

Supporting young children with type 1 diabetes in primary schools in the north of England

Marie Marshall

Increasing numbers of young children are being diagnosed with type 1 diabetes (T1D), which has significant implications for primary schools. This study examined support provided to young children with T1D diabetes in two primary schools in the north of England. Case studies were used to examine the influences, perspectives and interactions of all adults involved in diabetes management. The framework approach was used to qualitatively analyse data from the 19 participants. A mix of direct and indirect support was provided by school personnel. There were five common themes: safety, knowledgeable individuals, appropriate environment, being treated as an individual, and independence. Safety was the major primary concern. School personnel providing direct support to children with T1D are ideally placed to increase children's confidence, resilience and independence through diabetes self-management skills. Greater collaboration and flexibility will aid children's acquisition of the self-management skills needed over time.

The UK has the fifth largest population of children and young people with type 1 diabetes (T1D) in the world (International Diabetes Federation and International Society for Pediatric and Adolescent Diabetes, 2011), with a global increase in incidence of 3% annually and the greatest rate of increase seen in younger children (Soltesz et al, 2007; Patterson et al, 2009; Spinks and Mann, 2013). Furthermore, the diabetes control of children and young people in the UK remains suboptimal when compared to other European countries (Danne et al, 2012; NHS Diabetes, 2013; Royal College of Paediatrics and Child Health, 2017).

The effects of having a chronic condition in childhood impacts on both the child's home and school life. With an increasing number of young children with T1D attending primary schools, there is a need to understand how support is provided in this setting and who is involved.

Education is associated with positive health outcomes; however, long-term conditions in childhood negatively affect school attendance (Weitzman, 1986; Glaab et al, 2005; Hale et al, 2015). Children with T1D miss on average 10 days more school per year than their siblings (Parent et al, 2009). Younger children with T1D need more support to achieve optimal glycaemic control in the school environment, which will result in reduced absence (Danne et al, 2012; Semenkovich et al, 2016; Royal College of Paediatrics and Child Health, 2017).

The primary school years are formative in establishing and maintaining positive healthcare behaviours that children will take into adolescence and adulthood (Boden et al, 2012). Furthermore, towards the end of primary school these children need to be prepared for transition to secondary school, where the stigma of chronic conditions can result in secrecy and isolation from peers

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Article points

1. The children with type 1 diabetes in the case studies were supported directly and indirectly by a number of school personnel.
2. The themes identified from interviews with individuals providing support were safety, knowledgeable individuals, appropriate environment, being treated as an individual and independence.
3. School personnel are well placed to assist children in the acquisition of the diabetes self-management skills they will need as they grow up.

Key words

- Case studies
- Developmentally-appropriate diabetes care
- Primary school
- Transition readiness
- Young children

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Table 1. Characteristics of adult participants' roles.

| Participant (child supported) | Characteristics of the role |
|---|---|
| Paediatric diabetes nurse specialist (both) | Provides education, advice, support, training and knowledge on diabetes management to school personnel |
| Mother (James) | In contact with the school each day to provide support to the school and administer James's lunchtime injection |
| Mother (Mary) | In daily contact with the school relating to Mary's diabetes control |
| Class teacher and supply teacher (both) | Educational role with additional diabetes knowledge management experience and the skill to manage acute situations in the classroom |
| Teaching assistant (support) (Mary) | Good experiential knowledge and management of Mary's diabetes, confident in diabetes skills and communicates with all personnel |
| Teaching assistant (medical) (Mary) | Experiential knowledge about Mary and her diabetes |
| Deputy head and head teacher (both) | Promote an all-inclusive philosophy in the health and safety of all |
| Lunchtime coordinator (James) | Oversees James's lunch pack and informs his mother of his food intake |
| Cook (Mary) | Ensures Mary's meal choices are available at lunchtimes. Regularly liaises with the teaching assistant (support) |
| Nutritionist (Mary) | Called on by the school cook to advise on the carbohydrate value of school menus |
| School nurse (both) | Liaises with the school and diabetes team |
| First aider (James) | Supports James with routine blood glucose testing and acute diabetes care |
| Special needs coordinator (both) | Organises the systems that need to be in place for staff and children, including a healthcare plan and risk assessments. Identifies training need |

(Kyngas, 2004; Amillategui et al, 2007; Marshall et al, 2009).

Over the past decade changes in T1D management and the significance of maintaining glycaemic control parameters throughout the day have been cited as important factors for long-term health, since younger children are prone to erratic hypoglycaemia (van de Ven, 1986; Amillategui et al, 2009; Matyka and Gosden, 2010; Marshall et al, 2013). As during term time these children spend 6 hours a day, 5 days a week in primary school, T1D management needs to be appropriate

and timely (Clay et al, 2004; Bernard et al, 2010; Herbert et al, 2015). The younger the children with T1D, the greater their support needs will be, since the majority will be unable to provide much of their own diabetes care. For school personnel with limited healthcare experience, the need to feel confident as well as less anxious while caring for younger children with T1D is therefore important, especially since schools do not routinely have a school nurse on site. The use of a joint integrated educational healthcare plan has gone some way to addressing staff educational requirements. However, little is known about how schools in the north of England manage these requirements. There is also little information diabetes teams have in terms of the scope and depth of learning that staff require in order to support younger children with T1D to manage their health needs and whether good support facilitates improve access to information. The aim of this study was to examine who was involved in supporting young children with their diabetes management in primary schools and how support was offered.

Method

Two local education authority primary schools in the north of England with experience supporting a child with T1D were selected to participate in this study. Parents, children and school staff identified people they believed provided support to the young people with T1D (see *Table 1*). All of the individuals identified participated in face-to-face interviews.

The study was approved by North Wales Research Ethics Committee (Central & East 12/WA/-375). Informed written consent was obtained from adult participants; the children's assent was sought after parental consent was obtained.

The paediatric diabetes nurse specialist (PDNS) from a local NHS trust liaised with the families and schools. Data were generated using semi-structured interviews. A topic guide (see *Box 1*) was used to explore the support offered to each child and elicit any perceived barriers or facilitators to support. Participants were encouraged to identify additional items as they reflected on their own experiences throughout the interview.

Audio-recorded data transcribed verbatim were progressively analysed using NVivo 8 qualitative analysis software (QSR International, Vic, Australia). The data were examined in stages to identify themes. A cross case analysis was undertaken to identify convergent and divergent trends (van de Ven and Poole, 2000). The analysis was organised to enable comparisons of the perspectives of different groups within and between schools.

Results

Case study 1

James was 7 years old. His school was new to supporting a child with T1D. He had only been in the primary school for a number of weeks. Eight participants and key personnel were identified as providing direct and indirect support to James at school, see *Figure 1*.

Case study 2

Mary was 9 years old. Her school had gained extensive experience in supporting her with her diabetes management over a period of 6 years. The key personnel who consistently provided direct support and the personnel involved in providing infrequent indirect support to Mary are given in *Figure 2*.

Themes identified from interviews

The five themes that emerged across both case studies revealed the significance of the boundaries and limitations that needed to be in place within school environments in order to facilitate access to education. The themes specifically explored safety, knowledgeable individuals, appropriate environment, being treated as an individual and independence.

Safety

Safety was the key concern of all participants. Mary's teacher said: "The main remit of school is keeping a child safe. Yes, we should be educating the children, but, if we're not keeping them safe as their parents would do, then we're not doing our safeguarding job." It was also important that children and parents felt safe in order for children to attend regularly. James's deputy head teacher said: "One of the things that [his] mum said was

Box 1. Topic guide for the interviews.

- Take me through a typical school day.
- Who was involved at each point?
- Reasonable adjustments:
 - What is the nature of the adjustment for a child for his/her diabetes?
 - Are there areas where adjustment can be difficult/problematic?
- Communication between home, school and the diabetes team.
- What do you think you do well?
- What difficulties can be experienced and how are they overcome?

health wise, with his blood glucose up and down, he's not been in full-time education consistently."

Knowledgeable individuals

Experiential knowledge was described as important by staff in both schools.

Although James had only been at his new school a matter of weeks, staff members were already recognising patterns in his behaviour relating to high blood glucose (BG) levels, as reported by the first aider: "When his BG is high you could see an absolute change of behaviour, because usually he's chatty and he was completely different."

Personnel involved in the direct care of Mary had gained confidence and were able to reduce the anxieties of school personnel who were not directly involved, as reported by the special needs coordinator: "I feel much more confident with it [diabetes] because it's not just me, there's more of

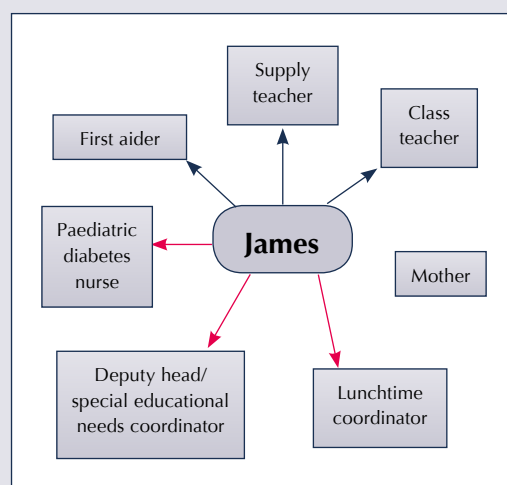


Figure 1. Study participants (n=8) from James's school. Navy arrows=key school personnel providing direct support; red arrows=personnel providing indirect support

“An important element of care for the mothers was that they wanted their children to be treated as individuals.”

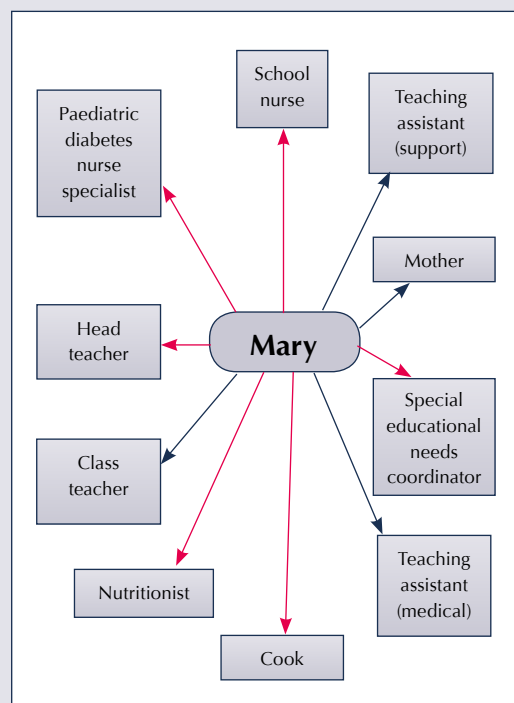


Figure 2. Study participants (n=11) from Mary's school. Navy arrows=key school personnel providing direct support; red arrows=personnel providing indirect support

us and we understand it so much better. I certainly don't feel anxious about it.”

Appropriate environment

Both mothers talked about the physical environment in which their children were cared for. Mary's mother emphasised the importance of a familiar environment, saying: “A lot is done in the classroom, which is where she is used to [...]. Say she's having a hypo outside (playground), she'd go to her classroom.” This would appear to be a place where Mary felt safe and confident she would receive the support she required.

James's mother valued the space arranged for his lunchtime injections. “Just having the calm room we could use where I could do his injection in private was a big thing for us,” she said. “It made us feel that they [the school] wanted to help us.”

Being treated as an individual

An important element of care for the mothers was that they wanted their children to be treated as individuals. In James's care, an example of this was lunchtime coordinators providing specific

information. The coordinator interviewed said: “At lunchtime, I will, or one of the other lunchtime coordinators will, make sure we know what he's had to eat from his lunch box. Then we can tell his mother so she can work out his injection. You have to make sure that he hasn't swapped his food or just given it away.”

The difference between being treated as an individual in relation to healthcare and being treated differently to other children in a wider context was a concern, however. This was something Mary's mother felt strongly about. “The only thing I could say about school is that they need to treat her like everybody else and not mollycoddle her,” she said. “I don't think they should do that. That's the only thing that I have got a problem with at the school.”

For children, differences in treatment can also promote a sense of them being different, as Mary reports: “I think I shouldn't get away with things [in school]. I can get away with my times tables, which I don't like. It's because I've got diabetes.”

Thus, while being treated as an individual is important for diabetes care, it can have negative social effects.

Independence

James's deputy head teacher highlighted the need to plan for his transition from infant to junior school, saying: “We're going to [...] look at him building up over the next 7 weeks to injecting himself, so that when he goes to the juniors he can inject himself with just support from people over there.” Thus the school recognised a need for James to become more independent and prepare for transition into junior school. His mother was less confident than the head teacher that James would be ready, however, saying: “When James was at his last school, I felt he was forced to grow up [...] when he clearly wasn't ready for that yet.” She felt that the pressure to increase his independence would have a potential long-term impact on James's willingness to engage with his diabetes self-management.

In Mary's school there was less evidence of preparing Mary for independence, despite her being older, which concerned her mother: “She is doing her own BG in school. At home the insulin pen [injection] I know she can do herself, and it

gives her her own independence. Mary's turned round to me and said: 'I do it at home, so why can't I do it at school?'"

The PDNS suggested that there may be a lack of flexibility and adaptation to children's development within schools. "Knowing how best to support a child to become independent with their diabetes in school appears to cause some difficulties at home and in school," she said.

Discussion

The two primary schools in this study differed in the level of experience they had in managing the care of children with diabetes. Despite these differences, there were common themes that threaded through the interviews: safety, knowledgeable individuals, appropriate environment, being treated as an individual and independence. These themes were not dependent upon the level of staff within the school setting.

Both schools had a range of personnel that were identified as being involved in different aspects of care for children with diabetes during the school day. Senior staff identified and implemented principles of inclusiveness. Teaching staff identified the need to develop and the benefits of developing experiential knowledge, enabling them to assess behavioural changes associated with BG instability. Support staff supervised the delivery of insulin injections at meal times and monitored glucose control in and outside of classroom activities. The PDNS and, where available, school nurse provided advice and support when requested by the parents and/or school personnel.

The involvement of key school personnel in providing direct care on a daily basis was an important source of reassurance for both mothers. The parents' confidence was based on knowing that school personnel had sufficient experiential knowledge of the children and their diabetes to identify how changes in the children's BG control manifested both behaviourally and physically. The parents were thus reassured that personnel would intervene at an early stage of hypoglycaemia. Such reassurance is central to positive diabetes care across school and home life, since parents report considerable fear of hypoglycaemia, which can affect a child's health and quality of life,

particularly if a child has experienced diabetes-related unconsciousness (Herbert et al, 2015).

Safety was the major primary concern of school personnel and parents. There were tensions, however, between institutional procedures for ensuring safety and meeting the children's evolving diabetes skills and knowledge acquisition. Involving children in the social context of learning and encouraging them to apply new skills and knowledge is essential for future self-management (Warburton et al, 2016). Schools are by nature organisations that are heavily rule-bound with strong routines and are therefore less amenable to change. Child development dictates that as children get older they want and are capable of participating in components of their diabetes management with support. Previous studies have identified that children over the age of 8 years are capable of testing their own BG levels and administering insulin at school (van de Ven and Poole, 2000; Nabors et al, 2007; Warburton et al, 2016).

Sustained personal contact through the provision of direct support enables personnel to develop experiential knowledge of an individual child's needs but can lead to tension with regards to promoting independence, confidence and resilience. This is a balance that parents must strike at home, and good communication and flexibility is required if there is to be consistency during the school day. If this balance is not achieved, there is the potential to reinforce child/adult dependency, which over time can conflict with children's growing sense of autonomy and identity (Marshall et al, 2009).

Children need to be adequately prepared for their transition through primary education to secondary school, and this will involve their evolution from a dependent child into a semi-autonomous young person. The challenge for schools, parents and paediatric diabetes teams is how they can collaboratively support the developmentally-appropriate care that young children with T1D require as they progress from primary to secondary/high school education.

Implications for practice

The main focus of schools is to ensure child and staff safety. This focus has the potential to conflict

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with children’s growing need for independence and their “diabetes readiness” for the different levels of independence they will require in primary, junior and secondary/high school. In addition to current provisions in the statutory healthcare plan for schools, therefore, schools also require information and direction from parents and paediatric diabetes teams on how to provide developmentally-appropriate support to children that will safely encourage them to use their acquired diabetes knowledge and skills in the school setting and help prepare them for their transition into secondary/high school.

Limitations

The case study design limits its generalisability. Although case study research is used to examine contemporary real-life situations, very few empirical research studies have been undertaken in this area of practice. The small numbers of cases in this case study is a limitation, but it also enabled the study to go into great depth with the participants, which is why the model was purposefully selected. Both schools were from the north of England and under local authority remit, and therefore cannot be generalised to other types of school in the UK.

Conclusion

School personnel who provide direct support to children with T1D are ideally placed to increase children’s confidence, resilience and independence through diabetes self-management skills. Greater collaboration between schools, parents and paediatric diabetes teams is required to support children to use their acquired diabetes knowledge and skills; this transition is something children must achieve in their readiness for high school. ■

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