

Original Article

Identifying the special needs of children with Type 1 diabetes in the school setting. An overview of parents' perceptions

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Abstract

Aims The aims of this observational study were to identify the special needs of children with Type 1 diabetes in schools from the parents' point of view and the difficulties experienced with full integration, and to define a series of interventions which may improve the situation.

Methods Parents of children aged 3–18 years with Type 1 diabetes were eligible. Those who agreed to participate completed a self-reporting questionnaire which determined the effects of the disease on children, parents and school personnel, and addressed aspects including children's integration, glycaemic control, insulin administration, meals, sports, trips and attitudes of teachers and school colleagues to their disease.

Results A total of 499 questionnaires were completed and validated. Median age of children was 11.5 years (95% CI 7.8–15.2). Only 34% of parents believed that teachers could recognize the symptoms of a mild hypoglycaemic episode. Seventeen per cent of parents experienced problems at their schools when they informed staff about their children's disease, 5% were finally not accepted and 8% were forced to change school. In some cases, they had to modify glucose monitoring (9%) and treatment administration (16%) because of a lack of cooperation from the school.

Conclusions Training sessions on Type 1 diabetes, an increase in the number of nurses, better availability of resources from diabetic associations to schools and improved communication between school personnel and parents were identified as key factors that may improve the full integration of the diabetic child in this setting.

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Keywords adolescents, children, day-care centres, diabetes mellitus, school nursing

Abbreviations ADA, American Diabetes Association; AADE, American Association of Diabetes Educators; DCCT, Diabetes Control and Complications Trial

Introduction

Type 1 diabetes is one of the most common chronic health problems in children, affecting approximately 1.7 per 1000 individuals under the age of 20 years [1–4]. Moreover, this incidence is increasing by 3.4% (95% CI 2.5–4.4) annually in children under 15 years of age [5]. An epidemiological survey conducted in the UK and Finland suggests that this increase is mainly attributable to an increasing incidence of the disease in

children aged 0–4 years of 11%. Although the reasons for this increase are unknown, environmental influences before birth or in early post-natal life could be responsible [5,6].

In Type 1 diabetes, lack of adherence to treatment and a failure to maintain glycaemic control can lead to long-term complications, with substantial loss of quality of life and utility from both individual and societal perspectives [7]. Additionally, children who are diagnosed at a young age may be at higher risk of long-term complications as a result of the prolonged nature of their illness and the difficulties in achieving adequate glycaemic control in this age group [8,9]. The Diabetes Control and Complications Trial (DCCT) and the American Diabetes Association (ADA) therefore recommended an intensive

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treatment regimen with the goal of maintaining blood glucose concentrations close to the normal range to decrease the frequency and severity of complications [10–12]. The benefits of the intensive treatment outweighed the increased incidence of severe hypoglycemia observed in childhood during the trial [11]. To achieve such optimal glycaemic control, frequent blood glucose monitoring and insulin administration when needed should be performed.

Whittemore *et al.* [13] observed that most families of school-aged children were able to adequately manage Type 1 diabetes, but the burden of responsibility that is laid upon the parents could provoke depressive symptoms and may have significant consequences for the care of their child [14,15]. One way to minimize parental responsibility related to diabetes management could be the transferral of roles from the parent to the child during middle adolescence [16].

Although extensive research into the psychosocial effects on parents of children with diabetes has been conducted over the last few years [15,17], less attention has been given to the difficulties experienced by these children themselves in the school setting [18] and the self management of Type 1 diabetes [19,20]. Recently, both the ADA [12] and the American Association of Diabetes Educators (AADE) [21] issued very useful guidelines regarding optimal diabetes management in schools. Children typically spend one-third of the day in school and they should achieve the same level of diabetes management there as they do outside the school environment. This means that children should incorporate frequent glucose monitoring, meal planning and possibly insulin injections at the school, but also they should be allowed to participate fully and safely in all school activities [12].

Children with Type 1 diabetes often need support to adequately manage their illness at school [22], but, according to several studies, the majority of school personnel have an inadequate understanding of diabetes [23]. Thus, the needs and rights of children with diabetes may not be adequately addressed in schools, probably because of the lack of a supportive environment and low levels of skill in the management of diabetes by school staff [18]. It is difficult for children with diabetes to go on field trips, to participate in sporting activities or to be given modified school meals [23,24].

In summary, more work is needed to describe what is happening in the school setting to be able to improve control of the disease and facilitate the complete integration of children with Type 1 diabetes into the school setting [25]. Parents' perceptions can be as useful as teachers' perceptions to identify children's needs at school [26]. The objective of this observational study was therefore to determine the unmet needs of children with Type 1 diabetes at school and at school-sponsored activities, and to make a full appraisal of the difficulties they may find during their school life, as seen from the parental point of view. The aim is to develop a plan that includes a series of interventions involving school staff, health-care providers and parents to improve the situation in schools for these children.

Patients and methods

Recruitment procedure

Parents of children aged 3–18 years with Type 1 diabetes attending the paediatric outpatient clinics in Madrid, Spain were eligible for inclusion, and were recruited between November 2004 and April 2005. The diabetes educator and/or the paediatrician informed parents about the objectives of the project. Written information about the project was also given to each parent and additional information was accessible by telephone or through the website (www.fundaciondiabetes.org). The study was conducted only after the parents had given their oral informed consent in accordance with the Spanish and European Directives, which require no approval from an Ethics Committee for this type of study design. Those parents who agreed to participate completed a 10- to 15-min self-reporting questionnaire. Most of the questionnaires were completed in the waiting area before scheduled appointments, with the remainder being posted to the children's homes and returned directly to the researchers.

No interventions or treatments were given. Participating centres were coded for the purpose of anonymity and study patients were numbered consecutively to ensure confidentiality. Participation in the study was voluntary.

Description of the questionnaire

A multidisciplinary team of paediatricians, endocrinologists, diabetes educators and parents designed the questionnaire. This was first tested in one single hospital in which 25 questionnaires were completed by parents. During the test, confusing or non-understandable questions were detected and modified accordingly. The questionnaire included 80 different questions of which some required a single answer [(Yes/No) or (for example, Bad/Regular/Acceptable/Good/Optimal)], while others comprised multiple answers of pre-coded items. Once the questionnaire had been validated, the project was presented to all major public hospitals in Madrid, and all agreed to participate.

In addition to demographic information, the questionnaire explored the effects of Type 1 diabetes on children's lives, parents' lives, school meals, school sports activities, trips and extra-curricular activities, and on attitudes of the children's school colleagues.

Parents were asked how diabetes had affected their family life, how they obtained information about diabetes, and whether they belonged to a diabetes association. They were also asked how their children reacted to their illness, whether it had affected their integration into family life, whether they knew how to measure blood glucose levels, whether they could administer insulin themselves, and what kind of behaviour they exhibited at school, during sports and during school-sponsored activities.

Parents also were questioned about their perceptions of the level of knowledge of school personnel, how they behaved towards their children, how much they helped and whether any resources were available for the teachers.

Statistical analysis

Completed questionnaires were validated and analysed by the statistician. Of the 526 questionnaires received, 499 met the inclusion criteria that children's age should be between 3 and

18 years and that at least 70% of the questions were answered. Questionnaires were recorded with the Gandia Barwin statistical program (TESI GANDIA, Valencia, Spain). After recording 100 questionnaires, a quality control exercise was performed to detect potential recording mistakes. The same process has been applied after recording 250 and 450 questionnaires. The objective of the analysis was to detect potential differences between the groups according to age. Student's *t*-test was used. From an estimated total of 1600 children aged 3–18 years with Type 1 diabetes in Madrid, 499 questionnaires were validated, an error of $\pm 3.7\%$ was assumed, rising to approximately $\pm 7.7\%$ for each disclosure, and with a finite population; $CI = 95.5\%$ and a variance = $P = q = 50\%$.

Results

Patient characteristics

The 499 accepted questionnaires were completed by either the mother or the father of children with Type 1 diabetes between November 2004 and April 2005. These children attended 320 different schools. Demographic characteristics of the children are shown in Table 1. There were slightly more boys than girls in the study (55% and 45%, respectively). The median age (\pm SD) and the median duration of diabetes (range) were 11.5 ± 3.7 and 5.5 years (0.3–14.0), respectively. Participants were mainly parents of children between 11 and 14 years of age (38% of cases). Parents of children aged 3–6 years old represented 12% of the sample.

Parents' lives and diabetes

Table 2 summarizes some of the results stratified per age group. Eighty-five per cent of parents reported that diabetes

Table 1 Patient characteristics

Demography	<i>n</i>	%
Age (years)	499	
3–6	61	12
7–10	128	26
11–14	189	38
15–18	121	24
Gender	496	
Male	272	55
Female	224	45
Diabetes duration	479	
< 3 years	156	33
3–6 years	184	38
> 6 years	139	29
Type of school	493	
Public or state	275	56
Semi-public	159	32
Private	59	12
Parental education	497	
Primary	160	32
Secondary	199	40
Graduate	138	28

affected their family life, whilst in 44% one of the parents had to change their work activity to attend to the needs of their children. Forty-seven per cent of families belonged to a diabetes association, and 56% of these parents felt these associations carried out some activity to improve children's adaptability to school life.

Only 16% of parents considered they did not have enough information about the disease. The most useful information came from physicians (64%) and diabetes educators (42%).

Children's life and diabetes

Parents felt that the major cause for concern in their children was the strict timetable involved in adequate glycaemic control and therefore not having any spare time (33%), and feeling different and not to be able to do the same things as others (32%). Other concerns were the need to be on a diet (31%) and not recognizing hypoglycaemia (26%). Parents said their children expressed annoyance (49%) or sadness (32%) when they had to administer insulin, and this seems to be more frequent in boys than in girls (52% and 44%, respectively). In contrast, 74% of parents considered that diabetes had not affected their children's integration within the family.

Twenty-five per cent of parents thought that their child hid their disease at school, and this figure rose to 36% in the 14 to 18-year age group. The majority felt that their children knew how to determine glucose levels adequately by themselves (88%), and 77% believed their children could identify when their blood glucose level was too high or too low. In all, 84% of parents believed that their children were able to adequately control their glucose levels unsupervised, while 16% felt their children needed help from teachers or another person. Seventy per cent of children were able to self administer insulin, and 62% knew the correct dose to be administered.

Sixty-eight per cent of parents felt that glycaemic control whilst at school was good or acceptable, and only 3% felt it was poor. However, 72% and 66% considered that the presence of a nurse or a well informed teacher, respectively, would help to improve control.

School and diabetes

Of the 320 schools represented in this study, 17% have both a psychologist and a nurse, 44% only a psychologist and 5% only a nurse available for the children. Psychologists are in 46% and 40% of public or semi-public schools, respectively, while only 14% of private schools have this type of professional on their staff. Nurses are in 36% of public schools, 38% of semi-public schools and 24% of private schools. In 95% of children, teachers were informed about their children's diabetes, but only 78% of physical education instructors were aware of the children's condition.

Seventeen per cent of parents, of whom around 30% had children in the 3 to 6-year-old group, said that they had experienced problems at schools after they had informed the

Table 2 Some selected questions and answers stratified by age group

	3–6 years n = 61	7–10 years n = 128	11–14 years n = 189	> 14 years n = 121	Total n = 499
Parent's life and diabetes					
How diabetes has affected your family life?					
Not at all	10	10	17	21	15
Little/quite/a lot/very much	90	90	83	79	85
Children's life and diabetes					
Does your child show annoyance during insulin administration?					
No	23	35	59	69	51
Yes	77	65	41	31	49
Does your child show sadness during insulin administration?					
No	52	64	70	78	68
Yes	48	36	30	22	32
Do you think your child hides diabetes at school?					
No	95	86	69	64	75
Yes	5	14	31	36	25
Does your child know how to determine glucose levels?					
No	69	12	0	0	12
Yes	31	88	100	100	88
How good is your child's glycaemic control					
Bad	3	4	2	3	3
Normal	28	26	32	29	29
Acceptable/good/optimal	69	70	66	68	68
School and diabetes					
Have you experienced any problems at school?					
No	70	77	84	93	83
Yes	30	23	16	7	17
Has your child experienced any discriminatory behaviour?					
No	77	91	94	94	91
Yes	23	9	6	6	9
Has your child been forced to reduce glucose monitoring?					
No	82	86	96	92	91
Yes	18	14	4	8	9
Where does the greatest support to your child come from?					
Institution	33	24	20	17	22
Teachers	66	78	68	50	66
Peers	16	55	73	79	63
Nobody	13	4	1	3	8
Have you made treatment modifications because of a lack of cooperation?					
No	65	80	91	88	84
Yes	35	20	9	12	16
Does your child engage in normal physical activities?					
No	18	2	1	6	5
Yes	82	98	99	94	95
Do you experience difficulties with 1-day trips?					
No	74	73	90	93	84
Yes	26	27	10	7	16
Has your child experienced any form of verbal abuse from peers?					
No	97	93	85	82	88
Yes	3	7	15	18	12

schools about their children's condition. Institutions (62%) and teachers (56%) were considered responsible for these problems. As a consequence, 5% of children were not accepted into the school of the parents' choice, whilst 8% were forced to change school. This affected 20% of children in the 3 to 6-year-old age group. In addition, 9% admitted experiencing discriminatory behaviour from the school, and another 9% admitted that they

were forced to reduce the number of blood glucose measurements because of lack of cooperation from school staff; in the 3 to 6-year-old age group, 18% had been forced to make changes.

In contrast, parents reported that the greatest support that their children received at school came from teachers (66%) and peers (63%). Parents stated that 58% of teachers had a basic knowledge about Type 1 diabetes, although 27% of

parents said that some teachers admitted confusion about the difference between Type 1 and Type 2 diabetes.

Seventy-five per cent of parents stated that their children, of whom 87% were in the 3 to 6-year-old age group, required glucose monitoring during the school day. In 26% of the cases, insulin had to be administered during the school day, but only 63% of the children were able to do this by themselves. In 16% of cases, treatment modifications were made because of a lack of cooperation from the school.

In the event of a hypoglycaemic episode, only 34% of parents believed that school personnel would be able to recognize a mild episode. In 64% of cases, the children themselves had been able to resolve such an event, with the greatest proportion (80%) being in the 14 years and older age group. Only 9.8% of children had experienced a serious hypoglycaemic episode at school, but, according to parents, 55% of schools did not have glucagon available. The majority of parents (97%) considered it essential that teachers should be aware of the symptoms of Type 1 diabetes and of the most basic steps to take in case of an emergency.

Parents reported that 27% of their children ate at school, of whom 72% could eat anything from the menu. In all, 63% of parents felt their children's meals were under control. However, in 14% of cases, parents said that schools were not able, or did not consider it their responsibility, to modify diets to enable children with Type 1 diabetes to eat a school lunch.

Ninety-five per cent of the children engaged in normal physical activities with their peers, although 51% had had at least one hypoglycaemic episode during these activities. In extra-curricular activities, 16% of parents experienced difficulties from their school over responsibility of the children during 1-day trips, affecting 27% in the 7 to 10-year-old age group. However, 87% said their children were able to undertake the same 1-day trips as their peers. This percentage fell to 34% when trips were extended over several days.

Parents said that 61% of their children's peers were sympathetic to a child with diabetes, but that 12% of the children with diabetes had experienced some form of verbal abuse or mocking.

When asked about what kind of support from schools they felt would benefit their children, parents said they would like teachers to have a better knowledge of the basic steps that should be taken during a glycaemic emergency (75%), to have a better understanding of the disease (70%), to have a nurse available at the school for the children (70%) and to have glucagon readily available, together with a person who was aware of how to administer it (64%).

Discussion

Type 1 diabetes is the second most common chronic health problem in children, after asthma [21], and its incidence is increasing at an alarming rate in children [5]. Optimal diabetes management involves intensive insulin therapy, creating important challenges for children, parents and schools.

This study is, to the best of our knowledge, the first to analyse quantitatively the needs of children with Type 1 diabetes in the school environment, from the point of view of the parents, in a variety of aspects such as integration, sports, trips and school-sponsored activities, glycaemic control and insulin administration, control of meals, and the role played by teachers and school colleagues, and their attitudes to children with diabetes.

The results of this study showed that 25% of children and adolescents hid their condition in school, probably in a desire to be seen to be no different from others. This could lead to children deliberately neglecting their own treatment, with serious consequences from poor glycaemic control [10,11]. It is also interesting that 17% of parents experienced negative reactions from their schools when they informed them about their children's disease, and that a proportion of these parents felt they were the victims of discrimination against their children in the form of their children not being accepted into a school (5%) or being forced to find another, more cooperative, school (8%). Currently, most developed countries have laws to avoid discrimination against children with disabilities, such as Type 1 diabetes, and therefore these centres should be informed that these practices are illegal [27].

More seriously, in some cases the number of blood glucose tests and insulin administration were modified because of a lack of cooperation from school personnel, particularly in the youngest age group. These findings conflict totally with ADA and AADE recommendations regarding diabetes care at school [12,21]. From our point of view, these results indicate the possibility that some school personnel feel incapable or uncertain about the disease and, because of that, they reject any responsibility for disease management. As a consequence, additional efforts should be made to educate school staff in the basics of diabetes and its care. Such education could be provided through training sessions, which would facilitate an understanding of diabetes and assist children to fully integrate into a school. Educational sessions should include information about glucose and ketone testing, insulin administration, treatment of hypoglycaemia, glucagon administration, physical activities and meal planning at school [12].

In contrast, only 3% of parents felt that control of their children's diabetes was poor, and 9.8% of children had experienced a serious hypoglycaemic episode at school. In addition, the majority of children with Type 1 diabetes undertook normal physical activities and the same 1-day trips as their peers. However, this percentage decreased dramatically when trips were extended over several days. This fact could reflect the lack of confidence of parents with school personnel and their ability to adequately manage an emergency [18,24].

It has to be taken into account that, in Spain, there is no obligation for school personnel to provide health-care assistance at school. If staff voluntarily agree to assist children, they are likely to be held personally responsible if claims for damages arise (the educational institution is not held liable). Although the health-care system is universal, and all residents have the

right to free treatment, this assistance is only provided in health-care centres and, exceptionally in emergency situations, outside these centres. In addition, there is no standard protocol to be followed by parents and schools to optimize the management of Type 1 diabetes in the school setting. Therefore, diabetic care in schools depends on the personal good will of every person connected with the child.

The results of this study describe only the special needs of children with Type 1 diabetes in the school setting from the parents' point of view. School-aged children's perceptions were not directly measured. These results may not always represent the reality of the school setting, and they could not describe properly children worries, but they do represent parents concerns about diabetes care at school and give some proposals to improve it. Most of the parents thought that the presence of a nurse in school would improve their children's control of the disease. In our study, only 22% of schools have a nurse and our results indicate a need to increase this percentage. Also, parents felt that educational sessions should be specifically developed for school personnel. These sessions should provide a basic understanding of the disease, but also information about the optimal management of emergencies. In this way, parents felt that resources from diabetes associations would be of value to school personnel. Nowadays, updated online resources providing guidance on the appropriate care of children and adolescents with this condition are readily available [28–30]. Lastly, better communication between school personnel and parents would help to reduce the lack of confidence in parents. Schools must accept that they need to play a key role in assisting children to accept their disease, to be responsible for their own treatment, and to avoid such negative emotions as anger, fear and depression when they have to administer insulin [12,31].

Our results are in agreement with previous results reported in the literature. Wagner *et al.* [32] observed that, when diabetes training sessions were provided to school personnel, and even to peers, diabetes control and the quality of life of children with diabetes significantly improved. Also, in a previous survey within educators on the impact of a chronic illness such as diabetes in the classroom [33], 53% of school professionals were worried about the possibility of an emergency, and 27% of them about legal liability, although overall most of them had positive attitudes about children with chronic diseases in their classrooms. These staff actually demanded more information from parents and health-care professionals to allow them to deal more effectively with these situations in school.

In conclusion, several possible interventions were identified from the parent's point of view to improve the integration of children with Type 1 diabetes into schools. These include training sessions on Type 1 diabetes, an increase in the number of nurses, better availability of resources from diabetes associations to schools, and an improvement in communication between school personnel and parents. All of these would improve diabetes care in the school setting, and also enable schools to understand the types of medications, equipment or

therapies needed, so that the daily care of a child with diabetes could be integrated into the daily school routine, helping children to learn how to overcome obstacles and to prepare to live in their community.

Competing interests

None to declare.

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Appendix

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