin pump may reduce rates of hypoglycemic events, but controlled trials of pump therapy comparing injection therapy in the pediatric population are currently limited.\textsuperscript{14,15}

<table>
<thead>
<tr>
<th>Type 1 Diabetes Mellitus</th>
<th>Type 2 Diabetes Mellitus</th>
<th>Metabolic Syndrome</th>
</tr>
</thead>
<tbody>
<tr>
<td>Onset: abrupt; often in childhood</td>
<td>Onset: gradual; originally adult disease, now increasing in childhood</td>
<td>Constellation of symptoms including:</td>
</tr>
<tr>
<td>Insulin dependent</td>
<td>Insulin resistant: hallmark feature</td>
<td>Abdominal adiposity</td>
</tr>
<tr>
<td>Defect: insulin producing cells of the pancreas</td>
<td>Associated with obesity, use of atypical antipsychotic medications</td>
<td>Elevated triglycerides</td>
</tr>
<tr>
<td></td>
<td>May be controlled with diet and exercise</td>
<td>Low HDL</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Hypertension</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Type 2 diabetes may be associated</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Risk for cardiovascular disease</td>
</tr>
<tr>
<td></td>
<td></td>
<td>May be associated with use of atypical antipsychotic medications</td>
</tr>
</tbody>
</table>

\textsuperscript{Fritsch et al 336}
There are both long-term complications of chronically high blood glucose levels on the vascular system and serious short-term problems with acute hypoglycemic events (Box 1). The preschool-age child may be more vulnerable to severe hypoglycemic events, and prepubertal children may be more protected from microvascular complications of T1DM. For the person with frequent “sugars running high,” measurement of the glycated hemoglobin levels (A1c) will be elevated. The recognized risk of hypoglycemia in younger children has led to the setting of higher HbA1c target levels compared with the expectation of “stricter” metabolic control for older children and adolescents.

Shorter-term complications of diabetes include difficulties associated with hypoglycemia, ranging from tremor, confusion, and lethargy to stupor and seizures. Acute hyperglycemia can lead to polyuria, nocturnal enuresis, weight loss, and risk for diabetic ketoacidosis, which can potentially cause coma and death. Thus, diabetes can cause acute life-threatening events in addition to chronic complications. For the developing child and adolescent, effects of hypoglycemic events and hyperglycemia may cause cognition and neurodevelopmental challenges (see next section).

Longer-term complications of diabetes affect all organ systems, with the causal agent being microvascular damage. Most notable potential complications include retinopathy, nephropathy, neuropathy, cardiovascular disease, and impotence. Additional complications can include gastroparesis, menstrual difficulties, necrobiosis lipoidica, and bone changes.

**EFFECT ON COGNITION AND NEUROPSYCHOLOGICAL DIFFICULTIES IN CHILDREN AND ADOLESCENTS**

Children and adolescent brains continue to develop through pruning, myelination, and other maturational processes. Childhood cognitive development is well recognized to undergo remarkable changes from barely recognizing letters to abstract thinking. The effect of hypoglycemia and hyperglycemia in the developing child on cognitive functioning and subtle neuropsychological deficits has been the subject of ongoing studies. In 2004, Desrocher and Rovet provided a comprehensive review of the literature, some of the controversies, and a discussion of some of the limitations of past research. Further research since 2004 is described in the next section and in Table 2.

**Box 1 Complications of T1DM**

<table>
<thead>
<tr>
<th>Short-term</th>
<th>Long-term</th>
</tr>
</thead>
<tbody>
<tr>
<td>Hypoglycemia</td>
<td>Retinopathy</td>
</tr>
<tr>
<td>Confusion</td>
<td>Microvascular disease</td>
</tr>
<tr>
<td>Seizures</td>
<td>Nephropathy</td>
</tr>
<tr>
<td>Hyperglycemia</td>
<td>Neuropathy</td>
</tr>
<tr>
<td>Externalizing behaviors</td>
<td>Pregnancy complications</td>
</tr>
<tr>
<td>Diabetic ketoacidosis</td>
<td>Impotence</td>
</tr>
<tr>
<td>Coma</td>
<td></td>
</tr>
</tbody>
</table>
Hypoglycemia

Earlier age of onset (<5 years) has often been associated with more frequent or more severe bouts of hypoglycemia. This is thought to be secondary to individual lack of hypoglycemia awareness (or lack of verbal skills to express the acute event) and sensitivity to nocturnal hypoglycemic spells. Repeated severe bouts of hypoglycemia (more than 3 episodes) have been associated with deficits in spatial memory, worse cognitive outcome and delayed recall, and smaller gray matter volume in the left superior temporal region. Greater exposure to severe hypoglycemia in childhood has also been associated with greater hippocampal volume, and researchers postulated that this enlargement may reflect a pathologic reaction, leading to gliosis, reactive neurogenesis, or impairment of normal pruning.

A recent small study tried to examine the immediate neuropsychological and neurometabolic effects of a severe hypoglycemic event (with associated seizure) in 3 prepubertal children. Immediate difficulties were noted with selective attention that improved during the subsequent 6 months, and the neuronal integrity in the anterior brain appeared particularly susceptible to acute hypoglycemia.

Hyperglycemia

Longer-term effects of chronic hyperglycemia have been noted to affect overall verbal intelligence, overall brain changes including decreased gray matter volume in the right cuneus and precuneus regions, smaller white volume in the right posterior parietal region, and increased gray matter in the prefrontal region.

Parents and children alike have anecdotally reported knowing when the child is running “high” glucose by reporting changes in behavior. McDonnell and colleagues studied prepubertal children with T1DM to test the potential association between glucose levels and behaviors. They, indeed, found an association between intercurrent high glycemic levels and increased externalizing behaviors, such as agitation and aggression. A recent study conducted imaging studies during hyperglycemia in children with or without associated diabetic ketoacidosis, and the frontal region was notably affected with elevations of taurine associated with increased risk for cerebral edema.

Summary of Neurocognitive Effects of T1DM

T1DM has significant acute and chronic implications for the developing child and adolescent brain. Severe hypoglycemic episodes for children less than 5 years of age and repeated severe episodes may have long-term cognitive and memory impairments. Chronic hyperglycemia may also affect overall verbal intelligence and brain volume, particularly in the frontal region.
age may later predispose the child to significant learning issues. On the other hand, chronically elevated glucose levels may predispose the child to lower verbal intelligence scores. Immediate effects of hypoglycemia may lead to problems with selective attention, whereas the child with “high sugars” may exhibit problematic externalizing behaviors. The child or adolescent and her/his family face the challenge of finding a correct balance.

PSYCHIATRIC COMORBIDITY ASSOCIATED WITH IDDM

Evidence suggests that maladjustment in children negatively affects glycemic control and subsequent metabolic functioning. Recent studies indicate elevated rates of psychiatric disorder between 33% and 42% in adolescents and young adults with diabetes,24–26 which are 2 to 3 times higher than those found in the general population.27–31 Diagnoses include internalizing and externalizing disorders. A recent study examined the effect of internalizing and externalizing disorders on the risk for readmission to the hospital for diabetes care, demonstrating an increased risk for readmission for adolescents (but not children) with internalizing behaviors and possibly an increased risk among those with externalizing behaviors.32 Many studies suggest that individuals with comorbid psychiatric disorders are less likely to adhere to treatment regimens, resulting in poorer control of the illness.30 Thus, disturbed adolescents with diabetes may be at “double jeopardy” for adverse physical and mental health outcomes.30 An association between mood disorders in the child or adolescent with T1DM and family conflict and very “tight” metabolic control has also been reported,33–35 raising the possibility that psychiatric symptoms may either contribute to or result from obsessive preoccupation with the demands of the diabetes treatment regimen.30 Depression and anxiety are most commonly seen in children and adolescents with diabetes, and early adjustment disorders are more predictive of these diagnoses. Eating disorders are also common, particularly among women, and are discussed in the later section.

Adjustment Disorders

From the time of diagnosis, there is an expected pattern of adjustment because both children and families are introduced to a new world filled with challenges, constraints, and uncertainties associated with a lifelong illness. Initial adjustment to the diagnosis of diabetes is characterized by sadness, anxiety, withdrawal, and dependency,36–39 and approximately 30% of children develop a clinical adjustment disorder in the 3 months subsequent to diagnosis.36,40 Such difficulties often resolve within the first year, but poor adaptation in this initial phase places children at risk of later psychological difficulties.26,30,36,38,41,42

Depression

Studies have associated a diagnosis of depression with substantially worse glycemic control and more serious retinopathy in patients without psychiatric disorders.43–45 Because of the overlap of symptoms such as fatigue, weight loss, and impaired memory common to both mood disorder and poor metabolic control, depression may be under diagnosed in children with diabetes.36,43 Therefore, it is useful to reevaluate patients with symptoms of depression after glycemic control has been established. If symptoms persist, a diagnosis of depression may be indicated. Massengale46 provides a recent review on the salient features of depression in the adolescent with T1DM. A 2003 study47 reported that there is a 10-fold increase in the incidence of suicide and suicidal ideation in the adolescent with diabetes. In addition to other means, insulin is a potential means for self-injury.48,49
With nearly one-third of diabetic adolescents experiencing comorbid depression and similar numbers reported in the adult population, researchers are looking for links of brain pathology/changes caused by the illness leading to increased risk for depression. McEwen and colleagues propose that the progressive atrophy of the hippocampus is seen in animals with diabetes, which is similar to changes seen in depression.

Psychotherapeutic and psychopharmacologic interventions have been found to be helpful in treating depression. Psychopharmacologic treatment should be accompanied by psychotherapy addressing the pessimistic attitudes that typically accompany depression in adolescents and that can limit the patient’s willingness or ability to do what is necessary to treat the diabetes.

Psychopharmacologic treatment use in conjunction with IDDM may present with unique challenges. Although the initiation of treatment with antidepressants does not usually cause serious problems, patients and parents should be alerted to the possibility of changes in blood glucose control. Tricyclic antidepressants frequently stimulate appetite that can lead to hyperglycemia. Selective serotonin reuptake inhibitors can have appetite-suppressing effects and may also enhance the action of insulin, thereby inducing hypoglycemic episodes.43 Because lithium carbonate seems to have effects that mimic those of insulin as well as stimulate the secretion of glucagon, either hyper- or hypoglycemia may result from its use.43 Successful treatment of depression may also bring about changes in eating habits, exercise patterns, and the regularity of insulin injections, thereby causing unforeseen changes in blood glucose control.

Anxiety Disorders

Symptoms of anxiety may also be more common in diabetic children and adolescents. As with other diagnoses, anxiety symptoms may occur in the context of poor glycemic control and must be differentiated from hypo- or hyperglycemic conditions. Self-monitoring of blood glucose concentrations can help the patients and parents discriminate between hypoglycemia and anxiety.43,52 It is often useful to help the child discriminate internalizing symptoms of worry or persistent fears associated with anxiety from physical symptoms of palpitations or diaphoresis associated with a hypoglycemic state. Treatment with antianxiety medications may lead to improved glucose control and even to hypoglycemia.43,52 Caution is advised when using β-blockers to treat anxiety symptoms, because they can block adrenergic symptoms that are useful in identifying the hypoglycemic state.

Eating Disorders

The coexistence of eating disorders, such as anorexia nervosa and bulimia nervosa, and diabetes has long been recognized in the clinical setting, particularly among female patients. The cause of eating disorders is multifactorial, involving psychological, biologic, genetic, family, social, and environmental factors. Overall, eating disorders that meet DSM-IV diagnostic requirements are more prevalent among adolescents with T1DM than the general population. Subthreshold eating disorder, eating-related disturbances, and misuse of insulin to influence body weight, which pose an increased risk for related medical complications and eating disorders, are common in the female adolescent diabetic population.

Considering the frequency of eating disorders based on DSM-IV criteria, some studies indicate that subjects with diabetes mellitus were 2.4 times more likely to have an eating disorder than controls and 1.9 times more likely to have a subthreshold eating disorder. Smith and colleagues compared adolescent women with diagnoses
of scoliosis and IDDM with a normal control group for an increased risk of eating disorders. Of the adolescents with T1DM, 27.5% were found to have either bulimia or binge-eating disorder based on DSM-IV criteria. Although many patients may not meet strict DSM-IV criteria for anorexia nervosa or bulimia, as indicated by refusal to maintain body weight at or above minimally normal weight for age and height and recurrent inappropriate compensatory behavior to prevent weight gain, respectively, deliberate insulin omission was cited as the most common weight loss behavior after dieting. Data suggest that between 15% and 39% of young women with diabetes manipulate their insulin to control their weight, with clinically relevant changes in eating attitudes in boys and girls occurring after their first year of treatment for diabetes. Although some diabetic patients tend to be slightly more overweight than controls, it is the rapid weight gain of rehydration and the anabolic effect of insulin that may be responsible for the rapid weight gain, particularly after diagnosis. Although these changes in eating attitudes were associated with significant changes in body weight, girls were more likely to experience changes in body dissatisfaction, preoccupation with food, body image, and body shape. In relation to bulimia, rather than purging, many diabetic women reduce their dose of insulin to achieve a similar calorie-voiding effect. The availability of this method of weight control, together with dietary restrictions imposed by the diabetes regimen, may explain why many diabetic patients may report less dieting to lose weight, even though they report more binge eating.

Such eating disorders or disturbances in adolescents with T1DM pose a particular health risk in that they are associated with impaired metabolic control and about a 3-fold increase in the risk of diabetic retinopathy. For the clinician, these findings emphasize the importance of considering an eating disorder, or at least disturbed eating, as a cause of poor control of hemoglobin HbA1c control in young women with diabetes.

FAMILY AND DEVELOPMENTAL FACTORS

Consideration of family functioning in families with children with IDDM has a long history. Minuchin and colleagues in the 1970s described “psychosomatic” families. These families were described as possibly manifesting 1 of 4 maladaptive transactional patterns: enmeshment, overprotectiveness, rigidity, and lack of conflict resolution. Although the finding has not been clearly replicated, it was found that acutely stressful family interactions could lead to elevated blood glucose levels.

Since Minuchin’s original work, there have been many investigations exploring the relationships of family factors mediating treatment adherence, effects of parental mental health issues on disease course, marital difficulties and its effect on the child with diabetes, and developmental aspects of the family and the child with a chronic illness. More recent work is looking at treatment approaches to the family, including multisystemic therapy (MST), office-based parent support, and the effect of psychoeducation. This is described in greater detail in the later discussion.

In any chronic illness, an understanding of the psychosocial context of the child’s life is critical to managing illness-related behavior and achieving adherence to management regimens that are often painful or uncomfortable and often in conflict with expectable developmental processes. For T1DM, the maintenance of treatment regimens is clearly related to medical outcomes. Short-term consequences of inadequate monitoring of blood glucose, changes in diet or exercise, or problems in insulin administration can potentially lead to seizures, unconsciousness, and death. Poor glycemic control can eventually cause blindness, renal failure, stroke, and myocardial infarction. The seriousness of these outcomes generates a great deal of
understandable anxiety in parents and providers, anxiety that often does not yield improvements in treatment adherence, and which may, in fact, lead to conflict, resistance, and additional difficulty.

Understanding family and developmental factors in all pediatric illness and the need for family-based interventions is increasingly being addressed. An understanding of illness-related behaviors in the child or adolescent and of the stress and emotional responses experienced by parents are critical if health care providers are to be effective in achieving helping the patients manage their illnesses effectively. In all serious illnesses in childhood and adolescence, parents can be expected to experience varying degrees of stress and frustration, which may lead to anxiety, depression, alterations in the marital relationship, and difficulties in the relationship with the child. When an illness causes ongoing disability, parents may need to grieve a real loss. These responses in parents are often associated with outcomes in the child, both morbidity (quality of life, psychosocial adjustment, physical complications) and mortality.

Adjustment to the illness and establishment of effective patterns of management of the illness are critical with T1DM. Adherence to treatment regimens and maintenance of metabolic control, while difficult for some to achieve during childhood, often becomes much more difficult with the transition to adolescence. Problematic family interactional factors such as high levels of conflict and low cohesion are associated with poorer adherence to treatment regimens, poorer metabolic control, and worse health outcomes.

The Effect of T1DM on Parents and Families

The diagnosis of T1DM in a child or adolescent is often an acute stressor in the lives of parents. They must quickly absorb a substantial amount of new and disturbing information. The physical demands of care are significant, involving blood glucose monitoring, insulin administration, attempts to regulate diet and activity, and time-consuming office visits and calls. Ongoing needs of the ill child’s siblings, other family members, and work must be dealt with, and feelings of inadequacy or helplessness are understandable. Many parents experience subthreshold symptoms of distress and mood disturbance after the diagnosis. A significant minority continues, weeks and months later, to experience anxiety and depression. One study observed 22% of mothers of children with T1DM to have clinically significant levels of depression. A study of pediatric parenting stress, as defined by the Pediatric Inventory for Parents, assessing the parents’ communication with others, emotional functioning (eg, sleep, mood), the stress of performing the medical regimen, and effects on role functioning (eg, ability to work, care for other children) found that those who experienced a lower sense of self-efficacy in managing the child’s medical care and greater parenting stress were more likely to report clinically significant symptoms of anxiety or depression.

The experience of having a child with T1DM is a challenge for the parents’ marriage, with consequences for the child’s medical and psychosocial outcome. Mothers typically take on most child care, management of the illness, and communication with providers. In the study on parenting stress mentioned earlier, anxiety and depression were greater for mothers than fathers. The presence of each spouse participating in the child’s care was a protective factor. Higher levels of mother-reported spousal support have been found to be associated with less conflict with an adolescent with T1DM and with greater adherence to treatment. Single-parent families clearly have greater difficulty with management of the illness than parents living together.

Parents’ emotional responses and coping styles interact with those of children and adolescents in a reciprocal or transactional manner. Maternal depression is associated
with the quality of life and depressive symptoms in children with T1DM. At the same time, maladaptive emotions and behavior on the part of the child add greatly to the stress on a parent.

**Effects of the Child’s Age or Developmental Level**

Developmental considerations of the child or adolescent with IDDM include the child’s age at diagnosis, the complexity of disease management, the ability to consent for treatment, and the trajectory through puberty. In many patients, diabetic control during the critical years of adolescence and early adulthood is determined by control established in late childhood. The challenges to psychological adjustment and family interaction vary with the age or developmental level of the child. The cognitive capacity of the child, stability of attachment to parents, need for autonomy and other developmental needs, and medical issues associated with the patient’s age all play a role. As children develop, they should gradually become the primary guardians of personal health and primary partners in medical decision making, assuming responsibility from their parents. Developmentally, this involves a significant range of responsibility for self-care, ultimately resulting in responsibility for appropriate food choices, blood glucose monitoring, knowledge of HbA1c, and appropriate insulin dose adjustment predictions to account the wide array of influencing variables.

It is not unusual for preschoolers to have become very ill and experienced an intense life-threatening condition that initially shapes their perception of what it means to have diabetes. Not surprisingly, this perception is also influenced by parental beliefs, expectations, and ability to effectively communicate with the child. Although the preschoolers have little responsibility in managing their diabetic care, they can begin to communicate subjective perceptions of what it feels to be hyper- or hypoglycemic. The greater risk of hypoglycemic episodes in preschool children often results in anxiety on the part of parents. Needle-related pain and distress may be a particular challenge with younger children, but children’s ability and willingness to use needles are not age related. Separation from parents, if hospitalization is necessary, can be a great cause of anxiety.

In latency, the child can begin to develop an understanding of the principles of diabetes, management techniques, and decision making related to considerations of consent. It is clear that “informed consent” has only limited direct application in children and adolescents. Only patients who have appropriate decisional capacity and legal empowerment can give their informed consent to medical care. In all other situations, parents or other surrogates provide “informed permission” for diagnosis and treatment of children with the assent of the child when appropriate. If physicians recognize the importance of assent, they empower children to the extent of their capacity.

Assent should include at least the following elements:

1. Helping the child achieve a developmentally appropriate awareness of the nature of his or her condition.
2. Telling each child what he or she can expect with tests and treatment.
3. Making a clinical assessment of the patient’s understanding of the situation and the factors influencing how he or she is responding.
4. Soliciting an expression of the patient’s willingness to accept the proposed care.

A child’s refusal to assent to treatment may represent misunderstandings, fears, and concerns, which if initially respected by the clinician, may provide an opportunity for the exploration of refusal and a strengthening of the therapeutic relationship.
Although coercion or force may ultimately be necessary for medical reasons, it should be the last resort, keeping in mind the negative consequences of possible increased aversion to medical procedures.

A developmentally appropriate understanding of the nature of diabetes for childhood assent can often be expressed by latency-age children in simple meaningful terms. Describing "hypos" and "hypers" related to "sugar levels," their direct relation well-being, associated somatic feeling of each condition, and the relationship of food/insulin can usually be understood and expressed by these children. Children need to be helped to have some understanding that the benefit of treatment outweighs the problems of discomfort and inconvenience.

A child’s expectation of tests and treatment is usually developed over time, as he or she begins to appreciate the regularity of injections. Appreciation of duration of treatment is more abstract however, and children may reference duration to the number of finger sticks throughout the day, rather than the lifetime.

In addition to simply asking the child to explain in his or her own words, making use of natural play can also indicate understanding of the situation and the factors influencing how he or she is responding. Demonstrations on dolls or asking the child how he or she would advise another boy or girl with diabetes is often perceived as fun and can often yield surprisingly insightful interpretations.

Although there has been little research about children’s beliefs and goals or their ability to comanage a serious chronic condition, some studies have revealed that some children possess the knowledge, skill, and maturity to make personal decisions about their health care. It has been found that from around 4 years of age, children start to understand the principles and take responsible moral decisions about managing their diabetes. And yet, other research has indicated that instead of age or ability, experience is the salient factor in a child’s intellectual and moral competence.

In school-aged children with T1DM, parents still have to take very active responsibility for management. Behaviors that are normal for the developmental stage, such as oppositional interactions, emotional liability, and increasing need for independence, can interfere with management. In addition to the life of the child in the family, challenges also arise with respect to school and peer relationships. The needs to regulate or at least monitor dietary intake and physical activity conflict with the child’s need to be active with friends, to participate in sports, and to join activities involving food. A particular difficulty and point of conflict is misbehavior at mealtimes, such as playing with food, talking rather than eating, or refusal to eat, which generates anxiety in the parent who is concerned about the need for consistent intake. Such behavior tends to elicit ineffective, overreactive discipline from parents. Patton and colleagues observed that more parental activity, directing or commanding the child to eat, was associated with less eating as the meal progressed. This was not categorically different from mealtime interactions in healthy controls, but it was associated with poorer glycemic control in children with T1DM. An intervention, using principles similar to those of Parent Management Training, effectively improved mealtime conflict by teaching parents to use short, direct commands that are associated with contingent positive attention.

The transition to adolescence is a time when conflict with the family often increases and adherence to treatment regimens often deteriorates. The same hormones that cause growth spurts in a child can also wreak havoc on his or her efforts to keep blood sugar level under control. As growth hormone increases during the early and middle adolescent years, the body becomes less sensitive to insulin. As a result, high glucose levels are common in late adolescents. When an adolescent reaches his or her full growth, these insulin-inhibiting hormones tend to decrease. The increased
adolescent physical demands of sports, dance, gymnastics, and many other strenuous activities can also change insulin requirements.

Increased autonomy in the formation of personal identity is an important developmental task of adolescence. This developmental task may be more complicated for adolescents with T1DM because at this time in their lives, metabolic control and treatment adherence often deteriorate and less parental involvement in diabetes care has been associated with poorer diabetes outcomes. Adolescents perceive support from family members primarily in the form of tangible support, such as reminding, helping, and even performing many of the self-management tasks. Parent–child conflict is common and may take the form of parental worry and intrusive behaviors or blaming. Late adolescents often feel that their parents have identified them more in terms of the diabetes than their personality. Misunderstanding of the hormonal changes of development may lead to parental accusations of irresponsible diabetes management. Adolescents are most sensitive to being misunderstood and often either blatantly disregard appropriated diabetes management in response or create factitious blood sugar levels to satisfy the parents.

Issues common in adolescence, including the need for separation and a sense of autonomy; the adolescent’s sense of invulnerability and propensity to risk taking; concerns about self-image, sexual identity, and peer group affiliation all complicate relationships with parents and management of the illness. At a time when peers are regarded increasingly as capable of managing certain aspects of their life and enjoy increasingly independent function, the adolescents with T1DM experience continuing vigilance on the part of their parents regarding their dietary intake, physical activity, and consistency with blood glucose monitoring and insulin administration.

Clinical practice consensus guidelines for “Diabetes in adolescence” were developed by the International Society for Pediatric and Adolescent Diabetes and published in 2008. Providers who are sensitive to these issues, hoping to be responsive to the adolescent’s need for a degree of mastery and autonomy may attempt a “loose” rather than a “tight” level of control of the illness. Parents and providers often need to be active in monitoring and managing treatment. Although adolescents have greater cognitive capacity and diabetes-related problem-solving skills than younger children, they were found to avoid using such skills in social situations in which they conflicted with acceptance by peers. Active monitoring by parents is associated with better control of the illness. Parents, providers, and adolescents need to find a sustainable balance between monitoring of the treatment regimen and allowing the adolescent to feel increasingly competent and independent.

There are clearly some protective factors. Those with more stable family communication and social support and with more positive self-perceptions experience less stress related to their illness and better glycemic control.

INTERVENTIONS

Many children and adolescents have some degree of difficulty in maintaining good glycemic control, and a subset of adolescents has serious problems. These chronically poorly controlled patients are likely to experience multiple risk factors, including other family psychopathology, low levels of parental support and monitoring, irregular contact with care providers, lower socioeconomic status, and minority or single-parent homes.

As noted earlier, children and adolescents may experience coexisting psychiatric disorders, such as anxiety, depressive disorders, and eating disorders. Other disorders that are fairly common in children and adolescents and not specifically related
to diabetes, such as attention-deficit hyperactivity disorder or learning disabilities, may greatly complicate management. If such comorbid disorders are present, the first priority must be to treat them according to appropriate practice parameters. Family conflict may require family psychotherapy, and treatment of depression, anxiety, or other disorders in parents, either related to the child’s diabetes or preexisting, may be indicated. Parents may be reluctant to seek help for themselves when they are preoccupied with a child’s illness, but they must be helped to see the need to be functioning well if they are to be helpful to their child and families.

Several interventions, including educational programs, cognitive behavioral therapy, coping-skills training, and family-based interventions, specific to the difficulties experienced by families with a diabetic child have been studied. In a recent article, several interventions from different theoretical perspectives showed promise with respect to psychosocial outcomes and health service use, but without definitive effects on metabolic control. A randomized controlled trial of an educational approach, Parent-Adolescent Teamwork, showed significantly decreased family conflict, but no significant effect on glycemic control. A recent review of family-centered interventions indicated promising results with both family conflict and improved HbA1c levels.

The specific and important issue of needle-related distress has been the subject of successful interventions. Distraction, cognitive behavioral treatment (CBT), and hypnosis have shown promising results. CBT is “well established” for procedure-related pain. Operant learning procedures with positive reinforcement including tokens, tangible rewards, or privileges are considered “probably efficacious,” with increased adherence to blood glucose monitoring.

MST is an intensive family-centered treatment modality that was originally developed to treat delinquent adolescents and has been extended to psychiatrically ill children and adolescents. It has been adapted to treat chronically poorly controlled adolescents with T1DM. The intensive home-based psychotherapeutic approach includes a wide menu of interventions appropriate to the individual patient and family. Family interventions included parent training regarding monitoring and improving communication. Individual interventions, such as CBT, for a depressed adolescent were used as needed. Treatment included collaboration with schools; involvement of peers, community, and extended family; and problem solving around barriers to keeping medical appointments and communicating with providers. A trend was seen regarding improvement of HbA1c levels, with a decrease of 0.8% in the families completing treatment. Although the mean did not decrease to a level considered acceptable, this degree of improvement is associated with improved medical outcomes. The frequency of blood glucose monitoring increased and the number of hospital admissions for diabetic ketoacidosis decreased.

SUMMARY

In summary, the psychosocial adjustment and behavior of patients with T1DM is critical to their medical outcomes and quality of life, and family support, monitoring, and communication are essential levels of consideration. The illness is a significant and ongoing stressor for parents, and it confounds and complicates many aspects of normal child and adolescent development. Several careful studies have delineated important moderators and mediators of outcomes, and promising interventions have been developed and continue to be studied. Pediatricians, family physicians, nurse practitioners, child and adolescent psychiatrists, and other medical and mental
health providers need to understand and address psychosocial adaptation to the illness if they are to improve the outcomes of their patients and their families. Protective factors such as family communication skills, spousal support, and enhancement of positive self-perception should be identified and promoted to minimize short- and long-term complications.

REFERENCES


