Psychological issues in the care of children and adolescents with type 1 diabetes

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The present article highlights some of the psychological issues in children and adolescents with type 1 diabetes and provides health professionals with some strategies for addressing them.

Key Words: *Adolescents; Children; Psychosocial factors; Type 1 diabetes*

Les enjeux psychologiques dans les soins aux enfants et adolescents atteints de diabète insulinodépendant

Le présent article permet de souligner certains des enjeux psychologiques qu'affrontent les enfants et les adolescents atteints de diabète insulinodépendant et fournit aux professionnels de la santé des stratégies pour y réagir.

Type 1 diabetes is unique among chronic diseases of children and adolescents in terms of the complexity of treatment and level of family involvement required for successful management. Families learn that by doing what it takes to achieve healthy blood glucose control, they are reducing the risk of short- and long-term complications. This message is hopeful, but the mission is daunting and further complicated by the normal developmental challenges of childhood and adolescence. Good metabolic control depends on a healthy psychological environment. Likewise, psychological well-being is affected by metabolic control (1-4). Thus, children and adolescents with diabetes and their families require the support of an expert paediatric diabetes team from the time of diagnosis. The team should include a physician, nurse, dietitian and mental health specialist, such as a social worker or psychologist, and their treatment approach should be one that incorporates an understanding of the social and psychological implications of type 1 diabetes in youth (1). The purpose of the present article is to highlight some of the psychological issues in children and adolescents with type 1 diabetes, and provide health professionals with some strategies for addressing them.

ADJUSTMENT TO LIVING WITH DIABETES

The diagnosis of type 1 diabetes represents a crisis for children and parents. Family members often experience the classic stages of grief as they begin to grapple with the lifelong nature of diabetes and its potential consequences (5). In the first few months, it is common for children and adolescents to feel sad, lonely, anxious and irritable. Outbursts of temper, pessimism about the future, and refusal to take insulin or go to school are less common responses and more cause for concern (6). Parents, especially mothers, also report feelings of depression and anxiety, which may be precipitated by guilt or worry about the child's future. These negative reactions in youngsters and their parents seem to be normative responses, and they tend to subside during the first year (6). When adjustment problems persist, however, there is greater risk for later problems with psychosocial adjustment and metabolic control (6,7).

What can health professionals do to facilitate early adjustment to diabetes? First, because adjustment problems can be anticipated, health professionals can ensure that all families have the opportunity to learn about and be prepared for the psychological effects accompanying the diagnosis of diabetes. They can also recommend early referral to a mental health professional for assessment and support. Second, in educating the family at the time of diagnosis, health professionals should take care not to overwhelm the family. In the first few days, they should provide key 'survival' information only and allow time for grieving. In-depth education and behavioural interventions are best offered in the weeks and months following diagnosis, as the family adjusts to living with diabetes and before negative habits develop (2).

As part of the adjustment process, the family is required to create a 'new normal'. This includes developing new priorities, reorganizing family responsibilities, renegotiating child/adolescent and parent relationships in the area of support and supervision, and formalizing structures to support the integration of new routines. The ultimate goal is successful diabetes management without letting diabetes interfere with the attainment of normal developmental tasks. This is not easy. Health professionals can help by providing families with opportunities for formalized social support

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through groups or parent-to-parent guidance. In addition, team members can take time at each encounter to talk with families about their challenges in living with diabetes. At each visit, expectations and management goals should be reviewed to make sure that they are realistic and congruent with the patient's age and stage of development. It is critical that success be measured not only by glycemic outcomes but also by the attainment of age-appropriate diabetes-related skills and responsibilities, as well as emotional, social and academic development (8).

PARENTING THE CHILD/ADOLESCENT WITH DIABETES

When and how to transfer responsibility for diabetes management from the parent to the child or adolescent is an important issue to consider. From a very young age, children can be encouraged to participate in developmentally appropriate diabetes tasks under the gentle guidance and watchful eyes of their parents. However, pushing youngsters too hard to autonomy may lead to serious problems. Adolescents who assume diabetes responsibilities too soon face an increased risk of problems with treatment adherence, poor metabolic control and preventable hospitalizations (9). Total autonomy with diabetes self-management is not a reasonable goal for adolescents. Experts agree that it is important to encourage some level of ongoing parental involvement throughout adolescence (8-11). This recommendation is in keeping with the current developmental theory, which supports adolescents to move toward interdependence with, rather than independence from, the family (10). Even when adolescents are capable of giving injections and doing blood glucose checks, parents need to be encouraged to actively supervise their adolescent's diabetes management skills, praise and encourage their successes and proficiencies, and help them learn from their mistakes.

Research has shown the importance of family function in relation to health behaviours and metabolic outcomes (7,12). For all age groups, an authoritative parenting style, characterized by warmth and structure, is associated with better adherence to the diabetes regimen. Conversely, poor communication skills and family conflict are associated with problems with adherence and glycemic control (8,13). Early intervention may prevent or minimize later difficulties with successful diabetes management. For example, parents can be counselled routinely about the importance of giving clear expectations and applying positive reinforcement for their child's successful diabetes self-care efforts. Criticizing, nagging and arguing when something is missed are commonly reported strategies that do not work. Goal-setting, charting, behavioural contracts and social problem-solving have been used successfully in improving adherence in children and adolescents (8). Situations indicating a need for a referral to a mental health expert for evaluation and treatment include those in which there is already family conflict, poor communication, high levels of parental stress and family isolation from social supports (8).

Although diabetes occurs in the context of the family, there are certain individual characteristics of children/adolescents that may impact on the adjustment to and management of diabetes. For example, children and adolescents with high self-esteem, competence and coping skills tend to show better management of their diabetes (12,14). The ability to handle peer pressure and maintain normal social activities can also affect the young person's adjustment to diabetes and vice versa. Children with diabetes should not miss school any more often than their peers. It is good practice to ask routinely about school attendance and performance because these can be good indicators of well-being and adjustment to diabetes. In addition, participation in diabetes camps and support groups should be encouraged as a source of social support. Finally, coping skills training has been shown to improve adolescents' metabolic control and quality of life (15).

ADOLESCENT ADHERENCE DIFFICULTIES

Adherence difficulties with diabetes management peak in adolescence. Metabolic control deteriorates in adolescents when compared with children and adults (16). This can be explained by the physiological changes and insulin resistance that occur with puberty as well as 'physiological resistance' and adherence problems that seem to peak in adolescence. The psychological factors that account for poor adherence are best understood within the context of normal adolescent development. Experimentation, rebellion and risk-taking are often associated with the adolescent's struggle for control of his or her destiny. This is a challenging time for adolescents, parents and health professionals. Out of fear and frustration, parents and professionals may feel compelled to motivate the adolescent with scare tactics, including the threat of complications. This rarely, if ever, works and may be counterproductive. Rather, the health professional can help the adolescent and parent label their respective concerns, promote a collaborative relationship between them and actively encourage shared decision-making. Mutual respect needs to be emphasized. Addressing the adolescent's number one concern first is a good starting point. A good question for health professionals to ask all young people from time to time is, "What is the toughest part about living with diabetes right now?" This presents a teachable moment and sets the stage for some focused problem-solving.

DEPRESSION, EATING DISORDERS AND RECURRENT KETOACIDOSIS

While the majority of children and adolescents cope reasonably well with the demands of diabetes, a small proportion experience serious psychological problems, such as depression, eating disorders and recurrent ketoacidosis (4). Adolescents who are depressed may find it very difficult to do even the minimum required to maintain safe metabolic control. As a result, they are at serious risk for short- and long-term complications (11). When depression is suspected or identified, a responsible adult needs to ensure that the

adolescent receives safe diabetes management while he or she gets help with the depression.

Clinical diagnosis of eating disorders using the *Diagnostic and Statistical Manual of Mental Disorders* (17) criteria can be made in 10% of girls with diabetes; an additional 10% to 15% meet criteria for subclinical eating disorders (18). Studies show that binge eating and insulin under-dosing for weight control are common practices in adolescent girls with diabetes. Three aspects of diabetes may trigger the expression of an eating disorder: acute weight gain that comes with the initiation of treatment or improvement in blood glucose control, dietary restraint as part of diabetes management, and the availability of insulin omission as a unique way to 'purge' through induced glycosuria (19). In adolescent girls with persistently poor metabolic control, eating disorders should be suspected. Referral should be made to a paediatric diabetes team that has access to mental health professionals with expertise in eating disorders.

Diabetic ketoacidosis (DKA) is a life-threatening event. With standard education, parental involvement in routines and access to team support during illnesses, DKA should not occur following initial diagnosis. Recurrent DKA is usually the result of insulin omission and represents a serious problem in the child/adolescent or his/her family (20). It invariably occurs in youngsters who are old enough to be giving (and, therefore, not giving) their own injections. Insulin omission may be a maladaptive coping strategy used, for example, to get out of school or an abusive situation, or it may be a sign of serious family dysfunction. It may also be a form of purging and an indication of eating pathology. Recurrent DKA can be arrested by putting a responsible adult in charge of preparing and giving all insulin injections while the underlying pathology is being assessed and treated (20).

SUMMARY

There is no question that living with diabetes is a heavy burden for children, adolescents and their families. Some seem to suffer more than others. Most, however, display incredible resilience. Overall, experience and research seem to show that the best preventive approach to the psychological difficulties seen in children and adolescents with diabetes is a strong, supportive family who is able to gain strength and direction from a team of professionals sensitive to the psychological issues associated with diabetes and who act on them appropriately.

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