



Management of type 1 diabetes in primary schools in Ireland: a cross-sectional survey

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Abstract

Background Parents reported experiences of support for diabetes management in schools are variable. Recent data from European countries are sparse and experiences in the Irish primary school setting have not been described previously.

Aim To describe parents' experiences of support for diabetes management in primary schools in Ireland.

Methods Questionnaires were distributed through nine regional and tertiary paediatric diabetes services to parents of children aged 4–13 years with type 1 diabetes attending primary school. Data sought included patient demographics, treatment regimens, diabetes education of school staff, assistances received, and interactions between the school and family.

Results Responses were received from 418 parents of primary school children with type 1 diabetes. Twenty-six percent of children were not on intensive insulin therapy. Children on a multiple daily injection regime who were unable to self-administer insulin had administration facilitated by attendance of a parent in 95% of cases. Seventy-eight percent of parents were phoned by the school regarding diabetes management, particularly those of younger children ($p < 0.001$). More than half of parents attended the school at least once per month to assist with diabetes management, particularly those of younger children ($p < 0.001$). Younger children were also more likely to have a special needs assistant ($p < 0.001$) and have a written management plan ($p = 0.001$).

Conclusions Our research has demonstrated deficits in care with respect to access to intensive insulin therapy, individualised care plans and a high burden on families which should be addressed through the National Clinical Programme for Paediatrics and Neonatology and relevant government departments.

Keywords Children · Legislation · School · Type 1 diabetes

Background

Epidemiological studies indicate that the incidence of type 1 diabetes (T1DM) in children is increasing worldwide and Ireland is a country with a relatively high annual incidence (28

per 100,000) [1]. Consequently, many primary schools in Ireland have experience of one or more children with T1DM. Young children with T1DM rely on parental support for daily activities such as blood glucose monitoring, insulin administration, carbohydrate or insulin adjustment for physical activity and the management of hypoglycaemic and hyperglycaemic events. As children progress through developmental stages, they gradually and incrementally acquire the necessary skills for self-care but primary school age children require adult supervision and support to ensure that their care needs are safely met. Direct parental support is unavailable for 6 hours per day while the child attends primary school.

T1DM may impact significantly on academic performance. There is extensive literature documenting the effects of acute glucose fluctuations on attention and information processing [2], which has translated into lower test scores in some, but not all papers [3–6]. Furthermore, suboptimal glycaemic control is associated with lower test scores and poorer school attendance

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[6]. Many parents of children with T1DM and the children themselves lack confidence in how diabetes is managed in the school setting [7], and the proportion of teaching staff with adequate diabetes knowledge in studies varies from 2 to 33% [8, 9].

In Ireland, children typically commence their formal education in primary school between the ages of 4 and 5 and continue until the age of 12 or 13. The school day is 5 hours in duration during the first 2 years and 6 hours thereafter. Meals are typically not provided by the school except in economically disadvantaged areas. Multiple frameworks exist which require schools to support the care of children with physical and intellectual disabilities. The *Disability Act 2005* and the *Education for Persons with Special Educational Needs 2004 (EPSEN) Act* aim to ensure that school environments are inclusive and the needs of such children are accommodated. While it is not considered a disability in educational terms, children with T1DM are covered under this legislation which stipulates that children should be supported to fully engage with the curriculum and any exclusions should be justified. Unlike other jurisdictions [10], Irish legislation does not mandate specific staff training or require schools to administer insulin to children with T1DM. Special needs assistants (SNAs) may be provided to assist children who need extra non-teaching support, and this includes children with a significant medical need such as T1DM. An overwhelming majority of schools do not have a school nurse. In 2011, a resource pack developed with input from *Diabetes Ireland*, a national charity supporting people with diabetes, was disseminated to all schools to support children with T1DM. It contains information on developing school guidelines for management of a student's diabetes, standardised healthcare plan templates and an Emergency Plan for teachers.

Irish national audit data demonstrated that the mean HbA1c of Irish primary school children ranges by centre from 63 to 75 mmol/mol (7.9 to 9%), and a perceived lack of support for administration of injections during the school day was a barrier to commencement of intensive insulin therapy in 60% of paediatric diabetes centres [11]. Over the past decade, initiatives to facilitate greater diabetes education for school staff and individualised diabetes care plans for children have facilitated successful introduction of intensive insulin regimens in primary schools in one UK region [12]. This has resulted in a marked improvement in HbA1c in this population with a reduction from 68 mmol/mol (8.4%) to 60 mmol/mol (7.6%) over a decade. There are, however, no publications documenting the burden of management of T1DM in the UK primary school setting prior to implementation of this programme. European data regarding the management of diabetes in the school setting is limited [7, 13, 14], and many of these studies are quite dated. A Spanish study conducted in 2006 [7] revealed that 35% of children with T1DM had no glucose monitoring in school, and half of schools did not have glucagon available. The majority of children did not receive

insulin during school hours. The ALBA project conducted in Italy in 2008 [13] reported that 42% of children had no glucose monitoring during school hours and only one third had insulin administered, usually by a parent. Only a third of teachers had formal diabetes education and only a quarter felt that their school was equipped to deal with diabetes-related emergencies. A 2008 Swedish study [14] found that 40% of children had no emergency management plan, and 57% did not have an identified staff member responsible for diabetes care needs. Following legislation, more recent studies from Sweden have documented improvements in supports and glycaemic control over time [15, 16].

The purpose of this study was to evaluate, from parents' perspectives, the current management of T1DM in Irish primary schools. We wanted to establish the supports that are currently provided to children in school and the challenges they and their parents face. The overall aim of the study was to obtain data to facilitate the development and implementation of a National Diabetes in Schools Programme in Ireland, in order to emulate best practice internationally for care for children with T1DM in the school setting.

Methods

Study population and data collection

The study was conducted between November 2014 and June 2015. Questionnaires were distributed to families attending nine paediatric diabetes centres across Ireland. These included four tertiary and five regional diabetes centres which collectively provide care to an estimated 76% of Irish children with T1DM [11]. A letter of invitation, explaining the rationale for the study, was issued to prospective participants presenting for their diabetes outpatients appointment. Questionnaires were distributed to consecutively consenting parents of primary school age (4–13 years) children at each study centre, over a 3 to 4-month period, which the parents were invited to complete, in conjunction with their child, where appropriate. As the Irish Childhood Diabetes National Register was only in existence since 2008, the estimated eligible study population was 1100 based on the most recent National Diabetes Audit [11, 12]. The study was approved by the Midland Regional Hospitals, Human Research Ethics Committee.

Questionnaire development

The questionnaire was developed by the senior author (MOG) in consultation with members of the National Paediatric Diabetes Working Group, a multidisciplinary group of paediatric diabetologists, diabetes nurse specialists, diabetes dieticians and a

representative of *Diabetes Ireland* (<http://www.hse.ie/eng/about/Who/clinical/natclinprog/paediatricsandneonatology/paeddiabetes/>).

Following agreement, the questionnaire was piloted in a single centre and was subsequently disseminated, unmodified, to all study sites. Themes explored in the questionnaire were grounded in difficulties commonly reported to healthcare professionals and patient advocacy groups.

The questionnaire was divided into eight sections which sought data including demographic information, a description of the patient's insulin regimen, the degree of assistance received from school staff (glucose testing reminder or assistance, meal supervision, carb counting assistance, assistance with hypoglycaemia treatment, administering or supervising the administration of insulin), the presence or absence of a dedicated staff member responsible for care of diabetes related tasks, existence of a school emergency management plan, diabetes education and training (by parents, by hospital-based team or other), interactions between the family and the school related to diabetes care and any restrictions imposed on the child and the availability of the parents to administer insulin during school hours (if required) should the child be incapable of self-administration. Some questions were multiple-choice or multiple answer, more required yes, no or do not know responses and other questions were open-ended.

Statistical methods

The data were entered into a Microsoft Excel spreadsheet (Microsoft Corporation, Redmond, WA, USA). Exploratory routines were used to identify missing and erroneous entries. Errors were corrected, and missing data were imputed where possible to do so accurately, without compromising the integrity of the data. As the majority of the questions in the questionnaire were mutually exclusive, imputation was only possible for data regarding insulin regimen, e.g. if the patient indicated they were taking glargine and were on four injections per day, it was imputed that they were on a rapid-acting analogue and they were classified as multiple daily injection (MDI). The data contained six different options for insulin type, namely rapid-acting analogue, regular, pre-mixed, detemir, glargine and intermediate acting. An MDI classification matrix was used, and all valid insulin combinations were re-coded as MDI, non-MDI and not possible. The matrix proposed 56 possible combinations of the six insulin types, 38 of whom were deemed not possible, 12 of whom were classified as non-MDI and 6 as MDI. Data were coded with SPSS version 20.0 (IBM Corporation, NY, USA) and tested for associations, differences in means and correlations using chi-square, Mann-Whitney *U*, *t* test, Tukey's honest significant difference (HSD), ANOVA and Pearson's *r*. A *p* value < 0.05 was considered significant.

Results

We received 418 responses from parents of primary school children with T1DM representing approximately 38% of Irish children with T1DM attending primary school [11, 12]. Data were not collected regarding non-respondents; however, there were no refusals when the questionnaire was piloted in the senior author's institution. Children with T1DM from 24/26 Irish counties were represented. The mean (SD) age of the children was 9.0 years (2.5) and duration of diabetes was 3.6 years (2.6). Two hundred and twenty (52.6%) of the respondents' children were male.

The most commonly prescribed insulin modality in primary school children was a pump or MDI regimen in 164 (39%) and 145 (35%), respectively. Primary school children on MDI were found to be significantly older than those on a non-MDI regimen or a pump (Table 1). Numbers of children receiving assistance with insulin administration and locations of insulin administration in school are outlined in Table 2. When presented in multiple-answer format, 314 (75%) parents reported that their children required some form of assistance (glucose testing reminder, glucose testing assistance, meal supervision, carbohydrate counting assistance, assistance with hypoglycaemia treatment, assistance with insulin administration or other assistance) with their diabetes care needs while in school. Ninety nine (24%) children required assistance with four or more care needs. There was a weak correlation between younger age and the number of types of assistance required ($r = -0.23$, $p < 0.001$). Indeed, for each individual task, there was a correlation between age and the receipt of assistance from school staff ($p < 0.05$).

Three hundred and twenty three (78%) parents had phone contact with the child's school in relation to their diabetes management (Table 1). Parents of younger children were more likely to be phoned by the school in relation to diabetes management. Two hundred and eighteen (54%) parents were requested to attend the school at least once per month to assist with diabetes management. Once more, parents of younger children were more likely to be requested to attend than those of older children. Just over half of respondents (217) had access to a special needs assistant (SNA), and 261 (62.5%) had a written diabetes emergency management plan. Younger children were more likely to have an SNA and to have a written management plan (Table 1). Having a written management plan was associated with having SNA ($\chi^2 = 30.04$; $p < 0.001$). Despite a similar age profile (Table 1), children on pump therapy were more likely to have an SNA, compared to children on a non-MDI regime (111/163 (68.1%) vs. 41/105 (39.1%); $p < 0.001$), while 65/144 (45%) of the older MDI cohort had an SNA. There was no significant difference in the mean ages of children whose parents had or had not been required to bring their child home from school; however, having an SNA tended

Table 1 Answers to selected questions from the questionnaire

		Count <i>n</i> (%)	Age Mean (SD)	<i>p</i> value
Treatment modality	<i>Pump</i>	163 (39)	8.7 (2.5)	< 0.001 ^a
	<i>MDI</i>	144 (35)	9.8 (2.5)	
	<i>Non-MDI</i>	107 (26)	8.7 (2.3)	
SNA	<i>Yes</i>	217 (52)	8.3 (2.3)	< 0.001 ^b
	<i>No</i>	194 (47)	9.9 (2.5)	
Diabetes management plan	<i>Yes</i>	259 (64)	8.8 (2.5)	0.001 ^b
	<i>No</i>	145 (36)	9.6 (2.4)	
Calls from school	<i>Daily</i>	43 (11)	7.4 (2.2)	< 0.001 ^a
	<i>2–4× per week</i>	43 (11)	8.6 (2.3)	
	<i>1× per week</i>	41 (10)	8.7 (2.1)	
	<i>1× per fortnight</i>	45 (11)	8.7 (2.5)	
	<i>1× per month</i>	0 (0)	NA (NA)	
	<i>< 1× per month</i>	149 (37)	9.2 (2.4)	
	<i>Never</i>	87 (21)	10.3 (2.5)	
Asked to attend school	<i>Daily</i>	25 (6)	6.8 (2.1)	< 0.001 ^{a, c}
	<i>2–4× per week</i>	10 (2)	8.7 (2.3)	
	<i>1× per week</i>	11 (3)	8.9 (2.7)	
	<i>1× per fortnight</i>	18 (4)	9.0 (1.7)	
	<i>1× per month</i>	46 (11)	8.8 (2.3)	
	<i>< 1× per month</i>	107 (26)	8.9 (2.4)	
	<i>Never</i>	187 (46)	9.5 (2.6)	
Asked to collect child	<i>Yes</i>	183 (45)	9.2 (2.4)	ns
	<i>No</i>	227 (55)	8.9 (2.6)	
Restrictions	<i>Yes</i>	40 (10)	9.2 (1.9)	ns
	<i>No</i>	369 (90)	9.1 (2.6)	

ns not significant

^a Analysis of variance

^b *t* test

^c Mann Whitney *U*

to be protective against being collected from school ($p = 0.05$). Restrictions on activities were imposed on 10% of children; however, there were no age-related differences in the frequency with which restrictions were imposed on children.

For parents of children on a non-MDI regimen, we posed the question whether they would be in a position to attend school to administer insulin if an MDI regimen was proposed by the treating clinician based on a six-point Likert scale where 1 was very unlikely and six was very likely. Responses to this item were received from 85/107 (79%). Twenty-seven (25%) and 29 (27%) respondents indicated 1 and 6 respectively. Overall, 40 parents (47%) gave responses between 1 and 3 indicating that they would be unavailable to attend school to facilitate insulin administration. Work was overwhelmingly the most commonly cited barrier 24/29 (83%) responses, followed by availability of transport 4/29 (14%).

Discussion

This cross-sectional study evaluated the landscape of diabetes management in primary schools in Ireland, based on the experience of parents. In addition, with 418 participants, it is one of the largest studies of its kind to date and captured data for approximately 38% of the Irish primary school population with T1DM. We identified significant deficiencies in supports provided to children with T1DM, including lack of diabetes management plans in 40%, lack of access to intensive insulin therapy in a quarter of children, lack of school staff training in diabetes, parents being contacted by the school and being requested to collect their children, restrictions on activities placed on nearly 10% of children and insulin injections being performed in school bathrooms. While legislation exists in Ireland, as it does in many European countries to ensure that school environments are inclusive and facilitatory towards children with chronic diseases such as diabetes, this differs

Table 2 Assistance with insulin administration, staff training and awareness of resources

		Yes n (%)
Inject at school (MDI) n = 145	<i>Require assistance</i>	107 (74)
	<i>Administration help</i>	41 (28)
	- <i>By Parent</i>	39 (95)
	<i>Self-administer</i>	66 (46)
Insulin at school (CSII) n = 164	<i>Require assistance</i>	109 (66)
	- <i>Administration</i>	72 (66)
	- <i>Supervision only</i>	37 (34)
Location of injection (MDI) n = 115/145	<i>Classroom</i>	44 (38)
	<i>Office</i>	32 (28)
	<i>Bathroom</i>	39 (34)
Location of injection (CSII) n = 108/164	<i>Classroom</i>	87 (81)
	<i>Office</i>	15 (14)
	<i>Bathroom</i>	6 (5)
School staff diabetes training	<i>Yes</i>	123 (29)
	<i>No</i>	149 (36)
	<i>Unsure</i>	146 (35)
Diabetes schools resource pack	<i>Aware</i>	108 (26)
	<i>Not aware</i>	310 (74)

significantly from an optimum environment where a child's healthcare needs are consistently delivered in the school setting. In Ireland, responsibility for management of a child's medical needs rests with the parents and there is no obligation on schools to administer medications routinely and no individual staff member can be compelled to administer medication. Sweden, on the other hand, provides a good template for chronic disease management in the school setting, and responsibility for supervision is transferred from the parent to the school authority and responsibility for support of self-care resides with school staff [14].

Comparison of our results with studies in other jurisdictions is challenging as the legislation, school environments, study populations and the study instruments and methodologies differ significantly. This study identified barriers in accessing intensive insulin therapy for a quarter of the cohort, particularly among younger children who do not have the same capabilities for self-care. Furthermore, despite being of similar age profile, children in our study on non-MDI regimens were less likely to have an SNA than children on pumps, meaning they were doubly disadvantaged. This was a surprising finding and may reflect that more motivated families access pump therapy and might be stronger advocates to secure support for their child in school. In a US-based study, similar proportions of children in elementary school required assistance to administer insulin, but this was mostly administered by a school nurse or other medical personnel [10]. This

compares favourably with a 2008 Italian study of a slightly older population (mean age 10 years) in whom 47% were on an insulin regimen which did not require administration of insulin during school hours [13]. Twenty-five percent of students self-administered insulin and in a further 20%, it was administered by a parent. Conversely, access to intensive insulin therapy did not appear to be an issue in a more recently published Swedish study; however, in the study population, only 3% could not self-administer insulin as the study included participants in *Grundskola*, which incorporates lower secondary school [14]. In the study by Särnblad [14], 89% of insulin injections during school hours took place in the classroom or school canteen as compared to our study where 28% injected in an office and 34% in the bathroom. In our cohort, 39 parents of children on an MDI regimen (9% of total cohort) attended school to administer insulin, lower than the 20% in the ALBA project in Italy [13]. We reported that 47% of parents whose children were on non-MDI regimens would be unable to attend school to administer insulin on a daily basis. The lack of support for insulin administration in Irish primary schools is thus denying students access to the optimum treatments for T1DM and placing significant demands on their parents. In Oxford UK, between 2004 and 2006, all young children were started on intensive insulin therapy and a sustainable structure of supports was implemented [12]. Furthermore, staff were indemnified to administer insulin. These structures facilitated an improvement in mean HbA1c in primary school children from 68 mmol/mol (8.4%) to 60 mmol/mol (7.6%) over 10 years. Based on the study data and outcomes achieved in the UK cohort, there are many potential benefits to embarking on a similar programme in Ireland.

In our study, 52% of children with T1DM had an SNA, compared to 42% of children in the Swedish study who had a member of school personnel responsible [14]. It was noted in both studies that younger children were more likely to have such assistance, and the difference may merely reflect the younger population in our study. Proportions of patients with a written management plan were similar.

In our study, the proportion of schools where staff was known by parents to have had diabetes training from their local clinical service was 29.4%. In the ALBA project, one third of a small cohort of teachers reported training from their local diabetes unit; the remainder had training from the parents [13]. We did not ascertain other potential sources of training.

While the burden of care on some parents in our study appeared quite high in terms of telephone contact with or visits to the school, the percentage of parents who had daily contact the school in relation to diabetes management was just 10%, compared to 43% in Sweden [14] and 50% from an older unpublished Danish cohort [17]. This is somewhat surprising given our cohort is younger and consequently have less capabilities for self-care. The significantly lower prevalence of

daily contact in our study may reflect the attitudes of the parents, attitudes of the school staff or a combination of both. In the Swedish study [14], 39% of parents never had any contact by phone with the school; in this study, 21% never had any contact with the school; however, another 36% had contact less than once per month, which was not an option provided in the Swedish study instrument meaning 57% of Irish parents of children with T1DM had contact with their child's school less than once per month or never. The mean HbA1c in the Swedish cohort was 62 mmol/mol (7.8%) in 2008 [14] falling to 55 mmol/mol (7.2%) in 2015 [15], whereas the mean HbA1c in Irish primary school children varies among centres from 63 to 75 mmol/mol (7.9 to 9%) [11].

This study has a number of limitations. One obstacle we encountered was that accurate contemporaneous data regarding the number of Irish primary school children with T1DM are lacking. We estimated the eligible population nationally from the most recent National Diabetes Audit [11], the stable incidence of T1DM in Ireland [1] and proportion of children (~40%) in the primary school age group [12]. The Irish Childhood Diabetes National Register (ICDNR), in existence since 2008, will enable more accurate data for future studies. Unlike the UK, there is no annual National Paediatric Diabetes Audit in Ireland and consequently, we do not have current accurate T1DM prevalence or HbA1c outcome data. Rather than look for a nominal proportion from each of the 19 centres which provide care to children with T1DM, our study population came from four tertiary and five regional diabetes centres who collectively provide care for 76% of the Irish population with T1DM [11]. As a consequence, the proportion of the study population on insulin pumps likely overestimates the proportion of primary school children on pumps nationally as many of the smaller diabetes services do not initiate insulin pump therapy. Based on the younger age profile of our cohort on pumps, it is likely that the proportion of patients on non-MDI regimens is underestimated and is likely to be higher than the 26% reported in this cohort, which is even more concerning. Another potential limitation of our study was that we did not quantify the number of non-respondents. There were no refusals by parents to complete the questionnaire during the pilot phase. Similarly, there were no refusals to complete the questionnaire in the Italian study [13] whereas 13% refused in the 2008 Swedish study [14].

Conclusion

Our paper is the first to report on the diabetes management experiences for more than a third of the primary school population in Ireland with T1DM and will inform a best practice document regarding management of T1DM during school hours. We demonstrated deficits in care with respect to access to intensive insulin therapy, individualised care plans, burdens

imposed on parents and restrictions forced on schoolchildren with T1DM. Significant changes are required to better support the care needs of children with T1DM in Irish primary schools, adapting elements from systems employed internationally for the Irish school system. This should include standardised pupil plans for all primary school children, standardised provision of SNA support for all children for whom it is required and further development of educational resources for schools. Provision of universal access to intensive insulin therapy for all primary school children may prove more challenging to implement and may require legislative change.

Author contributions DMcC researched data and wrote the first manuscript draft. OM and MC conducted the data analysis and critically revised the manuscript. MOG designed the study, conceived the study instrument, researched data and revised the manuscript.

Compliance with ethical standards

Conflicts of interest The authors declare that they have no conflict of interest.

Ethical approval All procedures performed in studies involving human participants were in accordance with the ethical standards of the institutional and/or national research committee and with the 1964 Helsinki declaration and its later amendments or comparable ethical standards.

Informed consent Informed consent was obtained from all participants described in this paper.

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