

Understanding Emotional and Psychological Considerations of Children with Diabetes: Tips for School Nurses

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Abstract

Any chronic illness in children is worrisome to parents who must transfer the care and safety of their children to others while the children are at school. Children, too, may have many concerns, including fear of failure, not wanting to be different from peers and needing to navigate the normal developmental issues of childhood and adolescence. When the illness is diabetes with its unrelenting regimen, it is critical that school personnel have an understanding of the issues involved so that they are in a position to help the child attain optimal health. This article is designed to foster understanding of the emotional and psychological issues children with diabetes and their parents face, so that school nurses and other personnel can better assist these students in the school setting.

Psychosocial and Behavioral Considerations

Diabetes impacts the life style, personality and overall emotional and physical well-being of the child. A diagnosis of diabetes can contribute to emotional disturbances both in the child and in the family (Kovacs et al., 1985). Adults and children who cope well with diabetes seem to find a balance as they fit diabetes care into their daily living, rather than forcing life to revolve around the diabetes regimen (Arslanian et al., 1994). Developing effective stress management, coping, and problem-solving skills is almost as important to successful therapy as are insulin administration, meal planning, blood glucose monitoring and exercise (Boland & Grey, 1996).

Children with diabetes are expected to have normal school attendance and academic performance. Often, the cares of diabetes take over and regulate the activities of daily living, and an imbalance occurs. This imbalance often requires tender loving care, possibly counseling, and an understanding of the developmental process (Betschart-Roemer et al., 2003). Sometimes there are difficulties that accompany life with diabetes that have an impact on developmental stages. Normal developmental characteristics such as the formation of body integrity and intactness, separation, and striving for independence are affected negatively.

Fear and Anxiety

Everyone hopes to have a secure, happy, well-adjusted child — at home and in the classroom. When diabetes is diagnosed, parents and children suddenly feel vulnerable. Parental expectations shift as their once normal, healthy child has a serious illness and they realize their child's mortality. The child may have had negative experiences of hospitalization, injections, separation, and the anxiety caused by parental grief. In young children, concerns over the intactness of their bodies are developmentally normal. A school-aged child who is newly diagnosed can sometimes temporarily regress to an earlier developmental stage and may become frightened by injections or finger sticks.

It is not uncommon for children with diabetes to worry about themselves. They know that their parents are anxious about them, and they also know what their parents expect with regard to performing their diabetes care tasks. They might worry that they

are not doing their diabetes tasks properly and on time, thus displeasing their parents. They might fret about fitting their diabetes tasks into their school schedule without disrupting the class and calling attention to themselves, or worry that they are having low blood glucose when they are hungry, tired, cold or anxious (Guthrie et al., 2003).

There are also significant costs, especially for the uninsured or underinsured, that compromise access to medical care and supplies vital to support the care. Although many children do not have to worry about the expense of their illness, others are acutely aware of financial strains within the family and the expense that the disease causes. They worry about the cost of supplies and medical bills and the burden upon the family. Some children take less insulin, reuse syringes and lancets, and test blood glucose fewer times than recommended because they are trying to save money.

***Tip for School Nurses:** Help the anxious child with firm direction, reassurance, and lots of hugs.*

Anxiety and Concern About Hypoglycemia

One of the weightiest concerns of parents of children with diabetes is that of hypoglycemia (Marrero et al., 1997). Hypoglycemia, which often cannot be prevented, is the greatest immediate danger to students with diabetes. Many parents regularly test blood glucose levels at night, even when it is not normally recommended, because they are afraid their child will become unconscious or have a seizure in the middle of the night. Parents are especially concerned about having inadequate treatment for

hypoglycemia available at school in case of emergency. Parental anxiety does not go unnoticed by the children, who sometimes incorporate their parents' anxiety into their own psyche. The children's fears are real and understandable. They often make visits to the school nurse's office for a variety of reasons, but mostly for reassurance that they do not have hypoglycemia.

Diabetes educators teach children to pay attention to physical signs and symptoms of low blood glucose. These include: feeling shaky, light headed, sweaty, dizzy, hungry, or sleepy. Children with diabetes are taught to carry something with them at all times to treat hypoglycemia. Yet, while in school, children might not be permitted to carry sugar and self-treat their hypoglycemia. This restriction can cause the child to feel insecure and vulnerable to having untreated, severe low blood sugar. ("What if I get low and need something right away?" "What if I have to make a big scene to tell someone?" "What if the nurse's office isn't open?" "What if nobody believes me?")

Some of the signs and symptoms of hypoglycemia are also signs of anxiety (due to the release of epinephrine). Children with diabetes can be confused as to what they are experiencing when they are having symptoms. At those times it is essential that they test their blood glucose to see whether they are actually experiencing low glucose or if their symptoms are due to something else. In addition to anxiety, the symptoms may be due to being hungry, sleepy, having had too much caffeine, or other reasons.

Tips for School Nurses: *Many children who are anxious about their diabetes frequent the nurse's office. Checking blood glucose, quickly treating low blood sugar, and sending the child back to class when things are satisfactory is important. Assure students with diabetes that they will be heard, will have the opportunity to treat themselves as needed in a prompt and appropriate way, and that adult help and supervision are available.*

Feeling Different

One of the greatest desires of a child in school is to fit in with peers. Children learn strategies to keep themselves from being different. Children who have diabetes might feel different from their friends because of the demands of treating their diabetes. Some are more sensitive than others to the issue of difference and

might be more reluctant to eat a snack, check blood glucose, or treat hypoglycemia in front of others. Fear of exhibiting symptoms of high or low blood glucose that are witnessed by peers can be ever-present and have a tremendous negative effect on self-esteem.

Tips for School Nurses: *Work to minimize differences whenever possible. Rather than singling out any child because of a diabetes need, work to allow the child a discreet and unobtrusive way to care for himself. Some children are "up-front" about their diabetes and do not care who knows. Others may wish to tell no one, and although there are obviously people who must be aware of it for safety's sake, others do not need to know. Respect these wishes and the child's way of dealing with things, and take cues from the child as to how things might be set up. Sometimes ingenuity needs to come into play. Often, asking directly will provide information about how each child prefers the situation to be handled.*

Depression

Increasingly, depression is being recognized among children and teens with diabetes (National Diabetes Education Program, 2003). It is common for children to have feelings of sadness, anxiety, loneliness, and isolation (Arslanian et al., 1994). One study designed to determine whether having diabetes 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 (Marrero et al., 1997).

Childhood and adolescence are very difficult times to have diabetes. The diabetes regimen does not fit in with the usual schedules and eating style associated with today's society. Even with an insulin pump, or flexible dosing of today's multiple daily dose regimens, there are impediments to diabetes control or normal life style. Children might feel pressure to please caretakers and not consistently meet required expectations. Sometimes they will make up blood glucoses or omit insulin doses. Guilt, feelings of failure, and depression can ensue. And when those with diabetes have been unable to do the required tasks, their healthcare providers sometimes label them as non-compliant or non-adherent, causing the children to feel that their parents and healthcare providers are disappointed in them.

Children also react to the focus on eating/not eating/healthy eating/food deprivation,

issues that go hand in hand with treatment. Thus, it is common for adolescents and children alike to feel guilty, sad and depressed. Eating disorders are common, especially in adolescent girls. The focus on food, proper eating, weight control, peer pressures and other psychodynamics can foster anorexia, bulimia and/or insulin omission for weight control (Daneman, 2002).

Tip for School Nurses: *School nurses and healthcare providers must be aware of emotional and behavioral issues and refer students with diabetes and their families for counseling and support as needed.*

Independence Issues

Parents might be overprotective of a child who strives for normal independence. However, the child or adolescent might not be able to achieve the independence of others. Parents want their child to be independent in diabetes care, yet are fearful that their child will not take adequate care of himself and therefore compromise health, well-being, and the future. Struggles can begin that lead to oppositional behavior and rebellion.

Conflict over diabetes issues might become the ultimate conflict within a family. One of the tasks of the adolescent period is to achieve independence from parents, but with diabetes, the task becomes more difficult. Bickering, arguing, nagging and "grounding" occur over issues of monitoring, eating, and taking medications. Parents become concerned that their teen will not take care of diabetes (as well they should be). Parents have a hard time letting go of the tasks and adolescents often have an even harder time doing the tasks. Very few adolescents take care of themselves well without the support and involvement of a parent, and even when they do so for short periods of time, they are not able to sustain the effort. Parents are fearful of surrendering the diabetes tasks to a teen who might not do the job required. Those who do best seem to have a balance of independence, trust and parental involvement.

When Poor Health Outcomes Occur

Few major chronic childhood diseases affect families and their social network as profoundly as type 1 diabetes (Almeida, 1995). It is well established that children at greater risk for acute and chronic complications of diabetes come from families in which there

are few supports, lower socioeconomic status, or chaotic home environments. Family stresses of this nature can contribute to physical abuse, physical neglect, and psychological neglect and abuse of children. Health professionals and school personnel might underestimate the degree of stress caused by diabetes upon the child and family.

Tips for School Nurses: *Be open to diabetes education in whatever form it comes. In some situations, the parent must be the educator for the school. However, many states, through their departments of health, have diabetes programs that are staffed by diabetes nurse educators. These nurses have been invaluable in helping schools understand the issues of diabetes.*

Hold a meeting with all school personnel who may be involved in the care of children with diabetes. Together with parents and the child, put together a written care plan with which everyone involved is comfortable. Parents need to understand what is not negotiable about state laws and the particular school district's approach to health care. The school personnel must understand the individual needs of the child and make certain the plan is followed—the health and safety of the child is at heart. A plan describing how communication will occur between the school and the parents and the child should be included. Schools can be quite effective in helping children stay on their diabetes plan and in motivating children to care for themselves outside of school hours.

Obtain *Helping the Student with Diabetes Succeed: A Guide for School Personnel*. This guide was produced by the National Diabetes Education Program (NDEP), a federally sponsored partnership of the National Institutes of Health, the Centers for Disease Control and Prevention and other partner organizations. It outlines the roles and responsibilities of school personnel, parents, and children and is available by calling the National Diabetes Education Program at 1-800-438-5383. One copy is free, each additional copy is \$3 with a 6 copy order limit. Copies also can be downloaded from the NDEP website, www.ndep.nih.gov. All sections of the guide may be reproduced and distributed with no copyright restrictions. A list of community resources is included.

Setting out with a positive and supportive attitude can go far toward decreasing anxiety in parents. Parents need to know that their children are safe and that the school is willing and able to keep them well. It takes time to

build mutual trust whereby parents know that the school is doing whatever it can to help and support their children. When concerns, issues, or conflicts occur, the child's diabetes team can often step in (with parental permission) to foster understanding and help decrease anxiety.

Summary

Dealing with diabetes on a daily basis can be a psychological burden. Yet, the news is not all bad! Many children and teens with diabetes are surprisingly resilient and courageous. They often have an early appreciation of their mortality, are more empathic and understanding of others, and have developed a discipline in their lives that others might not have. Therefore, it is important for school nurses and other school personnel to recognize the child's strengths and help to build on them. It is important that those involved will try to overcome any obstacles so that all children and teens with diabetes will eventually enjoy a healthier and higher quality of life.

Childhood and adolescent diabetes requires complex daily management skills and is a source of anxiety for parents, children, and school personnel. It is the incumbent upon those who work with children and teens with diabetes to have a sound understanding of the disease and the emotional/developmental issues that evolve. Only then will all involved be able to have a successful school experience that will ensure the safety of the child and reassure parents that their children are well taken care of at school. 🍀

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RESOURCES

A Child in Your Care Has Diabetes. A Collection of Information.
Hen House Press, Inc.
12 Route 17 North, Suite 212
Paramus, NJ 07652
201-291-9199; henhousepress@aol.com

American Association of Diabetes Educators (AADE)
100 West Monroe, Suite 400
Chicago, IL 60603
312 424-2426; www.diabeteseducator.org

American Diabetes Association (ADA)
Find your local ADA at: www.diabetes.org/local or
1-888-342-2383; <http://wouthzone.diabetes.org>

American Dietetic Association
216 W. Jackson Boulevard, Suite 800
Chicago, IL 60606-6995
1 800 877-1600; www.eatright.org

Bam! Body and Mind:
Feeling stress, tense, or under pressure?
Check out 10 tips to help keep your cool at
www.bam.gov/head_strong/top10Coping.htm

Diabetes books, CD-ROM and Video for children, teens and caregivers
By Jean Betschart Roemer
www.LearningDiabetes.com

Juvenile Diabetes Research Foundation International (JDRFI)
120 Wall Street
New York, NY 10005
1 800 223-1138; www.jdrf.org

KidShape® Foundation:
Find a weight management program for children and their families.
www.kidshape.com

National Diabetes Education Program:
1-800-438-5383

Find information about type 1 and type 2 diabetes and *Helping the Student with Diabetes Succeed: A Guide for School Personnel*.
www.ndep.nih.gov/diabetes/youth/youth.htm

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