Psychosocial Challenge of Diabetes and the Development of a Continuum of Care

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Good metabolic control of diabetes depends on balancing insulin dose, food intake, and exercise within the context of a consistent, scheduled life. It is the latter that is most difficult for patients, especially adolescents, who typically have erratic lifestyles. Acceptance of the demands of diabetes by the entire family is essential for good metabolic control in children.

The complex treatment requirements result in problems that are common to all children with diabetes. Diabetes sets the child apart from his or peers, an issue that must be dealt with both by parents and teachers. Siblings may resent the special treatment or attention given to the patient and develop problematic behavior. Children with diabetes may use their illness as a manipulative tool.

Parents may feel guilty for the hereditary aspects of diabetes and therefore may be overindulgent and overprotective, or they may be overprotective and anxious. The fear of long-term complications and consequent shortened life span results in some parents being perfectionistic and controlling. Others may deal with the diabetes by being indifferent or rejecting and give responsibility for management of the disease to their diabetic child before they are ready to handle it.

In general, patients with good metabolic control come from families with low marital conflict in which the family members are realistic and cooperative in treatment and in which there is a structured family routine. There generally is a low stress level in the parent-child relationships, and family members are able to resolve conflict. The parents are supportive at first but give more independence later on as the child is able to handle increasing responsibility. It is important to deal not only with the medical aspects of

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EMOTIONAL ADAPTATION

The diagnosis of diabetes is accompanied by various emotions: shock that the child has a serious lifelong disorder; anxiety about whether the parent and child can successfully manage the disease; fear about the acute and long-term complications of diabetes; sadness or grief over the loss of health and a carefree lifestyle; guilt that there may have been something the parent or child could have done to prevent the disease; pity for the pain and discomfort the child must endure; anger at the disruptiveness the daily treatment demands; feelings of "why me?" or "why my child?", sometimes accompanied by a sense of isolation or feeling "different"; worry about reactions to the child's diagnosis from family, teachers, friends, and peers; and on a positive note, relief that the worst fears about the child's recent illness and weight loss (a fatal outcome) are dispelled.

All of these reactions are common, although the saliency of any particular reaction may differ from child to child or family to family. The child's age or cognitive maturity at the time of diagnosis may influence initial reactions. For example, a young child may be oblivious to the long-term impact of diabetes and may be concerned primarily with the pain and discomfort of blood glucose tests and insulin injections. An older child may be concerned about how to tell his or her friends and teachers about diabetes and how the disease might interfere with usual activities. Adolescents may be particularly sensitive to feelings of isolation or differentness and wonder if diabetes may make them less acceptable or attractive to peers. Older adolescents and young adults may have concerns for their future, wondering whether diabetes will interfere with major life decisions and goals such as marriage, having children, employment, and longevity.

Some children and parents may experience mild anxiety and depression at the time of diagnosis; mothers appear to be more affected than fathers. However, this initial distress usually dissipates within 6 months. Some family members may welcome the opportunity to express their fears and concerns. Open discussion will permit the health provider to address misconceptions. Family members often are relieved to learn that psychological distress is common among newly diagnosed youngsters and their families and that it will dissipate as the family becomes more experienced living with diabetes. Offering a supportive environment (a phone number to call at any time) and an emphasis on problem-solving skills (how to handle difficult situations) will help the family move toward successful adaptation.

While health-care providers may emphasize the importance of tight control to delay the complications of diabetes, weight gain associated with high insulin doses may undermine adolescents' willingness to cooperate.

A substantial number of youngsters and their parents fail to adjust appropriately. Failure to adapt successfully within the first 6 months following diagnosis is an important predictor of continued difficulty in coping with diabetes. A history of marital problems, maternal depression, alcohol or drug abuse, parent-child conflict, child abuse or neglect, or behavioral/emotional problems in the child place the youngster and family at risk for poor diabetes care. These individuals and families need to be identified as early as possible and referred for regular counseling before the child's diabetes becomes an integral part of maladaptive interaction patterns. Delaying referral and psychosocial intervention will only make it more difficult to treat the youngster and family later, when problem behaviors have become well established.

DIABETES KNOWLEDGE AND SKILL ACQUISITION

Managing diabetes requires substantial knowledge about the illness and mastering of the skills needed to conduct blood glucose tests and administer insulin. The amount of information to be acquired presents a considerable challenge. Learning will be enhanced by repeated, brief educational sessions in which material from earlier sessions is reviewed and then expanded on. The content of educational sessions should be prioritized so that critical "survival" skills and knowledge are taught first. Plenty of opportunity for practice and questions should be provided. The review component of these repeated, short sessions also permits corrective feedback should the patient or family develop misconceptions about the disease or poor management techniques. Long, intensive educational sessions should be avoided as they tend to overwhelm the patient and family, leaving them confused or discouraged because they cannot remember all that was taught. Patients educated in this manner may carry their misunderstandings home where the use of inaccurate techniques may become a habit, and without review and reeducation can go undetected. Such an approach is labor intensive, requiring a unified health-care team composed of a
Some patients develop extreme fear of hypoglycemia and may actively attempt to remain hyperglycemic.

A variety of disciplines: physician, nurse educator, dietitian, and psychologist.

Anxiety is known to have a curvilinear relationship to learning and performance. Mild anxiety may motivate patients and families to acquire necessary information and skills. However, more severe anxiety may impede knowledge acquisition. Health providers and educators need to recognize that those patients and families with substantial anxiety and distress may have greater difficulty acquiring diabetes information. Educational techniques may need to be simplified and repeated. Educational sessions should include an assessment of what information the patient and family have actually acquired because increased knowledge and skill cannot be assumed. In some cases, helping the patient and family cope with their anxiety and distress may be a prerequisite to learning.

Diabetes educators must remain aware of the effect of the child’s cognitive maturity on his or her ability to understand diabetes and its management. Despite extensive experience, health providers often are insensitive to differences in children’s concepts of illness. Instead, they tend to treat all children as if they were about 10 years old. Younger children may be lost by explanations suitable for a 10 year old while adolescents may feel they are being “talked down to.” Diabetologists often expect youngsters to master diabetes skills at ages younger than those recommended by the American Diabetes Association despite published reports that children younger than 9 years of age often are inaccurate when they draw up and administer their own insulin. While children of all ages should be actively involved in their own diabetes care, parental supervision remains important until the child has developed the necessary manual dexterity and cognitive skills to engage in appropriate daily diabetes management.

ADHERENCE

Most families are faced with the immediate prospect of managing the newly diagnosed child’s diabetes on their own, at home, with continued support from the medical staff. Hospitalization of the child who does not have diabetic ketoacidosis (DKA) at the time of diagnosis is now the exception. Outpatient, daily education sessions allow the family to learn about diabetes management outside the controlled and stressful environment of the hospital. Issues discussed will be immediately relevant to their acquisition of knowledge and skills required to manage this disease. All family members should be encouraged to inject saline and perform a blood glucose test on themselves, establishing an accurate family consensus about the discomfort associated with such tasks. This will help the family respond appropriately to the child’s distress and complaints, providing empathetic support while avoiding exaggerated demonstrations of concern and pity.

Provider attention, enhanced by anxiety at the time of diagnosis, may serve to motivate patients and families to take good care of the child’s diabetes, so that adherence is greatest at the time of the child’s diagnosis. Unfortunately, as anxiety dissipates and provider support declines, many families become lax about the child’s diabetes care. Since many children “honeymoon” or produce some of their own insulin for 6 months to 1 year after diagnosis, their diabetes is easier to manage and lapses in adherence may go undetected for extended periods.

DEVELOPING CHILDREN AND CHANGING NEEDS

Although insulin-dependent diabetes mellitus can be diagnosed at any time from birth to adulthood, each developmental period presents its own challenges. The Table summarizes the effects of diabetes and the management implications at various stages from infancy to young adulthood.

CAMPING

Many children with diabetes would be denied the splendid growth opportunity of camping were it not for the existence of camps developed for youngsters with diabetes. Parental concerns about nutrition, provision of snacks, logistics of blood glucose monitoring, and insulin injections are dispelled by the provision of a safe environment, staffed by personnel experienced in diabetes management. The primary purpose of camp is to teach youngsters that they need not be limited by their diabetes by encouraging them to participate in a broad range of activities, such as rope courses, sailing, swimming, and land sports. In addition, exposure to other youngsters with diabetes helps them to feel less isolated; the informal cabin rap sessions, in which campers share experiences, often are more valuable to these children than formal education sessions.

The camping experience must be tailored to the age of the camper. Younger campers need a more structured recreation program and education that is aimed at such issues as technical skills and signs, symptoms, causes, and treatment of hypoglycemia, hyperglycemia, and ketosis. Older children are allowed more choice in activities and more free time to “hang out” with their peers. Their education sessions are often question driven and interactive. Older teenagers may
# TABLE

**Effects of Diabetes Mellitus on Children and Their Families and Management Implications Relative to Their Stage of Development**

<table>
<thead>
<tr>
<th>Age Group</th>
<th>Developmental Issues</th>
<th>Management—Parent/ Patient</th>
<th>Implications—Treatment Team</th>
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<tbody>
<tr>
<td>Infant</td>
<td>Patient is aware of discomfort of injections and blood glucose monitoring without understanding reason; may lead to parental guilt</td>
<td>Parents may fear being viewed by their child as punishing rather than nurturing; difficulty distinguishing hypoglycemic reactions from mood swings; need to educate babysitter</td>
<td>Anticipatory guidance and constant availability; parent-peer support system; near-normal blood glucose control not a realistic goal</td>
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<td>Toddler</td>
<td>Erratic eating behaviors and activity result in large blood glucose fluctuations; able to verbalize feelings of oppositional behavior: the age of “No”</td>
<td>Positive reinforcement for good behavior; consequences for negative behavior; need to set limits; unable to verbalize feelings of hypoglycemia; difficult to distinguish symptoms of hypoglycemia from temper tantrums</td>
<td>Frequent telephone contact needed; family respite weekends</td>
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<td>Preschool</td>
<td>More social; birthday parties, availability of sweets; feeling different from peers; beginning to verbalize feelings of hypoglycemia or not feeling well</td>
<td>Frequent injections; need to educate teachers and daycare workers about how to handle diabetes; moderate but do not prohibit sweets</td>
<td>Check blood glucose levels when child feels “low” to determine which symptoms are reliably associated with hypoglycemia; reinforce sick-day guidelines</td>
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<tr>
<td>Primary and elementary school</td>
<td>Reliably recognize symptoms of hypoglycemia; self monitor and participate in nutrition decisions; feeling of being different; poor school attendance</td>
<td>Parent no longer primary caregiver during day; need to speak to teacher and give school personnel handout before beginning of school year; teachers given concentrated glucose and snacks for hypoglycemia; need to supervise child in blood glucose monitoring, drawing up and injecting insulin</td>
<td>Speak to school about diabetes-related needs; available to answer questions from school; address child during clinic visit; reinforce positive behaviors without scolding for negative ones; strive for good glycemic control</td>
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<tr>
<td>Adolescence</td>
<td>Peer group is major source of support and motivation; feelings of being different; increased stresses; increased independence; erratic eating behaviors; poor food choices, dieting, and skipping meals; poor body image, skipping insulin injections, and surreptitious insulin administration (rare); dependence struggle, with defiance</td>
<td>Increasing responsibility for self-management but still requiring adult supervision and involvement; experimentation, poor adherence, and risk-taking behaviors leading to family conflict and further noncompliance; concerns about pregnancy; impotence, alcohol, drugs, smoking, and driving</td>
<td>Insulin resistance with puberty associated with higher insulin doses, blood glucose, and hemoglobin A1c levels; menses and team sports affect blood glucose levels; begin seeing patient alone; have patient involved in decision-making process; calling in blood glucose results within insulin dose recommendations; serve as patient’s, not parent’s, doctor; assuring confidentiality and privacy; understand without condoning (inappropriate affect, school or work deterioration, and recurrent diabetic ketoacidosis); discuss complications and future; need individualized and realistic goals</td>
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attend an adventure camp. Such camps provide a variety of opportunities including hiking, tenting, canoe trips, and outward-bound experiences. Through the camping experience, youngsters develop a sense of independence and feeling of control in dealing with their diabetes.

EATING DISORDERS
Eating disorders, including anorexia and bulimia, are uncommon in youngsters with diabetes. However, female adolescents with diabetes may be at increased risk for eating disorders and depression during the teenage years or young adulthood.10-12 Although concerns about weight are common during adolescence, both binge eating and severely restrictive food practices can have profound effects on diabetes control. Some girls may skip insulin injections as a means of losing weight. Youngsters who are exhibiting early signs of disordered eating practices or who are skipping injections need psychological intervention. While health-care providers may emphasize the importance of tight control (ie, keeping blood glucose levels near normal) to delay the complications of diabetes, weight gain associated with high insulin doses may undermine adolescents' willingness to cooperate.

FEAR OF HYPOGLYCEMIA
Hypoglycemic episodes are not only dangerous, they are physically aversive, socially embarrassing, and may affect employment. Some patients develop extreme fear of hypoglycemia and may actively attempt to remain hyperglycemic.13 It is important to explore adolescents' reactions to previous hypoglycemic episodes and fears they may have concerning future events, as these fears may interfere with the health-care team's efforts to keep the youngster in good metabolic control. The Diabetes Control and Complications Trial found that improved metabolic control was not without costs: both increased frequency of hypoglycemia and weight gain were associated with tight control.14 Again, to the health-care provider, the benefit of tight control is the possibility of delaying or avoiding diabetes complications. However, for the adolescent, fears of increased hypoglycemia and weight gain may prove more powerful than the promised benefits of tight control, which are years away.

CHRONIC UNSTABLE DIABETES: REHABILITATION
There are some patients who, despite intensive education and intervention, will have frequent episodes of DKA. These patients typically have chronic hyperglycemia with ketosis, and increasing the insulin dose does not result in improved metabolic control. More than 80% of patients studied with recurrent DKA have admitted that not taking their insulin was the cause.15 All such patients require intensive psychological intervention. In most cases, pathological family interactions underlie the youngster's poor diabetes control.

Although outpatient psychological intervention is often successful, there are some patients who persist in having recurrent DKA and school absences despite therapy. In those instances, inpatient therapy is required. To accommodate these children, a residential unit, the Diabetes Project Unit (DPU), was set up at the University of Florida.16 Patients were admitted to the DPU if they had recurrent DKA (average of nine episodes per year), excessive school absences (average of 23 days per year), and poor metabolic control. When compared with same-age patients from the clinic population, the DPU residents had lower levels of general information about diabetes and more deviant attitudes about diabetes. There was increased family disruption related to the diabetes, and the children more often saw themselves in a sick role.

During the first 6 years of operation, 52 children, ages 9 to 18 years, were admitted to the DPU with an average length of stay of 4 months. While in the unit, they attended public school, had a structured environment including a regular exercise regimen, regular homework time, individual psychotherapy, group therapy, and family therapy, as well as diabetes education. The DPU intervention resulted in decreased hospitalizations for DKA (from 9 to 1.3 per year) with improved school attendance (from 23 to 3 missed days per year). Follow-up hemoglobin A1C levels were better than on admission but not as good as the levels during the DPU stay. Sixty-three percent of the patients had their insulin dose decreased during the DPU admission to a mean of 0.9 U/kg/day, a mean decrease of 0.23 U/kg/day. Despite the decreased insulin dose, the children gained weight in the DPU. Both the children and their mothers had improved knowledge of diabetes at discharge. In addition, the families had normalization of their attitudes toward diabetes. The results of the DPU admission were best maintained if the families continued to undergo psychological counseling after discharge.

CONCLUSION
Growing up with diabetes is difficult for youngsters as well as for their parents, and for health-care providers who try to teach them how to deal with diabetes in a
positive, healthy manner. The ability to accomplish this is dependent on the input of a trained health-care team, including diabetes nurse educators, dietitians, physicians, and psychologists. Frequent phone contact is necessary to provide psychological and medical support. It is imperative that health-care plans adequately reimburse educators for the time spent in education and telephone follow-up, as these means are critical for preventing hospitalizations, promoting good diabetes management behaviors, and achieving the best metabolic control possible.

REFERENCES