

Experiences of Children and Adolescents With Type 1 Diabetes in School: Survey of Children, Parents, and Schools

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More than 160,000 children and adolescents with type 1 diabetes are enrolled in public and private schools in the United States.^{1,2} School children with type 1 diabetes must be afforded the proper time and tools for diabetes self-care to be safe, learn effectively, and be able to participate in all school activities.^{3,4} In addition, knowledgeable school personnel are needed to assist them when they do need help.

Thanks to the efforts of the American Diabetes Association (ADA), the Juvenile Diabetes Research Foundation (JDRF), the National Diabetes Education Program (NDEP), and the Children with Diabetes Web site, much progress has been made in the past 20 years to ensure that children in schools are safe and protected. Each of these organizations has provided valuable educational and advocacy resources for parents and educational materials for school systems.

The daily self-management of children and adolescents with type 1 diabetes is complex and dynamic. It requires frequent self-monitoring of blood glucose (SMBG), insulin injections, and individual meal plans.⁵⁻⁷ However, changes in daily schedules (e.g., recess, physical education class, school outings, and participation in sports) or an acute illness complicate children's blood glucose management while at school. In addition, children are continually growing during each academic year, requiring frequent changes to their individualized treatment plans. Decisions concerning adjustments in insulin doses occur often while children are in school and frequently must be made by a school nurse, parent, or guardian

following protocols in the comprehensive diabetes care plan prescribed by the children's physicians.^{8,9}

School nurses are the principal contact person between parents and guardians and health care providers with regard to updating children's individualized diabetes care plans for management of acute problems during the school day. Unfortunately, some school systems do not have enough adequately trained nurses to manage children with type 1 diabetes,⁵ despite the fact that federal law requires them to have such staff in place;¹⁰ section 504 of the Rehabilitation Act of 1973, the Americans with Disabilities Act, and the Individuals with Disabilities Education Act (IDEA) can be applied to children and adolescents with type 1 diabetes in schools.

The Americans with Disabilities Act calls for not only school nurses, but all school and daycare personnel involved with children with diabetes to have adequate training and understanding of general and emergent diabetes care. The most recent guidelines for diabetes management state that at least one adult should be available for all diabetes management needs if a school nurse is unavailable.¹¹ However, many school systems only have a single nurse working in multiple schools.^{9,12,13}

It has been the authors' experience that some children and adolescents with type 1 diabetes still have difficulties in certain school systems. Some schools are unaware of the federal laws applicable to children with type 1 diabetes, and some schools still do not have individualized care plans for children and adolescents with type 1 diabe-

tes.^{4,14,15} Interestingly, many children with diabetes and their parents feel that dealing with diabetes in school is among the worst experiences they have faced while growing up.^{4,6,14,16,17}

Previous studies have documented problems commonly experienced by children and adolescents with diabetes and their parents with regard to restroom privileges, performing SMBG, eating snacks, or administering insulin when needed.^{4,14,15} Children are often asked to leave the classroom to do these self-care functions or to go to the school nurse's office, which can be a long distance from the classroom. In many schools, only nurses are permitted to help children with SMBG, insulin injections, insulin pump boluses, and glucagon administration.¹⁸ Children often go unassisted to the nurse's office, which takes them out of the classroom for long periods of time and increases their risk in the event of a diabetes emergency. Even older children and adolescents who independently perform routine diabetes self-care are not allowed to test their own glucose levels or take their insulin in a classroom.

In some school systems in our region, children and adolescents with type 1 diabetes are still not allowed to participate in some sporting events, field trips, or other extracurricular activities without having a parent present. Thus, if these activities occur during the day, parents are often required to miss work to ensure their child's participation.

Finally, there are inadequate numbers of trained nurses available to provide the necessary routine or emergency care for children and adolescents with type 1 diabetes, which results in school systems forcing children to travel long distances to attend a school that has a school nurse, leaving behind siblings, friends, and teachers. Busing children long distances becomes a safety issue, and the training of bus drivers becomes important, as well.

The purpose of this study was to evaluate the experience of children and adolescents with type 1 diabetes in school by surveying patients, their parents or guardians, and the school personnel directly involved in

their care. Although there has been a significant increase in the prevalence of type 2 diabetes in school-age children, this survey was limited to students with type 1 diabetes because of the complexity of their diabetes management.

Methods

This study surveyed school-age children and adolescents (kindergarten through 12th grade) with type 1 diabetes, their parents, and the school personnel (e.g., nurses, teachers, administrators, and coaches) at the schools in which the children were enrolled. The investigators directly approached all of the approximately 130 children and adolescents and their parents or guardians in the University Medical Associates (UMA) Diabetes/Endocrine Center about their interest in participation. A series of questionnaires were designed by the researchers to identify the diabetes-related experiences of the children and adolescents, their parents, and their school personnel. (Copies of the surveys are available online at www.oucom.ohiou.edu/arhi/dec/dec.htm.) This was not a randomized trial, and all patients were asked to participate in the survey. Thus, a convenience sample was used.

Informed consent was obtained from each child's parent or guardian during routine clinic visits and assent was obtained from the children and adolescents themselves before they participated in the study. The participants were given surveys to either complete during the office visit or take home to complete. Families who did not complete the survey in the medical office were provided a self-addressed stamped envelope that could be sealed and returned to a drop-box in the clinic or via the U.S. mail. Parents and guardians of young children assisted them with survey completion and completed a separate survey themselves. Some children and parents completed the survey in the office; however, most took the surveys home and mailed them back at a later time.

Schools and key personnel were identified by participating families. A cover letter was mailed to members of all of the area's school

boards informing them of the study's purpose, risks, and benefits and requesting the participation of appropriate school personnel. Patients were enrolled in 20 schools from 14 school systems, and all but one agreed to participate in the study.

Once approved by the school boards, the same letter and survey were sent to the school nurses or other specific school personnel identified by the patients' parents. Surveys and a signed release from each participant were returned for analysis. School personnel surveyed were primarily school nurses (85%); however, some dietitians, teachers, and other school personnel directly responsible for a child's care in a particular school or for the development of policies concerning the care of children with diabetes in schools were included. The authors could usually determine whether a nurse, teacher, or administrator filled out the survey from each school.

The study was approved by the Ohio University (OU) Institutional Review Board. Raw data were maintained by the investigators in the OU College of Osteopathic Medicine Clinical Diabetes Research Center. Only researchers directly associated with the project had access to the data for the purpose of analyzing its content. Tables of frequencies and charts of responses by children, parents, and school personnel were produced using SPSS software (SPSS Inc., version 16, Chicago). Cross tabulation was used to compare responses among children, parents, and school personnel.

Results

A total of 80 children and their parents or guardians completed surveys. Twenty-eight surveys were returned by school personnel representing 20 schools. The number of children with type 1 diabetes in each school ranged from none (5.9%), 1–2 (27.5%), 3–4 (41.2%), 5–10 (13.7%), and >10 (11.8%). In general, all groups reported that their overall school experience dealing with diabetes in schools was positive. However, problems still exist and are highlighted below.

Table 1. Perceptions of Children and Adolescents With Type 1 Diabetes of Experiences in School

	Response (%)					
	Very Often	Often	Sometimes	Rarely	Never	Yes No
Self-perceptions of treatment at school						
Are you treated differently in school?	4.2	10.4	31.2	22.9		
Are you accused of using diabetes as an excuse?	14.6	6.2	16.7	12.5		
Have you been prevented from managing your diabetes?	8.3	8.3	12.5	14.6		
Have you been embarrassed in front of classmates?					11.4	84.1
Did you ever feel like quitting school or not getting involved?					16.7	79.2
Adequacy of school to care for diabetes						
Do you feel <i>care agents</i> know enough?	14.9	29.8	27.7	17.0	10.6	
Does the cafeteria have proper food?	20.0	40.0	20.0	6.7	13.3	
Do you have to take lunch to school?	11.1	11.1	13.3	17.8	46.7	
Do you get help on returning from hospital/illness?					11.4	84.1
Personal impact of type 1 diabetes						
Are you ever embarrassed by low blood sugar?					22.9	68.8
Are you ever embarrassed by taking your medication?					27.7	63.8
Do you ever have feelings of disconnectedness?					27.5	62.5

Overall self-perceptions of the experiences of children and adolescents with type 1 diabetes in school

Children and adolescents feel that they are treated differently in school because of their diabetes (Table 1). Nearly 70% reported that they feel this way at least some of the time; 14.6% felt this way frequently; 31.2% reported feeling this way sometimes; and 22.9% reported feeling this way rarely. Parents reported that their overall experience of having a child with type 1 diabetes in school was good; 61% reported that their experience was above average or excellent, and only 4.9% felt the experiences of their children in school were unsatisfactory (Table 2). Most school personnel (predominately nurses) felt that their

experiences dealing with children with type 1 diabetes were satisfactory, and, as with parents, only 4% indicated that there were significant problems. Furthermore, most (93.9%) of the school personnel felt comfortable working with children with diabetes in the school setting (Table 3).

Problems identified in schools

Diabetes self-management. Ability to perform routine diabetes self-management was a major concern. More than half of the children and adolescents (53.2%) reported having been prevented from self-management of their diabetes or from using the bathroom at school (Table 1). Only 16.7% reported that this occurred usually or always. Parents reported that schools do not always afford

adequate time for diabetes self-care, and only 41.5% responded that their child was always afforded adequate time for self-care. Almost 20% of parents reported that their children were often not granted full access to their diabetes needs (Table 4). Although children were allowed to perform routine self-management most of the time, nearly 50% of children and adolescents felt that school personnel thought they used their diabetes as a way to go to the bathroom, get a drink, or eat a snack and thereby “to get out of class” (Table 1).

Sixty-five percent of school personnel felt that their schools were very supportive of the self-care needs of children and adolescents with diabetes, 31.4% thought that they were somewhat supportive, and only

Table 2. Perceptions of Parents of Children With Type 1 Diabetes in School: Emotional Response (%)

	Very Often	Often	Sometimes	Rarely	Never	Yes	No
Emotional impact of your child's school experience							
Childs feel bad about experiences due to type 1 diabetes	12.2	7.3	24.4	12.2	43.9		
Child is embarrassed in presence of classmates	2.4	9.8	12.2	9.8	65.9		
Personal impact of having a child with type 1 diabetes in school							
Have you ever missed work due to child's illness?	0	8.1	21.6	21.6	48.6		
Due to inadequacy of school to care for needs?						30.8	46.2
Because child has to go to doctor?						63.4	17.1

4% felt that their schools were not at all supportive of students' needs (Table 5).

Nutritional services. The nutritional services offered by schools was a major issue identified by children and adolescents and their parents. Only 60% of children and adolescents felt that their school cafeteria menu was adequate for their diabetic meal plan, 20% felt that it was inadequate, and 20% brought lunch from home to compensate for these perceived deficiencies (Table 1). Twenty-six percent of parents reported that school nutritional services offered little or no cooperation, whereas 52.6% reported that schools were somewhat cooperative. For example, 55% of parents responded that the nutritional information needed to calculate lunchtime insulin boluses at school was never available, 30.5% reported that it was rarely available, and only 22% reported it was always available (Table 4).

Eighty-two percent of school personnel were aware that nutritional information and menus were made available to parents to plan insulin adjustments, but only 14% felt that their school's nutritional services were adequate to accommodate the needs of children with diabetes (Table 5). Twelve percent reported that nutritional information was not available at school, whereas 5.9% did not know if it was available. Fifty-two percent felt that the nutritional services in terms of

food choices were usually adequate; however, 34% felt that they were inadequate.

Emotional distress. Children and adolescents, their parents, and school personnel were questioned about the emotional impact of having type 1 diabetes at school. Twenty-three percent of the children and adolescents reported feeling embarrassed at school after experiencing hypoglycemia or other diabetes-related incidents requiring intervention. However, only 8.5% of the students reported that such incidents occurred often or very often. Twenty-seven percent of the students said they were embarrassed when they had to check their blood glucose or take medication at school. Yet, only 6.5% said such embarrassment happened often, and 17.4% said it happened sometimes at school (Table 1).

Forty-four percent of parents reported that they were aware of their child being embarrassed by diabetes-related issues; however, most reported that such embarrassment happened only sometimes or rarely. When parents were asked if their child or adolescent had ever felt like quitting school or not participating in a school activity because of diabetes, only 16.7% reported that they had. Furthermore, only 43.9% of parents responded that their child had never experienced emotional distress dealing with diabetes in school. Nearly 20% of parents reported that incidents happened often or very

often, whereas nearly 37% of parents reported that it happened but that occurrences were infrequent (Table 4).

Finally 11.2% of children and adolescents reported that they had felt embarrassed intentionally by school personnel; however, these occurrences were reported to be rare (Table 1).

School personnel were aware of the emotional needs of the children and adolescents and felt that their communication with the children and parents or guardians was good (Table 3). Twenty-five percent of school personnel were concerned often or very often about a student feeling bad emotionally at school because of diabetes; 62.5% were concerned sometimes, and 12.5% responded that they were rarely concerned.

Adequacy of school personnel training for diabetes management. Children and adolescents, their parents, and school personnel were asked about the diabetes care that the children received while at school. Only 27.6% of children and adolescents surveyed felt that school personnel were knowledgeable to adequately care for their diabetes, 45% felt that school personnel were usually knowledgeable, and 27.7% felt that personnel were knowledgeable sometimes (Table 1). Forty percent of parents felt that school personnel were adequately trained to care for their children, whereas 45%

Table 3. Perception of School Personnel Caring for Children and Adolescents With Type 1 Diabetes: Personal Experiences

	Response (%)					Yes	No
	Excellent	Above Average	Average	Below Average	Unsatisfactory		
Overall experience dealing with children	14.3	65.3	16.3	2.0	2.0		
School support for children with type 1 diabetes	Very	Somewhat	Not very	Not at all			
How supportive are school personnel?	64.7	31.4	3.9	—			
Cooperate with parents to meet medical needs?	78.4	15.7	5.9	—			
Feel comfortable working with child with type 1 diabetes?						93.9	4.1
Impact of type 1 diabetes on school personnel	Very Often	Often	Sometimes	Rarely	Never		
How often:							
Do children with diabetes miss school due to illness, etc.?	14.0	—	41.9	—	42.1		
Do you communicate with parents for problems?	38.8	32.7	12.2	8.2	8.2		
Do you communicate with physicians for problems?	6.2	18.8	16.7	37.5	20.8		
Do children have problems considered as risks?	8.7	13.0	41.3	26.1	10.9		
Do schools need to call parents to school?	2.0	20.4	38.8	36.7	2.0		
Is the frequency in the last 3 months to call EMS or an emergency call to a parent?	4.4	4.4	20.0	71.1			
Are you concerned that children with diabetes feel bad?	2.1	22.9	62.5	12.5			
Do parents place great responsibilities on schools?						38.8	52.2

felt that personnel were inadequately trained (Table 4). Nearly 70% of school personnel felt that their personal education had prepared them to address the needs of children with diabetes in school, whereas 30.6% did not (Table 5). However, only 46% of school personnel felt that nonmedical school staff members were adequately trained to care for children and adolescents with diabetes. Thirty-eight percent of school personnel expressed great concern

about the inadequacy of their training, and 65% expressed concern about the potential liability of caring for these children and adolescents at school (Table 5).

School preparedness for emergencies. Thirty-eight percent of school personnel were very concerned about their preparedness to assist a child with hypoglycemia, 48% were somewhat concerned, and only 20% felt adequately prepared to assist a child with hypoglycemia

(Table 5). Seventy-six percent of school personnel surveyed felt that a nurse should always be available on school premises during the school day if a student with type 1 diabetes is enrolled, 24.5% did not, and 6.1% did not know. Only 20% of school personnel surveyed felt that there were adequate numbers of nurses available to care for children with diabetes in their school systems. With regard to other school personnel, only 6.1% felt that physical

Table 4. Perception of Parents of Children With Type 1 Diabetes in School: Adequacy of Care and Support From School System

	Response (%)				
	Excellent	Above Average	Average	Below Average	Unsatisfactory
Overall experience of your child at school	36.6	24.4	34.1	—	4.9
Satisfaction with school support for your child	Very	Somewhat	Not very	Not at all	
Support from school personnel	58.5	34.1	4.9	2.4	
Support of child's participation in physical activities	78.0	14.6	7.3	-	
Adequacy of school nutritional services	21.1	52.6	7.9	7.9	
Availability of nutritional information	25.5	30.6	13.9	11.1	
Satisfaction with training of school personnel	Always	Usually	Sometimes	Rarely	
Personnel adequately trained to manage type 1 diabetes	40.0	20.2	15.6	35.2	
Proper/timely access to things to manage type 1 diabetes	41.5	39.0	12.0	7.3	
Impression of the supportiveness of school					
Support of school when child misses school	53.7	26.8	12.2	7.3	
Physician/school communication	29.7	37.8	24.3	8.1	
Absenteeism during marking period	12.2	34.1	22.0	31.7	

education teachers and coaches were adequately prepared to address the needs of children with diabetes in school, 53% felt they were “usually adequate,” and 40.8% felt that they were inadequately prepared.

School policies for care of children and adolescents with diabetes. Seventy-one percent of school personnel felt that their school's individualized diabetes care policies allowed children proper time and timely access to their self-care needs (Table 5). Of school personnel surveyed, 47.1% were aware of federal laws requiring specific policies and protocols for the care of children with diabetes while in school. Only 20% of schools had specific policies concerning children participating in gym, and another 28.9% were unaware of a policy. Thirty-one

percent reported that there were no policies in their schools, and 21.6% were unaware of specific policies.

Perception of supportiveness of schools for dealing with illness and missed school days associated with type 1 diabetes. Finally, we asked parents and school personnel about their experiences dealing with diabetes-related illnesses in terms of making up missed class work and communication with the child's health care provider. More than half of the parents (53.7%) reported that the schools were very supportive, 26.8% reported that schools were somewhat supportive, and 7.3% felt that schools were not very or not at all supportive of their child's diabetes needs (Table 4).

Nearly 32% of parents reported that their child rarely missed school

because of diabetes, whereas 34.1% reported that their child missed some days each period, and 12.2% responded that their child frequently missed school days because of diabetes (Table 4). When their child missed school because of a diabetes-related illness or doctor visit, nearly 54% of parents reported the school was supportive of their child when they returned, whereas 27% said the school was usually supportive, 12% said it was sometimes supportive, and 7.3% said their school was not supportive.

Sixty-eight percent of parents reported that communication with the school was excellent or above average, 24.3% reported average communication, and 8.1% reported below-average communication. Sixty-three percent of parents

Table 5. Perception of School Personnel Caring for Children and Adolescents With Type 1 Diabetes: Adequacy of School Policies and Diabetes Training

School policies for care of children and adolescents with type 1 diabetes	Response (%)					Yes	No
	Very	Somewhat	Not very	Not at all			
Adequacy of school policies	70.6	25.5	4.9				
Adequacy of nutritional services	14.0	52.0	18.0	12.0			
Is school aware of the Children's Bill of Rights?						51.0	49.0
Does school have:							
Clear diabetes policies/procedures/protocol?						47.1	31.4
Nutritional information/meal menu for parents?						82.4	11.8
Specific policies for physical education activities?						20.0	51.1
Specific policies for field trip?						21.3	46.8
Procedures to identify children with diabetes?						49.0	23.5
How great is your concern that:							
Personnel are not adequately prepared?	Always	Usually	Sometimes	Rarely	Never		
	38.0	48.0	6.0	8.0	2.0		
You are legally responsible for mistakes by kids?	65.3	20.4	12.2	2.0	24.5		
How prepared are physical education teachers/coaches?							
	6.1	53.1	20.4	14.3	6.1		
How adequate is the number of nurses available?							
		38.0	20.0	14.0	8.0		
Do personnel receive education information?							
						66.7	19.6
Should nurses be available at all times?							
						76.0	18.0

reported that they had missed work because of their child's diabetes-related illness; 30.8% responded that they had to miss work because of the school's inadequacy to care for their child, and 2.4% said they were forced to quit their job to take care of a child with diabetes (Table 4).

Only 14% of school personnel reported problems with frequent absences of children and adolescents because of illness attributable to diabetes, and only 8.2% reported problems with communication with parents regarding these absences (Table 5). Eighty-two percent of school personnel reported communicating with parents about medications or diabetes-related

problems often or very often, whereas 16.4% reported rarely communicating with a parent. Needing to communicate with the child's physician (health care team) was reported to occur often or very often by 25%, sometimes by 16.7%, rarely by 27.5%, and never by 20.8% by school personnel.

Discussion

Although the majority of children and adolescents surveyed felt that they were treated differently in schools because of their diabetes, the results of this survey demonstrate that their perceived experiences and those of their parents are generally good and have improved compared

to earlier surveys.¹⁵ Sixty-one percent of parents felt that their child's experience was above average or excellent. This positive perception includes receiving support from school personnel, having excellent communication with school, and receiving assistance in making up school work after absences. In addition, nearly 80% of school personnel reported that their experience dealing with children and adolescents with diabetes was satisfactory, and more than 90% felt comfortable working with children with diabetes.

Almost half of the children and adolescents felt that they were sometimes treated differently because of their diabetes, and almost half of the

children reported that schools had prevented them from performing routine diabetes self-management at times. This was confirmed by their parents. There was a small subset of negative overall experiences reported by children, adolescents, and their parents. The cause of these negative experiences is beyond the scope of this survey; however, some may have resulted from social or economic dysfunction within the family unit, whereas others may have occurred in a few school systems that appeared to be inadequately prepared to manage children and adolescents with diabetes.

Ongoing issues identified as a result of this survey include 1) the inadequacy of diabetes training of teachers (particularly physical education teachers) and coaches to handle diabetic emergencies such as hypoglycemia or hyperglycemia, 2) absence or lack of standardization of individualized diabetes care plans for each child or adolescent with diabetes in certain school systems, 3) inadequate numbers of school nurses or other trained personnel to ensure the safety of children and adolescents in certain school systems, and 4) inadequacy of nutritional services or nutritional information provided to parents by schools to help plan insulin dosing requirements in certain school systems.

There are significant limitations to our study, including study size, self-selection by patients and parents who would respond to such a survey, and perhaps our geographical location, which may limit generalization to other regions. It is our expectation that these problems are more common in rural regions than in urban regions. We plan to conduct a national survey using the Children with Diabetes Web site in the near future to determine whether these are region-specific problems.

Requiring schools to develop an individualized diabetes management plan for each student with type 1 diabetes is federal law, as are the protections afforded each student for equal access to learning and to a safe learning environment.¹¹ However, in our survey, only 47.1% of school personnel surveyed were aware of

specific policies and protocols for the care of children with type 1 diabetes in school. Increased awareness of this inadequacy is mandatory from the state and county level. This is especially important in states such as Ohio that do not have a strong central regulatory system, leaving many policies up to small local school boards. Many states, including Florida, Missouri, New Jersey, New York, and Texas, have developed and published diabetes management care plans; the authors believe this should be mandatory in all states. There are tremendous resources, including sample Individualized Education Plans and section 504-mandated plans, available for parents and schools at the Children with Diabetes Web site (childrenwithdiabetes.com). However, there needs to be greater federal oversight of states that are still lacking in this area.

Despite the advances in care of children and adolescents with type 1 diabetes in schools that have occurred during the past 20 years, there is still a great need to continue improving the school experiences of these children. School systems at the state or county level need to sponsor annual continuing education programs for nurses, coaches, teachers, and other staff concerning the special needs of children and adolescents with type 1 diabetes, the emergency management of hypoglycemia and hyperglycemia, and sick-day assessments. Even information about glucose testing and insulin pumps should be provided to school personnel dealing with children with diabetes.

The NDEP has developed a guide for school personnel titled "Helping the Student with Diabetes Succeed: A Guide for School Personnel," which could be used as an example in all states. Through a combined effort by families, schools, and health care providers, children with diabetes can be included in all school-sponsored activities, enjoy a safe and nurturing school experience, and succeed in learning throughout all levels of education.

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