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SYMPOSIUM

Behavioral Challenges in the Management of Childhood Diabetes

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Abstract

For many individuals, the diagnosis of diabetes is accompanied by the need for significant lifestyle changes, many of which seem difficult or impossible to implement. When diabetes is diagnosed in a child, those lifestyle changes may involve radical alterations in family life and significantly impact the child's normal growth and development as well as the family's social and economic status. This article describes some of the behavioral challenges associated with childhood diabetes and the importance of identifying strong, developmentally appropriate family support. Specific emphases are given to the complexity of the treatment regimens, the physiologic and emotional challenges associated with normal growth and development, and the family's role in ensuring successful diabetes management. Challenges inherent in both type 1 and type 2 diabetes mellitus are discussed as are factors important to ensuring adherence to the treatment plan.

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Introduction

The goal of managing childhood diabetes is to develop a physically healthy and emotionally mature adult, free from the complications associated with the disease. Some of the challenges associated with this goal include the complexity of the treatment regimen, the physiological and emotional changes associated with normal growth and development, and the identification and nurturing of developmentally appropriate familial and social support. This article explores several factors associated with these challenges.

Type 1 Diabetes in Children

The standard of care for children with type 1 diabetes mellitus (T1DM), regardless of age of onset, is rapidly becoming multiple daily injection (MDI) therapy.[1] Multiple daily injection therapy includes one or two daily injections of a long-acting basal insulin supplemented by an injection of rapid-acting insulin at each meal. Mealtime insulin is adjusted by a correction factor for blood glucose (BG) levels above or below a target range. Continuous subcutaneous insulin infusion systems (CSII) or insulin pumps are an alternative to MDI and have been shown to lower overall levels of glycemia while reducing the occurrence of serious hypoglycemia. With both MDI and CSII therapy, the mealtime insulin is based on the carbohydrate grams included in the meal to be consumed. Thus, nutrition plans for children with diabetes can be flexible to the extent that they provide essential nutrients and calories for adequate growth while reducing

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Abbreviations: (BG) blood glucose, (CSII) continuous subcutaneous insulin infusion, (MDI) multiple daily injection, (SBGM) self-blood glucose monitoring, (T1DM) type 1 diabetes mellitus, (T2DM) type 2 diabetes mellitus

Keywords: behavioral self-regulation, childhood diabetes, cognitive development, familial support, growth and development, motivation, obesity

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the risk of hyperlipidemia. Regular physical activity, 20–30 minutes per day and 4–6 days per week at a minimum, is important not just for achieving cardiovascular fitness but also for reducing BG levels. Exercise carries with it the risk of hypoglycemia and thus extra calories may be recommended for strenuous or prolonged activities. The entire therapeutic plan is monitored and adjusted based on self-blood glucose monitoring (SBGM) performed by the child or parent. Self-blood glucose monitoring is typically performed before each meal and at bedtime. An overnight (2–3 a.m.) BG measurement is obtained at least weekly and additional tests are performed before and after strenuous exercise. Parents and children must learn how and when to inject insulin, how to determine the insulin dose, how to count carbohydrate grams, how to adjust insulin or food for exercise, and how to monitor BG at the onset of the disease. Specific challenges of this treatment plan for children include variable insulin doses, irregular food intake, irregular physical activity, variable food likes and dislikes, food refusal, and other behaviors that make it difficult to implement the plan. For many parents and children, the treatment can seem like a continuous juggling act, requiring executive functioning skills that include organization, planning, problem solving, memory, and behavioral self-regulation.[2] Executive function has been shown to correlate with glycemic control in children.[3]

The second important challenge in managing childhood diabetes centers on normal growth and development. Insulin doses change over time as the child grows. In addition, insulin requirements increase by about 30% as children enter into their pubertal growth spurt. Growth is always plotted at diabetes clinic visits so that parents and their health care providers can identify patterns of overgrowth or undergrowth before they become serious health problems.

Normal cognitive and psychological development needed to execute the treatment plan can be significantly affected by a chronic illness such as diabetes.[4] Each stage of development—infancy, toddler, school-age, adolescent, and adult—includes different psychological characteristics, different cognitive skills, different psychological issues and different concepts of illness. The participation expected of the child in his/her management plan must take into account the child's psychological stage, cognitive ability to understand the need for such treatment, and concept of illness. Different childhood diabetes programs approach these challenges differently. Wysocki and colleagues[5] surveyed 229 pediatric endocrinologists as to the age at which they felt that 50% of their patients with diabetes could successfully master different treatment skills. Physicians agreed that, by age 4.5 years, children could recognize and report hypoglycemia and that, by 14 years, they could perform the most complex task of planning exercise considering insulin and food. The same survey was completed by 480 parents of children with T1DM. The parents reported that the mean age of mastery of obtaining a blood sample from the fingertip was 3 years and that, by 3.5 years, half of their children could recognize and report hypoglycemia. Parents also stated that, by 12 years, half of their children should be able to master the most complex skill of planning for exercise while considering insulin and diet. Our practice group surveyed our own patient population using the same instrument. Most of the children believed they could master the technical skills (SBGM, insulin drawing, and injections) by 10–12 yrs, but only 31% of 16-year-olds were comfortable making dietary decisions. Thus, there is a great disparity among physicians, patients, and parents as to the appropriate age of diabetes autonomy. It has been shown that deviation from developmentally appropriate self-care autonomy is associated with poorer glucose control and that children whose families who continue to maintain involvement in their child's diabetes regimen have a better outcome.[6,7]

The third challenge in the management of childhood diabetes is the identification and nurturing of developmentally appropriate family and social support. Parents often assume that the child will naturally assume responsibility for their own diabetes care as they age, but surveys of parent-child dyads have demonstrated that there is often disagreement over the person responsible for several items of the treatment plan.[8] In other words, when parents withdraw from diabetes management responsibilities, the adolescent does not necessarily assume those responsibilities. While education may be critical to the accurate performance of self-management skills, education and knowledge by itself does not affect adherence to the medical management plan. Motivation for tasks that are tedious and interfere with daily activities is often difficult to establish even when the short-term reward appears worthwhile. A good example is requiring an adolescent to wear diabetes identification in order to obtain a driver's license. Many teens would rather not drive than relent and wear an identification bracelet or chain. In fact, with a disease whose potential complications are not readily apparent and whose rewards for successful management seem nonexistent, there may be little or no motivation to adhere to the treatment plan.

McNally and colleagues[3] reported that adherence to the medical management plan moderates the relationship between executive functioning and glycemic control. Higher levels of executive functioning were associated with adherence, adherence was related to glycemic control, and glycemic control depended on treatment adherence. The family's contribution to adherence, in addition to providing a developmentally appropriate level of emotional support, includes a restructuring of their own routines to accommodate their child's needs and sharing the responsibility for diabetes management with their child.[9] The child simply cannot do this on his/her own!

Family support also includes providing the financial resources required to execute the treatment plan.[7,9] The cost of diabetes care in the United States is over $174 billion per year.[10] One in every five health care dollars is spent on diabetes. The average person with diabetes has health care costs of over $6,000 per year. Other social challenges include ensuring that one's child with diabetes is safely cared for while at school.[11] Also, adolescents and their families need to seek out and discuss diabetes-specific information regarding driving safety, use of alcoholic beverages, career planning, sexual functioning including contraception, and hereditary factors.

Type 2 Diabetes in Children

There is no question that the growing obesity epidemic is directly associated with the increasing incidence of type 2 diabetes mellitus (T2DM) in children. Although the Diabetes Prevention Program demonstrated that T2DM can be prevented in adults by intensive lifestyle intervention that includes exercise and weight loss, there have been no similar studies in children.[12] One can only infer that such an intervention will benefit children. Its implementation, however, may be problematic. Most obese children come from families with obese parents, many of whom already have T2DM and may be dealing with health problems of their own.[7] Whether or not such families can provide the necessary support for their children, as outlined earlier for families of children with T1DM, remains to be proven. Medical treatment options for children with T2DM are limited to metformin alone. Thus, lifestyle intervention may be even more important for children than for adults and should be included in each child's treatment plan.

The management of T2DM in children is no less cumbersome or less intrusive to lifestyle than that of T1DM. Normal growth is altered by excess weight, and puberty often occurs earlier than in the nonobese child. Depression is common among children and parents with T2DM and adherence to the treatment plan is often discouraging.

Conclusions

The management of T1DM and T2DM in childhood is complex and tedious, affecting every aspect of the child's physical and emotional growth and development. The challenges to successful management are legion and the need for developmentally appropriate family support and health care professional guidance is evident. Identification of specific and remediable challenges and barriers unique to each child with diabetes requires persistent vigilance and an understanding of how these challenges may manifest themselves.

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