

Difficulties facing young people with diabetes at school

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Young people with diabetes spend a large proportion of their day in school. Therefore, they need to feel comfortable in this environment in order to confidently manage their diabetes. The results from this questionnaire-based study identify those areas in which this population may encounter difficulties while in school. This information can then be used by parents, guardians, schools and healthcare professionals to address school policy and provide targeted educational information.

Diabetes mellitus affects 1 in 550 children in the UK (DfES, 2005). This group will very often need to administer extra glucose, check blood glucose levels, or even administer extra units of insulin while in school.

In 1996, a good practice guide for supporting pupils with medical needs was introduced (Department for Education and Employment/Department of Health, 1996). The Department for Education and Skills (DfES) later replaced this in 2005 with up-to-date guidelines, *Managing Medicine in School and Early Years Setting* (DfES, 2005).

A study conducted in the US has shown that 30% of parents opined that the in-school support for their child with diabetes was insufficient (Lewis et al, 2003). A different study showed that children were embarrassed about having diabetes and, as a result, although they are capable of carrying out diabetes-related tasks, they may not consistently perform them (Schmidt, 2003); thus, it is important to find ways to help children to overcome this embarrassment.

Before we can tackle the difficulties that

young people with diabetes may encounter while at school, it is necessary to find out exactly what these difficulties may be. We devised a questionnaire-based study to look at these difficulties. This study also looks at the type of information that participants and their parents or guardians would like other people to know about diabetes. This information can then be used to target education for relatives, friends and selected school staff, for example.

An interview-based study was published in the US while the current study's results were being analysed (Hayes-Bohn et al, 2004). The US study found that areas of concern included the knowledge and training of school staff, the food available at school and school rules such as those on the possession of syringes. To date, a search using Medline has not identified any similar studies done in the UK since 2001 (studies prior to 2001 were deemed not relevant by the authors due to changes in diabetes care and public awareness).

It is hoped that the current study will contribute in further elucidating the problems the school environment poses to young people with diabetes and also provide useful

Article points

1. Children under 11 years rely predominantly on their parents for their diabetes care, however once at secondary school a young person will have to manage some aspects of their diabetes while at school.
2. The recognition and appropriate management of hypoglycaemic episodes by school staff has been identified as an important goal for DSNs.
3. Better provisions for the management of diabetes while at school need to be implemented.

Key words

- Young people
- School support

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Page points

1. Two questionnaires were devised, one for young people with diabetes aged between 12 and 16 years and the second for parents or guardians of children with diabetes aged between 7 and 11 years.
2. In the 7–11 years age group, all parents or guardians had informed the child’s school about their diabetes and healthcare professionals had also advised the schools.
3. Young people have to care for diabetes in school themselves by snacking, checking blood glucose levels or by injecting.

targets and solutions that can be implemented by the young person, parents, guardians, the healthcare professional and the school together.

Methods

Two questionnaires were devised, the first aimed at young people with diabetes aged between 12 and 16 years and the second for parents or guardians of children with diabetes aged 7 to 11 years. The decision to send questionnaires to parents or guardians was based on the assumption that they probably still played a very significant role in the management of their child’s diabetes, especially in terms of liaising with the school. The parents, guardians and children were of course free to discuss the questions and answers.

The questionnaires contained both open and closed questions that were approved by the Local Research Ethics Committee in Rochdale, as was the protocol. Forty young people with diabetes were selected from four diabetes clinics: half of the participants were aged 7–11 years and half 12–16 years. The questionnaires were sent out with a cover letter, an information sheet and a stamped addressed envelope. The return deadline was set at 6 weeks after the questionnaires were mailed out. A second batch of questionnaires was sent to non-responders six weeks after this deadline.

Results

Out of 40 questionnaires, 22 were returned, 11 from individuals aged 12–16 years and 11 from the parents and guardians of children aged 7–11 years, giving an overall response rate of 55%. Not all participants made comments, but the comments that were made are recorded (*Tables 1, 2 and 3*). Lack of an extensive answer does not indicate a lack of concern about that aspect of diabetes care.

Results from the 7–11 years old age group

Three children in this group were diagnosed after the age of 5 and the rest were diagnosed at a younger age. The youngest age of diagnosis was 14 months. *Tables 1 and 2* show the results obtained from these questionnaires. Note that some parents and guardians gave more than one answer for the open-ended questions.

In this age group, all parents and guardians had spoken to the school and given information about their child’s condition. Additionally, healthcare professionals had spoken to all relevant schools. Similar to the older age group, parents and guardians of this younger group were concerned about their child’s snacks in school and what happens when they have a hypoglycaemic episode. Some expressed a desire to have guidelines about treatment of these episodes available in the school. When asked about the difficulties a child may encounter

Table 1. Results from the yes/no questions completed by parents or guardians of children with diabetes aged 7–11 years.

Question	Yes	No	Comments
Did you speak to the school regarding diabetes?	11 (100%)	0 (0%)	
Did any healthcare professional discuss diabetes with the school?	11 (100%)	0 (0%)	
Does your child ever need blood glucose, insulin injection, special snacks or hypostop in school?	11 (100%)	0 (0%)	
If yes, is there a special place where your child can do this?	6 (55%)	4 (45%)	Classroom and medical room.
Is there any special provision for your child in school?	1 (9%)	9 (82%)	One did not know. One parent/guardians commented that their child is well-supported at all times. Another said that all the adults know about their child’s diabetes.

when going out, 5 out of 11 parents or guardians said the child does not stay out overnight because of various concerns about their diabetes.

Results from the 12–16 years old age group

Eight (72%) of the responders were diagnosed at or above the age of 10 years. *Table 1* shows the results obtained from the questionnaire, including comments. Unless stated, one responder made each comment.

Most young people have to care for their diabetes in some way while at school. In the 12–16 year age group, the majority (91%) have to eat a snack in school due to low blood glucose levels. Fifty-four per cent of this group checked their blood glucose levels and 27% have injected while in school. Only 6 (54%) of this group

said that there is an allocated area for them to perform these tasks. One person commented that they used the toilet, two other places mentioned were the medical room and the sports hall.

Three (27%) of the 12–16 age group reported problems with the care of their diabetes: one pointed out that a hypoglycaemic episode may not be recognised and teachers and peers have interpreted it as misbehaving. Another individual was asked to leave the school because he was taking a snack for his hypoglycaemic episode.

The majority of participants said that they have not been singled out because of their diabetes and 82% said that they do not feel any different to other pupils. All those sampled said they would like their friends to know about

Page point

1. There are several problems associated with diabetes care in school, such as no allocated area in which to self care or that hypoglycaemic episodes are not recognised or are interpreted as misbehaving.

Table 2. Results from the open-ended questions answered by the parents or guardians of children with diabetes aged 7–11 years.

Question	Comments
What information have you given to school regarding the diagnosis?	6 – verbal information 2 – guidelines for action 6 – leaflets 2 – a school pack
Who helps your child with their diabetes management while they are in school?	7 – teachers 2 – adult other than parent or teacher 1 – they themselves help their child 5 – the child him- or herself 2 – friends One parent commented that the teacher would not help.
What would you like your child’s teachers to know about diabetes?	5 – information regarding low and high blood glucose levels 4 – everything relevant 2 – guidelines on what to do if there is a hypoglycaemic episode 1 – checking blood glucose 1 – the need for a private place for the child to eat a snack 3 – regular snacks are needed 1 – diet information Two parents said that they are happy with the information already supplied and do not feel any more is needed.
Are there any difficulties (related to their diabetes) when the child goes out with friends or when they stay over at friends’ houses?	5 – child not yet ready for overnight stay <i>Concerns included:</i> 3 – snacks 1 – limited knowledge other people have about diabetes. 3 – injections 1 – hypoglycaemic episodes
What information do you give to your child’s carers regarding their diabetes?	7 – snack and diet 5 – glucose levels and what action to take 3 – personal contact details 2 – finger prick <i>Other comments included:</i> Family members do not want the responsibility. Try not to bombard people with too much information. Does not want to risk child under someone else’s supervision. Happy with relatives’ knowledge. 1 – leaflets 1 – injection

Page points

1. The study found that 45 % of pupils did not have access to a private area in which to carry out their care, an issue which is important to address.
2. Further understanding about diabetes is needed in school staff.

their diabetes, or that their friends already know about their condition. From the study, it appears that young people at school are most concerned about their diet and hypoglycaemic episodes. We can also infer that some pupils with diabetes would like to have assistance from their friends if they become symptomatic.

Discussion

We were able to obtain valuable information from the completed questionnaires, particularly from the open-ended questions, which allow responders to comment freely.

In the 12–16 years age group, despite the majority requiring care for their diabetes during

school hours, a degree of difficulty was still reported. Forty-five per cent of this age group do not have access to a private area for their care or treatment. One of the participants used the toilets as a place to manage their diabetes. Because only two from the group specified where they carried out their care, we do not know the extent of the problem and this needs further investigation. Ideally, a person should have a designated area in which to carry out care. This does not need to be a medical room, but has to be somewhere clean and private where the individual does not feel threatened, penalised or embarrassed.

Some problems were reported from a lack of

Table 3. Results from the questionnaire completed by young people with diabetes aged 12–16 years (n=22).

Question	Yes	No	Comments
Do you ever have to do your blood sugar in school?	7 (64 %)	4 (36 %)	'Didn't but should have.'
Do you ever have to give yourself an insulin injection in school?	3 (27 %)	8 (73 %)	'Not allowed to have a midday injection.'
Do you ever have to take a snack in school because of low blood glucose?	10 (91 %)	1 (9 %)	'Everyday.'
Do you have to check your blood glucose or have a snack before or after a particular lesson?	6 (55 %)	5 (45 %)	'After PE.' 'No but should have.'
Is there a place in your school where you can check your blood glucose, give insulin injections or eat a snack when you need to?	6 (55 %)	5 (45 %)	'Medical room.' 'The toilet.' 'Have to go to the sports centre or other places to find a snack when required.'
Do you ever have any problem with any of your teachers if you have to check your blood glucose, give injection or eat a snack during a lesson?	5 (45 %)	6 (55 %)	'Yes, not all are aware of my diabetes and thought I was making it up or misbehaving when I was hypo.' One pupil described in detail a particular incident after which they were asked not to return to school.
Is there anybody picking on you because of your diabetes?	1 (9 %)	9 (82 %)	One responder: 'Just people messing about, nothing serious.'
Do you feel any different to your friends? If yes, in what ways?	2 (18 %)	9 (82 %)	'My diet makes me feel different' 'Don't like hypo's, I get embarrassed and frightened.'
Would you like your friends to know that you have diabetes?	4 (36 %)	See comments	Six said their friends already know, one said they did not mind either way.
Is there anything you would like your friends to know about diabetes?	5 (45 %)	6 (55 %)	Five said hypoglycaemic episodes and two of these said they would like their friends to know what they can and cannot eat.

understanding from the school staff. The authors find it of concern that a hypoglycaemic episode can be misinterpreted as 'messing around'. This is potentially a very dangerous situation. In another instance, a pupil was excluded from school because he ate a snack during a hypoglycaemic episode. In the authors' opinion, this misunderstanding is due to a lack of knowledge of diabetes in the general community. A previous study has shown that children with diabetes feel supported in school but increasing the flexibility of teachers and nurses may improve their ability to manage the pupils' diabetes in school (Nabors et al, 2003). Therefore it is important for us, as healthcare professionals, to educate school staff about diabetes, the signs of hyper- and hypoglycaemia, the life-threatening consequences of lack of intervention and the urgency of treatment.

From this small sample of young people with diabetes, it appears that the areas of most concern are hypoglycaemic episodes and diet. Therefore, educating them and their friends about hypoglycaemia, including how to recognise it and where their supply of glucose can be found should be regarded as very important. In people of this age, it may be worthwhile for friends to be involved during a school or diabetes nurse visit.

Children in the 7–11 age group are much more dependent on adults for their care of diabetes. In this sample over half of the children were diagnosed at a preschool age, meaning that a transition was required between management in the home environment and the school environment. The parents, guardians, school and child need a lot of support for this transition.

Children aged 7–11 with diabetes need a lot more supervision from adults and, in some cases, parents or guardians may need to come into the school to help the child with their diabetes as teachers can sometimes be reluctant to assist. It is important for healthcare professionals to continue to support parents, guardians and schools in the management of diabetes, for instance by producing guidelines or leaflets for schools and a contact number if the school would like further education. The same can be done for relatives who may be involved in the

care of this group.

Some young people can adapt to a change of environment quicker than others. This means that in those individuals less adaptable to change further support may be necessary when moving to secondary school where there is generally less support and supervision. Starting secondary school can be a daunting experience and if a child also has diabetes there can be additional worries. In order for the transition to be smooth, the parents, guardians, child, school and healthcare professional have to work together to plan around the anticipated changes. Possible methods include the following.

- Introducing the secondary school nurse and form teacher in advance of starting.
- Being shown the medical room.
- Spending time in the secondary school prior to starting full time.

Implications

Using the results from this study, the authors have discussed the issues raised with their DSN team. The DSN then liaised with the schools and provided further appropriate education.

From this study we can see that young people with diabetes received mixed support in the management of their condition while at school. Particular areas of concern included finding appropriate places for injections, checking blood glucose levels, taking snacks and the abilities of members of school staff to recognise hypoglycaemic episodes.

It would be beneficial for the DSN team to target school education in these areas, in particular symptoms and signs an individual child may have when they are experiencing a hypoglycaemic episode, hopefully to avoid a situation where the child was thought to be 'messing around', as found in this study. It would also be helpful to involve all the teachers that have contact with the pupil rather than just the form teacher. Encouraging the school to provide a private area for the pupil to inject, check blood glucose levels and eat snacks would be beneficial.

For younger children, the family may also benefit from educating the extended family as this may reassure the parents or guardians when the child goes to visit or stay overnight. ■

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