

Psychosocial Issues for Children and Adolescents With Diabetes: Overview and Recommendations

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The psychosocial impact of diabetes in childhood is ubiquitous and involves the entire family, as well as schools and society as a whole. The International Society for Pediatric and Adolescent Diabetes (ISPAD) developed guidelines in 2000 to assist health professionals in the management of young people with diabetes. These guidelines are based on the St. Vincent Declaration, the Declaration of Kos, and the Declaration of the Americas, which define the rights of all people with diabetes and focus on significant areas of responsibility for those involved in the care of diabetic children and adolescents.

This article addresses and expands the section of the ISPAD guidelines dealing with psychosocial issues in children and adolescents with diabetes in order to aid in the diabetes management decision-making process. The goal of both this article and the ISPAD guidelines is to aid in the development of diabetic children into well-adjusted adults with the highest possible degree of diabetes control.

Diabetes in infants, toddlers, older children, and adolescents poses serious physical, mental, and emotional challenges. Striking a balance among hypoglycemia/hyperglycemia, growth/development, and other life factors is not easy for health care providers, patients, or families. In addition, personal, family, or environmental conditions present before the onset of diabetes may compound the delicate balance needed to maintain good glycemic control. Therefore, there is a great need, especially at the time of initial diagnosis, to assess the developmental, behavioral, and psy-

chosocial history of children with diabetes and their families.

Assessment should occur both at the time of diagnosis and periodically thereafter. If problems are identified, early interventions should be initiated.

Psychosocial Impact

Any potentially life-threatening condition has some psychological impact, and that of diabetes is profound. If the care regimen is complex, the impact is greater in terms of financial cost, misunderstandings, external influences (e.g., patients may be accepted or rejected by the community), and the needs imposed by the disease itself.

Family members often experience the classic stages of grief, progressing from anger and denial to bargaining, depression, and finally resolution or acceptance.¹ Unresolved grief leads to families becoming dysfunctional if they were not already so.² Although most families reach grief resolution, Lowes and Lyne³ describe the chronic sorrow that can be found when families address this lifelong disease and its potential consequences.

Adjustment to a diagnosis of diabetes takes 6–9 months for children and 9–12 months for parents.⁴ Diabetes control and usual family functioning are difficult during this period and require support from the medical team.⁵

The stressors of everyday life can greatly affect both family functioning and blood glucose control.⁶ Stressors such as divorce, family arguments, violence, or abuse can lead to elevated blood glucose levels and increase the need for intervention by a supportive health care team.⁷

Families play the key role in the adjustment of children to diabetes, to their level of care, and to their specific management regimens. The impact of diabetes depends on children's and families' perceptions and knowledge of self-care and self-management, as well as on the background, structure, and functioning of families as a whole. For some, and especially low-income families, limited access to health providers and high costs of health care also affect diabetes control and family stability. A history of diabetes complications among patients' relatives can significantly affect the outlook (optimistic or pessimistic) of both diabetic children and their families.

Insights From the Literature

A complete review of studies on the psychological impact of diabetes in children is beyond the scope of this article. However, insights from a few important studies merit discussion.

A study⁸ using the Child Behavior Checklist to determine whether having diabetes as a child affects psychological adjustment found that both internalized and externalized behavior problems were increased in children with diabetes. Boys with diabetes became more aggressive than boys without diabetes. The initial findings of Hausen and associates⁹ demonstrated that health care professionals can predict short- and long-term adherence based on the answers to a questionnaire related to family conflict, cohesion, and organizational skills. Northam and associates¹⁰ found that the impact of a diabetes diagnosis varied with the age of the child and the socioeconomic status of the fami-

ly. They also found that Australian families became less flexible over time in diabetes-related activities. Holmes and associates¹¹ demonstrated that if intervention is not carried out immediately after diagnosis or whenever problems arise, behavior problems are more likely to develop or compound. A high level of family conflict acted as a predictor of behavioral problems, especially if the family was less cohesive, reinforcing the need for a team approach.

Team Diabetes

In 1979, Laron and associates¹² reported that a multidisciplinary team was needed for optimum care of people, and especially children, with diabetes. This view has gained acceptance worldwide and has been supported by data compiled from the Diabetes Control and Complications Trial¹³ and from a later study employing a crisis intervention program.¹⁴

Because a diagnosis of diabetes has an immediate impact on both child and family, it is not uncommon for families to find themselves in a state of shock. Any type of shock requires a crisis intervention treatment approach.¹⁵ Multiple professionals are needed to address the various concerns and responses such an event elicits.

Infants and Toddlers

In infancy and toddlerhood, children have more rapid changes in behavior and development than at any other stage of childhood. For very young patients with diabetes, preventing severe hypoglycemia and diabetic ketoacidosis is crucial. Although insulin administration and careful monitoring of blood glucose levels are a necessity, these should be carried out with the least discomfort possible to ease the psychological adjustment to such invasive and potentially uncomfortable procedures.

General parenting and discipline should be the same for children with diabetes in these stages as for their peers without diabetes. Special attention must be given to children under the age of 5 years who experience frequent severe hypoglycemia or hyperglycemia. Such occurrences appear to be associated with learning disabilities.^{16,17} Therefore, concerns about the

adequacy of blood glucose levels must be counterbalanced with the psychosocial and neurophysiological functioning of these children—a fine line to walk.

Infants and toddlers are dependent on their parents for care. This puts parents under a great deal of stress until their child can participate in the diabetes care regimen or at least attend a daycare or kindergarten program.¹⁸ Even the adjustment from initial hospitalization to home can be difficult unless the parents have been properly prepared. Vandagriff and associates¹⁹ found that parents of younger children with diabetes worried more than those of older children with diabetes, although the level of worry did not correlate with the degree of diabetes control.

Because the burden of daily diabetes management for young children falls largely on parents, these parents should be aided in identifying ways to reduce their own stress levels (e.g., going for a walk while their child is supervised by someone else; taking a few minutes to exercise; practicing yoga, quiet meditation, or prayer; or participating in relaxation training).²⁰

Schoolchildren

School-aged children and adolescents with diabetes must contend with a range of issues and feelings that vary with developmental stage. Feeling different from their peers is the most common issue they must face. Miller²¹ found that these concerns fell into five categories: 1) recognizing they had a “disease,” 2) the degree of discipline that required, 3) their concept of wanting to be normal, 4) things that were considered good or bad (e.g., “good” or “bad” blood glucose levels), and 5) degree of support from family and friends, both for daily self-care and for the costs of the disease, such as doctor visits, hospitalizations, and supplies.

Separating from parents when starting or returning to school also causes schoolchildren with diabetes to fear for their safety. Are teachers, school nurses, and other staff educated properly to treat hypoglycemia or to respond appropriately to high blood glucose levels? If meals are offered in school, is the time for eating or the amount of food available a problem?

Are too many sweets available? Often, these fears are shared by parents.

Teachers and school nurses must be educated about diabetes. Considerations must be given to appropriate teacher-pupil relationships so that children with diabetes do not get singled out as misfits in the classroom. Without adequate education, participation by students with diabetes in all available academic and social activities is often blocked or questioned. All parents of children with diabetes should, but many do not, visit their child’s school to discuss specific needs with teachers, the principal, and, when available, the school nurse.

When there is no school nurse on staff, a health professional could be assigned to visit the school. If no health professional is available, a willing individual should be trained to assess and assist in meeting the child’s needs (from testing blood glucose to treating hypoglycemia) in the school environment so that having diabetes at school will be safer and less fearful for children, parents, and teachers.

Adolescents

Jacobson and associates²² noted in a 4-year prospective study that families with diabetes who participated in their study tended to be more dysfunctional than families without diabetes. These families were confused about diabetes-related goals. There were more problems for girls caring for their diabetes than for boys (e.g., eating disorders or issues involving the starting of menstrual periods). For families not functioning well, there was more need of support from outside the home, such as from peers, schools, or clinic personnel.

Adolescents with chronic illnesses have described their situation as “hard.”²³ A study by Hanna and Guthrie²⁴ revealed that adolescents with diabetes tend to ignore their vulnerability to the potential consequences of their disease in their age-appropriate preoccupation with the present. Only one-fifth of the diabetic adolescent participants felt that they complied fully with what they believed they were expected to do regarding diabetes management. The desire for more independence was one of the barriers to compliance identified by these adolescents. However,

this conflicts with fears young people have reported developing after they experience “doing something weird” during an insulin reaction.²⁵

Because adolescents live in the here-and-now, they usually feel invulnerable to long-term complications. Those who do fear such complications sometimes respond by adopting risky or haphazard behaviors while they perceive that they are still able—a response too often observed in older adolescents.

Peer support has been found important for adolescents not only in adjusting to diabetes but also in controlling blood glucose.²⁶ On the other hand, diabetic adolescents can be influenced by peer pressure toward cigarette smoking, alcohol and drug use, and unprotected sex and must be counseled by the diabetes team on the dangers of such activities.

The prevalence of eating disorders in adolescents raises questions about the use of rigid dietary restrictions. Weight gain during the pubescent period can lead to low self-esteem and depression.²⁷

Long-term contact and supervision by parents, health care providers, educators, and others may be viewed as an annoyance by these young people or may leave them fearful of “doing something wrong.” On the other hand, such contact may help them learn the necessity of careful guidance and follow-up that will be useful in adapting and coping with their disease.²⁸

Adolescents require guidance in learning to compromise and to achieve a livable balance among the demands of diabetes, life stressors,²⁹ and their desire for a carefree lifestyle. Adolescents who experience multiple hospitalizations as a group are more vulnerable and in need of psychosocial support.³⁰ Rosilio and associates³¹ have identified numerous other factors associated with the need for additional support in French children with type 1 diabetes.

Independence issues in adolescents need to be resolved individually, taking into account each child’s level of maturity and emotional affect.³² It should be considered unsafe for adolescents to take responsibility for their own diabetes care and self-management before reaching an adequate level of maturity.

As adolescents strive to be more independent, sex education and planning are necessary to prevent sexually transmitted diseases and unwanted pregnancies and to address the problems that sex and sexuality issues can impose on already socially stressed teenagers. Social support and a positive attitude toward birth control has been associated with more consistent use of birth control methods among young women with diabetes.³³

Adolescents need to be followed by a health care provider knowledgeable in these issues and in the changing needs of children with diabetes during the teenage years. Social support also must be provided in the context of adolescents’ development stage.³⁴ It is therefore recommended that children of all ages who are diagnosed with diabetes be referred to a diabetes specialist.³⁵

Parents

Parents of children with diabetes must deal with many pressures. The greatest of these is the fear that their child will experience severe hypoglycemia, especially when it is associated with seizures or a loss of consciousness.³⁶ Parents may also feel guilty for having transmitted the genetic components of diabetes to their child and worried that they have not done enough to manage the disease. Parents of children with diabetes are extremely concerned about how poor glycemic control has influenced their child’s growth and development.³⁷

A review by Lowes and Lyne³⁸ found that parents have differing ways of coping with these pressures based on their environment and interpersonal skills. And in spite of their various fears and concerns, parents of adolescents with diabetes also perceive benefits resulting from their child’s adoption of responsibility for self-management.³⁹

Chaney and associates⁴⁰ studied the needs and concerns of fathers. They found that fathers had greater influence than do mothers on children’s adjustment to having diabetes.

Having a child with diabetes places significant stress on marriages. One parent may blame the other not only in regard to genetics, but also in regard to division of diabetes management responsibilities and how that

might influence the overall level of diabetes control.⁴¹

Parents may also be in conflict about being too responsible (overprotective) or not responsible enough (neglectful). This is most evident when children reach adolescence. Planning the gradual transfer from child-centered diabetes care (performed by parents) to adult-focused care (performed by the adolescent or young adult with diabetes) may prevent the precipitation of poor metabolic control.^{32,42} Newer modes of treatment (e.g., insulin pumps) and medication (e.g., “designer” insulin analogs) should help to ease this transition by increasing lifestyle flexibility and facilitating more normalized blood glucose levels.

Siblings

The close parental supervision necessary for children with diabetes can lead to sibling rivalry and jealousy, even though the extra attention one child is receiving is directly related to the treatment regimen. Siblings of children with diabetes are affected by the disease within the family in this and other ways.⁴³

These siblings may be an asset to the sibling with diabetes and to the family as a whole, ready to assist when parents are not present. If not included in the care regimen, siblings may experience jealousy. Siblings also may fear developing diabetes themselves.⁴⁴ Without appropriate education, they might even fear that just being around their sibling makes them more likely to “catch” diabetes. Then again, they might feel that they have somehow “caused” their sibling’s diabetes because, in a moment of anger, they wished for some disaster to befall that sibling. Counseling and education can help resolve these conflicts.

As with any family, the participation of siblings in family meetings or at other times when they can express their concerns and fears will be therapeutic. Siblings should be allowed to reminisce and share their feelings about their brother or sister and their own thoughts and concerns about diabetes.⁴⁵

The Whole Family

Because diabetes affects not only the children who have it but also their whole family, it needs to be addressed

with the whole family in mind.

Although mothers usually take on most of the care of children with diabetes, fathers need to be involved both to support mothers and to demonstrate to the children that their lack of involvement in day-to-day management does not mean rejection or a lack of caring.

In many cultures, it is difficult for fathers to be involved because chronic diseases or disabilities are considered marks of imperfect children. Societal education and time are the only agents available to change such traditional beliefs.

Families facing diabetes must deal with a variety of needs and concerns that demand time and attention. But in such cultures, families may find there are few role models, let alone diabetes care centers, to help them navigate these issues.⁴⁶ Taanila and associates⁴⁷ noted the need to plan for contact and rehabilitation of the whole family and not just children with diabetes.

With the proliferation of one-parent families, it has become more important to provide relief and assistance to single parents of children with diabetes. Single parents must be encouraged and assisted in training other family members or reliable individuals to care for their diabetic child in case of emergency or in case they need a break from the demands of care.⁴⁸

Families and health care teams share a responsibility to ensure that children with diabetes eventually learn to care for themselves. As Wysocki and associates³² have noted, diabetes management should still be supervised into the middle to late years of adolescence. The psychological benefits to adolescents of learning to manage their own self-care include a higher degree of self-confidence and an improved concept of self-worth.

Learning self-management requires ongoing education. Parents should gradually give adolescent children increasing responsibility for decision making while continuing to supervise and educate them about self-care. Providers of children in families of nontraditional structure should be aware of the correlation between increased behavioral problems (common in such families) and level of blood glucose control.⁴⁹

Societal Responsibilities

Parents of children with diabetes need to know that their child has the same social rights as other children. Parents should work closely with their child's schools, daycare centers, and work settings to ensure that their child is being included in all types of activities.

Parents must educate school personnel regarding the specific needs of each child with diabetes and make appropriate supplies available for school use. Employers must also be educated to recognize that adolescents and young adults with diabetes can be qualified and motivated employees. Most importantly, the peers of diabetic children should have opportunities for open discussion so that they do not stigmatize a diabetic child.

In coping with the everyday demands of diabetes, many children seek out social support resources.⁵⁰ In most cases, these resources are provided by parents, but it has also been found that older children and adolescents can become adept at contacting specific teachers, a school nurse, a coach, or a health care provider on their own. Training in the use of social supports can be carried out successfully in young people, providing them with coping resources for both present and future use.⁵¹

Because unity brings strength, family members of children with diabetes should be encouraged to join organizations that support the services and research necessary to combat this dreadful disease. Providers can educate families about the types of services specific organizations promote. These contacts can also afford families an opportunity for social support and relieve their feelings of isolation. Finally, such groups can be strong advocates for research funding and for services necessary to improve the quality of life for people with diabetes and their families.

Social responsibilities also involve health care professionals. Providers must help families of children with diabetes rebalance after diagnosis and maintain that balance by acquiring education and experience and developing a willingness to assume an active role in diabetes care.⁵²

Coping Strategies

Families should be assessed and provided with interventions to help them develop coping skills as soon as possible after diagnosis, and these skills should be reassessed about 2 years after diagnosis.⁵³ Simple skills such as recognizing and treating hypoglycemia must be taught early.⁵⁴ All such interventions must be designed with age-appropriate developmental capabilities and intellectual capacities in mind.⁵⁵

Training in non-emotion-based coping strategies, which have been associated with better metabolic control and self-care practices,⁵⁶ are helpful, as are interventions to help families "re-normalize" after diagnosis.^{57,58}

Seppan and associates⁵⁹ reported on a 4-week parental coping program that assisted parents in dealing with denial and guilt, handling their child's care, and reorganizing their household to be more compatible with their child's changing health care needs.

Health care professionals must always be aware that, in the absence of healthy coping strategies for family members and young patients with diabetes, the potential for psychological problems is great, especially in situations in which culture and health care strategies clash. Dysfunctional families are far less likely to develop healthy coping strategies.⁶⁰ Professionals who learn to observe patients' coping strategies and educate those at risk have found the outcome to be an increase of healthy coping choices.⁶¹

Conclusions

The care of children and adolescents with diabetes is especially important because these children are part of our leadership for the future, they are a particularly vulnerable population, and they require both family and professional support in order to become healthy and productive adults.

Individual communities and countries are challenged to meet the needs of socially deprived infants, children, and adolescents. Additional resources may be located through national and international diabetes organizations around the world.

Although not all cultures or countries are presently able to meet the recommendations laid out in this article, such guidelines are nonetheless impor-

tant in helping to measure what has been and what remains to be achieved. We trust that health care professionals involved in the care of young people with diabetes will attempt to overcome the psychological and sociological obstacles they face so that all such children and adolescents will eventually enjoy a healthier and higher-quality life.

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