

Original Article

Special needs of children with type 1 diabetes at primary school: perceptions from parents, children, and teachers

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Objective: To identify the special needs of children with type 1 diabetes at primary school taking into account the perceptions reported by parents, children, and teachers.

Methods: This was a cross-sectional survey carried out at nine public hospitals with a cohort of 6- to 13-yr-old children. Parents were personally informed about the objectives of the survey and the necessity to involve their children and the teachers. The self-reporting questionnaire included demographic information as well as some questions that helped to evaluate the general situation of children with type 1 diabetes at primary school, main worries about the disease, and possible improvement measures.

Results: A total of 430 questionnaires were completed and validated of which 39% were filled in by parents, 35% by children, and 26% by teachers. The majority of children were 10–13 yr old and came from public schools. At school, most children required glucose monitoring, but few of them (9–12%) needed insulin administration. Some parents (7%) experienced problems at their schools when they informed them about their children's disease, 2% were finally not accepted, and 1% were forced to change school. Major children's concerns included the ability to recognize hypoglycemia or to self-administer insulin. Parents, teachers, and children demanded better information at school about diabetes and about emergency management.

Conclusions: The three population groups agreed about the necessity of having more available information on diabetes at schools. Although some discriminatory behavior was still occurring, it seemed it has been diminishing in recent years.

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Type 1 diabetes, also known as insulin-dependent diabetes, is the most frequent chronic disease of children after asthma in developed countries (1). Moreover, its incidence is increasing rapidly worldwide, predominantly in younger individuals (2).

Type 1 diabetes is treated with insulin replacement therapy. Since the publication of the Diabetes Control and Complication Trial (3, 4), it has been demonstrated that intensive diabetes treatment delays the onset and slows the progression of diabetic complications in adolescent subjects and that the benefits obtained with

this treatment outweighed the increased risk of hypoglycemic episodes. The objectives of diabetes management in children are now clearly established and include achieving a metabolic control as close as possible to normal situations through strict glycemic controls. That usually means frequent glucose monitoring, several insulin injections per day, and, quite probably, a higher incidence of severe hypoglycemia. Although the introduction of new insulin delivery systems as well as glucose monitoring devices may have facilitated the optimal management of type 1 diabetes in the family

environment (5), it is still unknown whether these recommendations are being followed in the school setting.

To achieve an intensive diabetes treatment, it is crucial to have age-appropriate continuous education programs for children, but also for parents and other related adults (6). These education programs include care measures, practical information, and skills training and are addressed to improve the metabolic control, the psychosocial well-being of children, and the self-control and self-management of the disease. However, in a recent mothers' perceptions study of children aged 6–18 yr (7), it was observed that in spite that older children demonstrated higher levels of self-care abilities, they have also more negative attitudes about diabetes than did younger children. This observation may indicate that, within children aged 6–18 yr, younger children may be more receptive to education programs than older ones.

According to current recommendations (8, 9), children with type 1 diabetes should achieve the same level of disease management at school as they do outside this environment, but also these children should be fully incorporated into all school activities in a safe way. To do this, children often need to incorporate glucose monitoring and insulin injections into their school routines, but also they may require additional support from school staff. However, a recent survey among school nurses indicated that these children need more support at school than they are currently receiving (10). Hence, there is a need to improve the support these children are receiving at school to achieve an optimal management of the disease in this setting. Also, the normal school attendance of these children should be rigorously pursued by parents and health care professionals to achieve full integration (11).

The Spanish Diabetes Foundation and the Castilla-La Mancha Diabetes Foundation (FUCAMDI) are non-profit health organizations that are devoted to improving the quality of life of people affected by diabetes. To achieve their main objective, people working in these organizations develop educational and research projects for families with diabetic children in Spain. Recently, the Spanish Diabetes Foundation reported the results obtained from an observational study in which the special needs of children with type 1 diabetes in schools were evaluated from the parental point of view (12). However, the perceptions of school-aged children and teachers were not investigated. Therefore, it was not possible to ensure whether these results reflected the situation in the actual school setting.

The objective of the present survey was to identify the special needs of children with type 1 diabetes at primary school and to determine the best course of action to improve their current situation. To achieve this objective, it was necessary to interview all the main players in this setting (i.e., parents, children, and teachers) and to

analyze whether there were discrepancies between the perceptions of the three population groups.

Patients and methods

Recruitment procedure

A cross-sectional survey was carried out in nine public hospitals in Castilla-La Mancha (Spain). The cohort of children was aged between 6 and 13 yr, which in Spain is the age for primary school.

Recruitment took place between January 2006 and April 2006. Parents of children between 6 and 13 yr of age with type 1 diabetes who attended the pediatric unit of each participating hospital were contacted by the diabetes educator and/or the pediatrician. They were informed about the objectives of the survey and about the need to include in the survey both their children and the teachers at the school. In addition to information given by word of mouth, written information about the project was also given to each parent. Additional information about the project was also accessible by telephone or through the Web site (www.fundaciondiabetes.org). The study was conducted only after the parents had given their oral informed consent. No interventions or treatments were given. Participating centers were coded for the purpose of anonymity and study patients were numbered consecutively to ensure confidentiality. In accordance with the Spanish and European Directives, this survey did not require approval from the institutional review board at the hospitals.

Those parents who agreed to participate completed a 10- to 15-min self-reporting questionnaire in the waiting area before scheduled appointments. They were also responsible for supervising the successful completion of the questionnaire by their child and for giving a copy of it to their child's teacher at the school. Teachers who voluntarily decided to participate filled in the anonymous questionnaire on their own and sent them back to FUCAMDI by regular mail.

Description of the questionnaire

A multidisciplinary team of pediatricians, endocrinologists, diabetes educators, and parents designed the questionnaire. The parent's and the teacher's questionnaires were first tested in one single hospital in which 25 and 5 questionnaires were filled in by parents and teachers, respectively. During the test, confusing or non-understandable questions were detected and modified accordingly. The parents' questionnaire included 76 different questions of which only 64 questions were applicable for children and 47 questions were applicable for teachers. Some questions required a single answer [dichotomic (yes/no) or were on a hierarchic scale (i.e., not at all/little/quite/a lot/very much) in which scores from 1 to 5 were assigned]. Other questions comprised multiple answers of precoded items. Once the

questionnaire had been validated, the project was presented to all major public hospitals in Castilla-La Mancha. All public hospitals agreed to participate.

In addition to demographic information, the questionnaire evaluated the general situation of children with type 1 diabetes at school, main worries about type 1 diabetes, and actions that could improve integration of these children at school.

Statistical analysis

Completed questionnaires were statistically validated and analyzed. Of the 434 questionnaires received, 430 (99%) were accepted, in that at least 70% of the questions were answered. Questionnaires were recorded with the Gandia Barwin statistical program. After recording 25, 50, and 75 of the questionnaires, a quality control was performed to detect potential recording mistakes. The objective of the analysis was to detect potential differences between the three population groups (parents, children, and teachers). Student *t* test was used to perform the statistical analysis of the data.

From a population of 161 842 children aged 6–13 yr in Castilla-La Mancha (13), and with an estimated prevalence of type 1 diabetes among children of 1.52 per thousand (1), a population of 246 children aged 6–13 yr with type 1 diabetes was estimated to be living in Castilla-La Mancha (Spain). Taking into account that 430 questionnaires were received and validated of which 167 were from parents, 152 from children, and 111 from teachers, the following errors were calculated: parents: ± 4.4 ; children: ± 5.0 ; teachers: ± 7.1 , assuming a finite population, a confidence level of 95.5%, and a variance = $p = q = 50\%$.

Results

Patient characteristics

The 430 accepted questionnaires were completed by either the mother or the father of the child with type 1 diabetes (167, 39%), the child itself (152, 35%), or the teacher at school (111, 26%). Demographic characteristics of children with type 1 diabetes are shown in Table 1. Small differences were observed between the three population groups interviewed in this survey. The majority of children were 10–13 yr old (62–71%). Male and female gender were equally represented. The median duration of diabetes was around 4 yr. Most of the children went to public or state schools (86–88%).

General situation of children with type 1 diabetes at primary school

Table 2 summarizes some of the answers obtained from the survey and stratified per population group. Some

parents (7%) reported they have experienced problems at schools when they informed about their child's condition, 2% of them said that their children were finally not accepted into the chosen school, and 1% (1 case in 167 parents interviewed) was forced to change school. Also, 3% of parents reported they have experienced discriminatory behavior from staff and teachers at school. Teachers stated that they were notified about a child with type 1 diabetes among their pupils either by the parents of the child (87%), by previous teachers at the school (42%), or by the child itself (28%).

At school, most children (61–65%) with type 1 diabetes underwent glucose monitoring during the day, which they usually (81–87%) performed without any assistance. In spite of this frequency of checking, few children (9–12%) actually required insulin administration during the school day. Parents (20%) and children (26%) reported that there had been one, or more than one, hypoglycemic episode before or during an exam. However, 92% of teachers said they had not observed any such episodes. In 46–51% of the responses from the three population groups, it was acknowledged that there was no glucagon available at school; and in particular, 8% of teachers admitted that they did not know what glucagon was used for. More parents (25%) than teachers (14%) knew there was somebody at school who was able to administer glucagon if needed.

Regarding physical activities, 21 and 18% of parents and children, respectively, thought that the physical education teacher would not be able to recognize a hypoglycemic episode during these activities. However, only 4% of teachers believed that to be the case. Surprisingly, 35–40% of parents, children, and teachers stated they did not know the answer to that question. In extracurricular activities, 16% of parents experienced difficulties in getting their school to accept responsibility for the children during 1-d trips. Nevertheless, 86% of parents said that their children undertook the same trips as their peers.

Finally, significantly more parents (17%) and children (18%) reported experiencing negative comments from peers than was perceived by teachers (4%).

Major concerns about type 1 diabetes

Several questions were devoted to identifying children's concerns regarding diabetes care at school and to identifying parent's and teacher's perceptions of the child's concerns. Children's major concerns included not being able to recognize a hypoglycemic episode [mean: 3.64 (± 1.43)], followed by not being able to administer insulin to themselves [mean: 3.11 (± 1.64)]. In contrast, they seemed to be less worried about the necessity of following a diet [mean: 2.29 (± 1.41)] or adhering to a strict management timetable [mean: 2.31

Table 1. Patient characteristics

Demography	Parents (N = 167), n (%)	Children (N = 152), n (%)	Teachers (N = 111), n (%)
Age, yr (N = 430)	N = 167 (100)	N = 152 (100)	N = 111 (100)
6–9	58 (35)	44 (29)	42 (38)
10–13	109 (65)	108 (71)	69 (62)
Mean (\pm SD)	10.37 (\pm 2.15)	10.68 (\pm 1.92)	10.08 (\pm 2.26)
Gender (N = 306)	N = 161 (96)	N = 145 (95)	NA
Male	81 (50)	71 (49)	NA
Female	80 (50)	74 (51)	NA
Diabetes duration (N = 314)	N = 164 (98)	N = 150 (99)	NA
<3 yr	60 (37)	49 (33)	NA
3–6 yr	67 (41)	67 (45)	NA
>6 yr	37 (22)	34 (22)	NA
Mean (\pm SD)	4.11 (\pm 3.02)	4.25 (\pm 2.90)	NA
Type of school (N = 423)	N = 166 (99)	N = 147 (97)	N = 110 (99)
Public or state	142 (86)	129 (88)	95 (86)
Semipublic	24 (14)	18 (12)	15 (14)
Private	0 (0)	0 (0)	0 (0)
Other diseases (N = 271)	N = 142 (85)	N = 129 (85)	NA
Thyroid alterations	13 (9)	10 (8)	NA
Celiac disease	11 (8)	11 (8)	NA
Dermatitis	9 (6)	6 (5)	NA
Asthma	8 (6)	6 (5)	NA
Allergies	7 (5)	6 (5)	NA
Other	16 (11)	9 (7)	NA

SD, standard deviation; NA, not applicable.

(\pm 1.39)], as well as about feeling different from their peers [mean: 2.36 (\pm 1.48)].

Parents thought their children were more worried about diet than they reported in the questionnaire. Regarding other concerns, parents' perceptions of children's worries were in agreement with their children's worries. In contrast, in most cases, teachers' perceptions of children's worries reflected that they thought these concerns were less important to the children. The only exception was regarding the need to follow a diet, where values assigned to teachers were midway between those obtained from parents and children.

Regarding teachers' concerns specifically about type 1 diabetes, their major worry was the possibility that the children could go into a coma at school [mean: 4.62 (\pm 0.79)] or that they (the teachers) would not be able to recognize a hypoglycemic episode [mean: 4.04 (0.98)]. Also, they seemed very worried about the possibility that these children could feel marginalized [mean: 3.96 (1.32)].

Measures to improve integration of children with type 1 diabetes at school

Parents and children reported that the greatest support that the children received at school came from teachers (68–71%) and peers (68–80%). Support coming from other school staff was lower, at 19–25%. Thirty percent of children said that they were unable to resit an exam they had not been able to take because of their disease, whereas 86% of teachers reported that they were always

able to resit an exam and 14% reported that children were sometimes able to repeat it. None of the teachers said that the children could not resit the exam. Percentage values assigned to perceptions of parents were between those of children and teachers.

Both parents and teachers were convinced about the importance of more written information about type 1 diabetes (95 and 99%, respectively) to improve integration at school, whereas 12% of children thought it would not be necessary. In fact, all the teachers said they would like to have some explanatory material about the optimal management of emergencies.

Most teachers (89%) felt that peers at school were sympathetic to children with type 1 diabetes. However, only 81% of children and 71% of parents believed this to be the case.

With regard to the kind of measures that could be taken at school to support children with type 1 diabetes, both parents and children stated that they would like teachers to be better informed about diabetes (77 and 70%, respectively), to have a better knowledge of the steps they should follow to manage an emergency (65 and 64%, respectively), and to have glucagon readily available along with a person who knows how to administer it (62 and 54%, respectively). Other measures included the presence of a nurse at the school (49 and 48%, respectively), providing peers with information about diabetes (47% for both), and ensuring that glucose and fruit juices were readily available for them (31 and 40%, respectively).

Table 2. Some selected questions and answers from parents, children, and teachers

	A, parents (%)	B, children (%)	C, teachers (%)
General situation of children with type 1 diabetes at primary school			
Does the child require glucose monitoring at school? (N = 409)			
Yes	107 (64)	91 (61)	60 (65)
No	59 (36)	59 (39)	33 (35)
In case it is needed, who helps the child to perform glucose monitoring? (N = 390)			
A teacher	14 (8)	9 (6)	7 (12)
Other personnel	4 (2)	4 (2)	1 (2)
A peer	6 (4)	8 (5)	3 (5)
Nobody	70 (40)	84 (53) ^{AC}	18 (31)
Doesn't need help	80 (46) ^B	53 (34)	29 (50)
Do the child need insulin administration at school? (N = 419)			
Yes	18 (11)	13 (9)	12 (12)
No	148 (89)	139 (91)	89 (88)
Has the child ever experienced a hypoglycemic episode before or during an exam? (N = 419)			
Yes	32 (20)	38 (26)	9 (8)
No	130 (80)	110 (74)	100 (92) ^{AB}
Is there glucagon available in the first-aid kit at school? (N = 427)			
Yes	32 (20)	38 (26) ^C	16 (14)
No	83 (51)	68 (46)	60 (51)
I don't know	48 (29)	41 (28)	31 (27)
I don't know what glucagon is for	0 (0)	0 (0)	10 (8) ^{AB}
Is there anybody able to administer glucagon at school? (N = 413)			
Yes	41 (25) ^C	28 (19)	15 (14)
No	41 (25)	53 (36) ^{AC}	22 (21)
I don't know	79 (50)	67 (45)	67 (65) ^{AB}
Are physical education teachers able to recognize a hypoglycemic episode? (N = 418)			
Yes	65 (40)	63 (42)	65 (61) ^{AB}
No	33 (21) ^C	27 (18) ^C	4 (4)
I don't know	63 (39)	60 (40)	38 (35)
Has the child experienced any form of negative comments from peers? (N = 426)			
Yes	28 (17) ^C	27 (18) ^C	5 (4)
No	118 (72)	124 (82)	102 (92) ^{AB}
I don't know	18 (11) ^{BC}	0 (0)	4 (4)
Main children's worries about type 1 diabetes			
Do you think the child is worried about not being able to administer insulin himself? (N = 379)			
Not at all + little (1 + 2)	61 (42)	57 (40)	41 (46)
Quite + a lot + very much (3 + 4 + 5)	85 (58)	86 (60)	49 (54)
Mean (\pm SD)	2.86 (\pm 1.51)	3.11 (\pm 1.64)	2.82 (\pm 1.28)
Do you think the child is worried about not being able to recognize hypoglycemia? (N = 386)			
Not at all + little (1 + 2)	48 (33)	36 (25)	35 (37)
Quite + a lot + very much (3 + 4 + 5)	99 (67)	108 (75)	60 (63)
Mean (\pm SD)	3.30 (\pm 1.34)	3.64 (\pm 1.43) ^{AC}	3.07 (\pm 1.29)
Do you think the child is worried about being different from his peers? (N = 382)			
Not at all + little (1 + 2)	98 (67)	85 (62)	74 (76)
Quite + a lot + very much (3 + 4 + 5)	48 (33)	53 (38)	24 (24)
Mean (\pm SD)	2.20 (\pm 1.39)	2.36 (\pm 1.48)	2.10 (\pm 1.00)
Do you think the child is worried about the necessity of following a diet? (N = 381)			
Not at all + little (1 + 2)	75 (51)	93 (66)	60 (65)
Quite + a lot + very much (3 + 4 + 5)	73 (49)	48 (34)	32 (35)
Mean (\pm SD)	2.76 (\pm 1.32) ^{BC}	2.29 (\pm 1.41)	2.36 (\pm 0.99)
Do you think the child is worried about the necessity of following a strict timetable? (N = 371)			
Not at all + little (1 + 2)	82 (58)	90 (65)	62 (68)
Quite + a lot + very much (3 + 4 + 5)	59 (42)	49 (35)	29 (32)
Mean (\pm SD)	2.43 (\pm 1.29)	2.31 (\pm 1.39)	2.22 (\pm 0.94)
Possible actions to improve integration of children with type 1 diabetes at school			
If the child couldn't do an exam, was there another opportunity for him to do it? (N = 73)			
Yes	26 (90)	25 (67)	6 (86)
No	3 (10)	11 (30) ^{AC}	0 (0)
Sometimes	0 (0)	1 (3)	1 (14)
Do you think that written information about type 1 diabetes is needed? (N = 426)			
Yes	158 (95)	132 (88)	109 (99) ^B
No	3 (2)	18 (12) ^{AC}	0 (0)
I don't know	5 (3)	0 (0)	1 (1)

Table 2. *Continued*

	A, parents (%)	B, children (%)	C, teachers (%)
Do you think that more information about type 1 diabetes would improve children's integration at school? (N = 406)			
Yes	123 (79) ^B	96 (64)	81 (81)
No	23 (15)	23 (15)	10 (10)
I don't know	10 (6)	31 (21) ^{AC}	9 (9)
Do you think peers at school are sympathetic to children with type 1 diabetes? (N = 425)			
Yes	116 (71)	122 (81) ^A	99 (89) ^{AB}
No	27 (17) ^C	14 (9)	4 (4)
I don't know	20 (12)	15 (10)	8 (7)

SD: Standard deviation. A, statistically significant difference by *t*-testing with results of column A; B, statistically significant difference by *t*-testing with results of column B; C, statistically significant difference by *t*-testing with results of column C.

Discussion

In this survey, the situation of children with type 1 diabetes at primary school has been evaluated and analyzed taking into account parents', children's, and teachers' perceptions. It is of interest to analyze briefly the differences observed between these three population groups. A high proportion of teachers did not have a real perception of the true incidence of hypoglycemic episodes or of the degree of negative comments received compared to parents and children. This is in agreement with results obtained from a previous survey of mothers' perceptions in which children between the ages of 6 and 18 yr showed a high ability and independence in managing their own disease (7). In contrast, it is disappointing that 10% of teachers said they did not know what glucagon was used for and that 65% of them did not know if there was somebody able to administer it. From our point of view, these results highlight the need to improve teachers' knowledge about type 1 diabetes and its management (8, 9, 14). It is also disappointing to observe that only 61–65% of children with type 1 diabetes performed glucose monitoring at school. From our point of view, this percentage should be closer to 100% to achieve a strict glycemic control taking into account that most of these children are engaged in normal physical activities with their peers and are taking different snacks at school.

Recently, the Spanish Diabetes Foundation reported the results obtained in a previous observational study performed between November 2004 and April 2005 throughout 499 questionnaires completed by the parents of children aged 3–18 yr with type 1 diabetes (12). The study questionnaire was quite similar to this one, and the answers were stratified by age groups (3–6, 7–10, 11–14, and older than 14 yr). If we took into account the results obtained from this survey and those obtained in the previous study (12), it may be concluded that both studies yielded quite similar results. Thus, in the previous study, 23 and 16% of parents of 7- to 10- and 11- to 14-yr-old children, respectively, stated that they had experienced problems at schools after they had

informed about their children's condition, while in this survey this percentage was lower, at 7%. Also, 9 and 6% of parents of 7- to 10- and 11- to 14-yr-old children, respectively, reported discriminatory behavior by school staff compared to 3% reported in this study. In spite of these improvements, it is clear there is still a need to draw the attention of members of staff and pupils in schools about the illegal nature of this type of behavior (15).

Moreover, other results from this survey agreed with some of the conclusions reached in the previous study in spite of the fact that at that time only parents' perceptions were measured (12). Thus, in this survey both parents and children recognized that the greatest support came from teachers and peers, whereas other school staff were less helpful, as found in the previous study. Although parents experienced difficulties with the school in taking responsibility for their children during 1-d trips, nevertheless the majority of children were able to take them anyway.

Regarding the major concerns of children, the results obtained indicate that in general parents seemed to have a closer understanding of their children's feelings than do teachers. In fact, it seems that teachers minimized children's worries. For the three population groups, the major concerns were related to the uncertainty to recognize hypoglycemic episodes or the children's ability to self-administer insulin. Other aspects such as the necessity of following a diet or adhering to a strict management timetable seemed to be less important to children than parents and teachers believed. Also, teachers appeared to be unsure about recognizing the symptoms of diabetes or how to respond in an emergency. These findings are in agreement with previous findings (16) as well as with the lack of confidence showed by parents and children about teacher's capabilities in case of an emergency (14, 17).

The usefulness of several possible courses of action to improve integration of children with type 1 diabetes into schools was also evaluated by parents, children, and teachers. Parents and children believed there

should be better information for teachers about diabetes and emergency management as indeed did teachers. Information could be provided through educational sessions at schools, written information, and updated on-line resources. In fact, educational sessions for school personnel and peers have been shown to improve the control of diabetes in children as well as their quality of life and to provide flexibility in performing their diabetes management tasks at school (18). Other measures highly desired by parents and children were the availability of glucagon as well as fruit juices and glucose on the school premises, and the provision of school nurses. These interventions have also been previously demanded (12).

In summary, the three population groups agreed about the necessity of having more information on diabetes available at schools. Although some discriminatory behavior was still seen, it appears to have been diminishing in the past year. We believe that drawing the attention of schools to the illegality of this behavior, along with the provision of activities to improve diabetes knowledge at schools, will bring about further improvements for the situation for young children with diabetes in primary schools.

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Appendix

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