

How are children with diabetes supported in primary education: a teacher/parent perspective

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Abstract

This research investigated how children with Type 1 diabetes (T1D) is supported in primary education from a teacher/parent perspective. T1D in children and young people (CYP) is a condition in which the body no longer produces an important hormone known as insulin (Mayo Clinic, 2017). A review of literature identified areas of concern amongst teachers and parents and highlights concerns from teachers when administering insulin and their ability to do so safely and effectively. From an analytical review of questionnaires and semi-structured interviews, findings suggest that these concerns are still as prominent today as they were nine years ago, and further research is needed to support families and teachers.

Inclusive practice for children with diabetes is under-researched. There is little data available showing how schools work collaboratively with parents and the policies and procedures in place to create and deliver an inclusive and stable learning support system, which could offer 'maximal participation in and minimal exclusion from school' (Nutbrown and Clough, 2006).

Musgrave (2014, p.6) highlighted from her research that "detailed knowledge is required to adopt the needs of children with diabetes to maintain healthy blood sugar levels." Past researchers have found that there is a lack of knowledge with teachers around the topic of diabetes and many are unwilling to administer injections as they fear they are delivering it incorrectly. It could be argued that teachers are not on their own. Other professionals such as social workers, nursery practitioners, etc., working with CYP with T1D also lack some knowledge and understanding of how to best support a child with diabetes and the impact it has on children's education, well-being, and day to day routine.

Literature Review

Children with T1D is suffering from one of the most chronic diseases in childhood and adolescence years (Pansier and Schulz, 2015). According to the Juvenile Diabetes Research Foundation (2013), 29,000 CYP have this condition and figures has risen year on year by 4% and becoming increasingly worrying for parents and carers. Childhood diabetes and its symptoms are not widely known, and therefore research around this topic is limited.

UK Diabetes Survey (Diabetes UK, 2015) highlighted that almost one in three (29 percent) parents and carers of CYP with T1D are less than satisfied with the care and support their child receives in school with 34% of children not having an individual care plan that meet their needs. There are limited data available on how much parents are involved in the planning and day to day care of their children once they are in school. It has been a requirement for schools to provide support for children with T1D since September 2014.

The Early Years Foundation Stage (EYFS) (DfE, 2017) is a mandatory statutory curriculum framework for all early year's providers in England. The framework seeks to 'provide equality of opportunity, ensuring that all children are included and supported (p.5). For children with T1D, this means that schools have a duty of care to ensure that they are supporting and giving equal opportunities to children with T1D to be the best they can be, taking part in activities, for example, school trips, and for them to feel included in school. The policy is in agreement with section 3 (5) of the Children Act (1989) which places a duty of care on the person caring for a child to do all that is 'reasonable in the circumstances to safeguard and promote the child.' This entails knowing what to do in an emergency for a child with diabetes.

A study by Musgrave (2014, p.83) highlighted that 'low number of children with diabetes in day-care settings may mean that their diabetic care needs are problematic for practitioners and therefore children with diabetes are excluded from school.' This is particularly worrying as the Supporting Children at School with Medical Condition (2015) (SPSMC) policy states that 'governing bodies should ensure that all school leaders consult health and social care professionals, pupils, and parents to ensure that the needs of children are properly understood and effectively supported' (p.12).

There is an evolving discourse in the quality of childcare in primary education and according to Reed and Canning (2012), 'implementing quality is a continuous process.' The Nutbrown Review (2012) recommended that the government should aim to create ways to provide "consistently high-quality childcare" (p.4). This discourse could be, in effect, disempowering and marginalizing children with diabetes as they are not given the initial support needed to succeed in primary education and with some excluded from school, we are not addressing the problem at hand but adding to it, creating a dominant discourse. To prevent such discourse, governing bodies and local authorities must ensure key members of staff are adequately trained to support a child with diabetes (SPSMC, 2015, p.13, 17), though funding plays a significant role in achieving this.

Primary school children spend 25% of their waking hours in school. Going back six years, a study by Boden et al. (2011) examined the concerns raised by staff working with children with T1D and related these matters to the views of Healthcare Professionals working with school personnel. The study found that staff was concerned about injecting and glucose testing and the corresponding reactions of parents to school decisions on health-based matters. It is evident that this is still relevant today.

Research by Marshall et al. (2013), McMillan et al. (2014), and Charalampopoulos et al. (2017), highlighted similar areas in which teachers felt they lacked knowledge of the symptoms involved with diabetes and training needed to administer basic 'emergency' assistance. Marshall et al. (2013) found that the relationship between school staff and parents at times affected the level of support provided while McMillan et al. (2014) explored perceptions of facilitators and barriers to Physical Education (PE) in youth with T1D and highlighted five areas:

- Experiences and diabetic support

- Diabetic knowledge and support in PE
- Effects of having T1D on performance
- Limited facilities for diabetes preparation and management
- Lack of training and support for teachers.

Methodology

Creswell, (2008, p.3) defined research as a "process of steps used to collect and analyse information". I used questionnaires and semi-structured interviews as my data collection methods. Using a mixed method approach allowed for both quantitative and qualitative data collection. I chose these methods because I had limited time to collect my data and this enabled me to gather more in-depth information and provide another option for participants as some may find it easier completing questionnaires rather than taking part in interviews.

Ethical Considerations

Ethical approval was granted and BERA (2011) guidelines followed. Working with the parent beforehand presented an opportunity for us to form a level of trust and through conversation, I informed her of my research investigation. All participants were aware that they can withdraw at any time if they feel uncomfortable or if they no longer wish to take part in the research (BERA, 2011, para 15).

Analysis

Twenty questionnaires were distributed amongst teachers and three semi-structured interviews conducted. One of the challenges I had was the low feedback from participants taking part in the questionnaires. Out of the twenty questionnaires, only six were returned completed. This is one of the disadvantages of using questionnaires discussed by Lambert, 2012, as it meant that feedback from the data collected was 'limited or superficial' (p.103) resulting in the information collected not giving a true representation of how many teachers are confident in their knowledge and ability to support a child with T1D within the setting.

From the data collated, it is evident that the school has informed not only teachers but also pupils of the basic procedure to follow should a child with T1D need emergency care:

"dependent upon level of need pupil and peer seek out trained staff member or staff member comes to child" (Teacher 1).

The research has brought to light what Musgrave (2014, p.6) found from her study that "detailed knowledge is required to adopt the needs of children with diabetes to maintain healthy blood sugar levels." Of the six questionnaires, all teachers felt they could or need to improve their knowledge and understanding on caring for children with T1D, five teachers had training for T1D and three teachers felt confident in administering injections with one needing support or supervision:

"I like to have support giving insulin" (Teacher 2).

This is congruent with the research of Marshall et al. (2013), McMillan et al. (2014), and Charalampopoulos et al. (2017), and information gathered from my research, show that on average, most teachers felt they could improve their knowledge and ability through further training and are aware of basic knowledge, though some lacked confidence. This data coincides with research by Boden et al (2011) who highlighted some of the concerns raised by staff about injecting and glucose testing.

Interviewing the trained staff member, brought to my attention the level of care, knowledge and understanding needed to effectively care and support a child with T1D. He noted the importance of supporting other staff members and following each care plan as they all differ between children:

“Supporting staff with advice...different to the individual” (Designated Staff Member).

During the interview with Mom, she spoke of the effects with dealing with her son's illness. She had to start checking labels on food packaging and mentally calculating numbers to ensure her sons' meals were balanced. This is an area with very little research and exploring this further is of great interest. Mom felt “confused and angry with herself” but her fears were put to ease by staff at the school:

“school are supportive when he is ill and needs time off. I am always put at ease by any member of staff with regards to any concerns I may have” (Mom).

Mom worries about his attendance some days and stated that “academically he is bright”. Although her son cannot self-medicate, he can check his own blood sugar levels and know when to request treatment if he is low. To further support families, the school limit where possible, the impact the illness has on the child's education:

“We limit the impact as much as possible- sometimes special measures are put in place where physical activities are involved” (Teacher 3).

McMillan et al. (2014) discovered insights of facilitators and barriers to Physical Education (PE) and discussed some key areas including limited facilities for diabetes preparation and management. However, from my research, this limitation is not seen as the setting has made available the use of the medical room and ensured that most staff are trained in this area with staff and pupil having basic knowledge of T1D and how it may affect children. His study raised concerns from parents of the PE teacher's lack of knowledge on their children's condition. As stated before, within my work placement, the P.E teacher is aware of these children and given information on the procedures to follow:

“It is important for information regarding T1D to be passed onto me, so we are not putting children's health at risk during exercise” (PE Teacher).

He was notified of children with T1D as soon as he started working at the school and told whether the child could do their own blood sugar test (SPSMC, 2015, p.20).

“The children will know there is a change as they have monitors that they regularly check” (PE Teacher).

In conclusion to the interview, he would like all schools to inform PE teachers of children with T1D:

“In my experience, I believe that there could be certain areas for improvement in terms of every school making sure the PE teacher has the relevant information” (PE Teacher).

Conclusion - Our Children’s Health Matters

This study investigated how children with diabetes is supported in primary education from a teacher and parent perspective. Key findings suggest that there are still concerns with teachers when providing care and support. Findings from the research echo that of past researchers such as Musgrave (2014), McMillan et al., and Charalampoulos et al. (2017), on the lack of knowledge of children living with T1D and how it affects their education. This is reflected throughout the research and further highlight gaps found in past data. More should be done within schools to support staff working with children and their families. Teachers should be trained not only on their knowledge and ability to administer insulin, but also how to offer emotional support as discussed by Clark (2003, p.61). Results show that there are still fears amongst teachers and that they felt more confident with their knowledge than they were with giving emergency care. Although regular training is provided, most teachers felt reluctant in administering these injections.

A review of literature also highlighted parental concern because the school their children attended did not disclose medical information to the PE teachers which could potentially put their child health at risk. Marshall et al. (2013) and Charalampoulos et al. (2017) both highlighted the need for improved staff support in their research and brought to light the concern of parents. Within my placement, all staff, including the PE teacher is well informed of children with T1D and the procedures in place to support both children and families. Working in partnership with medical staff, the school provides training on diabetes including safely and effectively administering injections. Building on parent partnership as well as working with different professionals will provide a stronger support network for children, parents and teachers. Along with past research, this remain an area of concern for most staff as they have fears of not administering it correctly.

Recommendation

While recognising the limitations of my analysis, this small-scale study has raised an awareness of the fears and concerns amongst staff members within the setting I conducted my investigation. It highlighted areas of provision for other educational establishments with an insight into the training needed to better support families and children living with T1D. To further improve this research, a longer time scale would be beneficial, as well as using other data collection methods such as one to one interviews and extending my investigation further afield to other schools. Investigating how parents with little knowledge of numbers calculate their children's meals would be the next step as this was an area brought to light from the findings of my research.

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