

Australian Diabetes Educators

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Diabetes and Paediatrics

Peer Review

Type 1 Diabetes in Australian Primary Schools:
Parental Concerns and Strategies for Improvement

Feature Articles

Type 2 Guidelines and the Role of the Primary Health
Care Nurse

Diabetes and Schools - Who Cares?

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Takes Diabetes out of Hospital
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Contents



ADEA Update

Constitution Review Update	6
CredentiaLLing Update	7

Peer Review

Type 1 Diabetes in Australian Primary Schools: Parental Concerns and Strategies for Improvement	12
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Feature Articles – Diabetes and Paediatrics

Type 2 Guidelines and the Role of the Practice Nurse	27
Diabetes and Schools – Who Cares?	43

Consumer Perspective

Experience of Parents and Parents' Perspective of Raising a Child with Diabetes	19
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Reflective Practice

A New Paediatric Model of Care Takes Diabetes out of Hospital to the Home and Community	21
---	----

Models of Practice

Diabetes at School and Preschool – Changes in Victoria	32
--	----

Complementary and Alternative Therapies

Children, Adolescents and Complementary and Alternative Therapies	34
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CDE Profile

JDRF Diabetes Educator Award 2013. Profile of a CDE	40
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Editor's Note 4 CEO Update 4 Book Review 8 JDRF Update 10 NDSS Update 10
Diabetes and Technology 30 Research Insights 38

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Our sustaining members make an important contribution to our ongoing growth. Their financial support assists ADEA in pursuing its goal of achieving optimal health and wellbeing for all people affected by, and at risk of, diabetes, through education, advocacy, support and research.



Type 1 Diabetes in Australian Primary Schools: Parental Concerns and Strategies for Improvement

Anne Marks, Valerie Wilson & Jackie Crisp

Abstract

Purpose

The purpose of this study was to explore the management of type 1 diabetes in Australian primary schools (Kindergarten to Year 2), from the parent's perspective. The study aimed to explore the concerns of parents regarding diabetes management in the school setting and the strategies needed to improve diabetes management in the school setting.

Method

A cross sectional, descriptive approach was used to collect data from parents ($n = 66$) of children with type 1 diabetes attending an Australian primary school (Kindergarten to Year 2). An online self-administered questionnaire was designed in Survey Monkey and was available via a dedicated Facebook page. Qualitative data from the questionnaire were analysed using thematic analysis adapted from grounded theory coding. Quantitative data were statistically analysed using the Statistical Package for the Social Sciences (SPSS) version 21.

Results

Parental concerns included difficulties with participation in school activities, inclusion at meal times, lack of independence and missing school due to fluctuating blood glucose levels (BGLs) or lack of full staff support. Children often missed classroom activities or time with peers when they had to attend the office for routine care. Safety was also a problem at school and many parents expressed the importance of adult assistance during fluctuating BGLs and easy access to hypo treatment. Two strategies for improving diabetes management at school were education of school staff and allocation of appropriate school staff support.

Conclusion

Difficulty with participation in school activities is a common concern among parents of children with diabetes. In order for the child to experience a safe inclusive school environment, the appropriate level of education, staffing and ongoing support is required.

Introduction

Type 1 diabetes is one of the fastest growing chronic health conditions in childhood. Australia has the sixth highest rate of new cases of type 1 diabetes among children in the world.¹ In 2008 the prevalence amongst Australian children aged 0-4 years was 28.8 per 100,000 and 128 per 100,000 for children aged 5-9 years.² The prevalence is increasing by 3% per year.^{3,4}

Updated prevalence data are not yet available, however it was estimated that by 2013 the figures would rise to 35.9 per 100,000 for the 0-4 age group and 136.1 per 100,000 for those aged 5-9 years.² Therefore the number of children with diabetes attending early primary school has increased and is likely to rise even further. This increase will add pressure in terms of resources and planning for the ongoing needs of children, their families and the school system itself.

Generally parents perform diabetes treatment for young children due to the child's limited developmental stage and the complexity of the tasks required. Treatment can be problematic when children enter the school system as these children require more planning and resources from parents, school personnel and diabetes educators than older children.

Whilst there are a number of international studies on diabetes in the school setting⁵⁻¹¹ there is a lack of published research in Australia. Therefore the aim of this study is to explore the concerns of parents regarding diabetes management in Australian schools and to identify potential strategies for improvement and for more research and improved outcomes.

Research design

This cross-sectional study collected data to explore three aspects of diabetes care at

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school: the management of type 1 diabetes, parental concerns and strategies for improvement. This article will report on the second and third aspects: parental concerns and strategies for improvement.

Study population

The study was conducted in Australia and focused on children attending early primary school: Kindergarten, Year 1 and Year 2 (aged 4-8 years). The inclusion criteria were: a parent or carer of a child with type 1 diabetes attending an Australian primary school in Kindergarten, Year 1 or 2, ability to read and write in English at an eighth grade level and access to a computer with Internet connection. Sixty-six parents were included in the analysis. Demographic data are outlined in Table 1.

Method

A self-administered electronic questionnaire was modeled on an existing tool¹² and was also informed by the literature review, questions for the study and the researcher’s professional diabetes experience.

The self-administered questionnaire was designed and administered via the online survey and evaluation tool, Survey Monkey.¹³ Facebook was used to recruit participants for the study. A Facebook page was created, ‘Diabetes at school survey’ which included information about the study and a link to the electronic questionnaire.

From February - March 2013, online posts from ‘Diabetes at school survey’ were placed on Facebook pages and online groups

that were focused on diabetes or parenting a child with diabetes within Australia. Electronic links were then available for the online anonymous questionnaire if parents chose to participate. Quantitative data were statistically analysed using SPSS. Qualitative data from the questionnaire were analysed using thematic analysis adapted from grounded theory coding.¹⁴

Results

Four major themes with eleven related sub-themes emerged from the qualitative data analysis and are displayed in Figure 1. These themes will be discussed in detail in the following paragraphs.

Theme 1 - Taking an

Table 1: Demographic data related to research participants

Variable	n	%	M	SD	Range
Participants					
Mother	60	91			
Father	4	6			
Carer	1	1			
Not identified	1	1			
Child’s Gender					
Male	33	50			
Female	33	50			
Child’s age					
Years			6.22	1.1	4-8
School grade					
Kindergarten	23	35			
Year 1	23	35			
Year 2	20	30			
Type of insulin delivery					
Insulin Pump	35	53			
Injections	31	47			
Length of diabetes diagnosis					
Years			2.33	1.62	0.08-7
Recent HbA1c					
Percentage			7.6% (60 mmol/mol)	1.17	5.6-12% (38-108 mmol/mol)

interest

Willingness

A number of parents expressed how appreciative they were of the school's willingness to learn about and support their child's diabetes care. Class teachers and teacher's aide's were particularly supportive. The school's positive approach, co-operation and understanding, provided parents with a sense of ease. These qualities conveyed that staff had a genuine interest in their child.

In contrast, some parents expressed dissatisfaction with their child's school and felt that the school was unwilling to assist with diabetes care. Insulin administration was an area of particular concern for parents. Unwillingness to help with diabetes care created a great deal of stress for families and gave the impression that the school didn't care or weren't interested. Some parents described the experience of being 'unheard' by the school and felt that they had to constantly advocate for their child's needs.

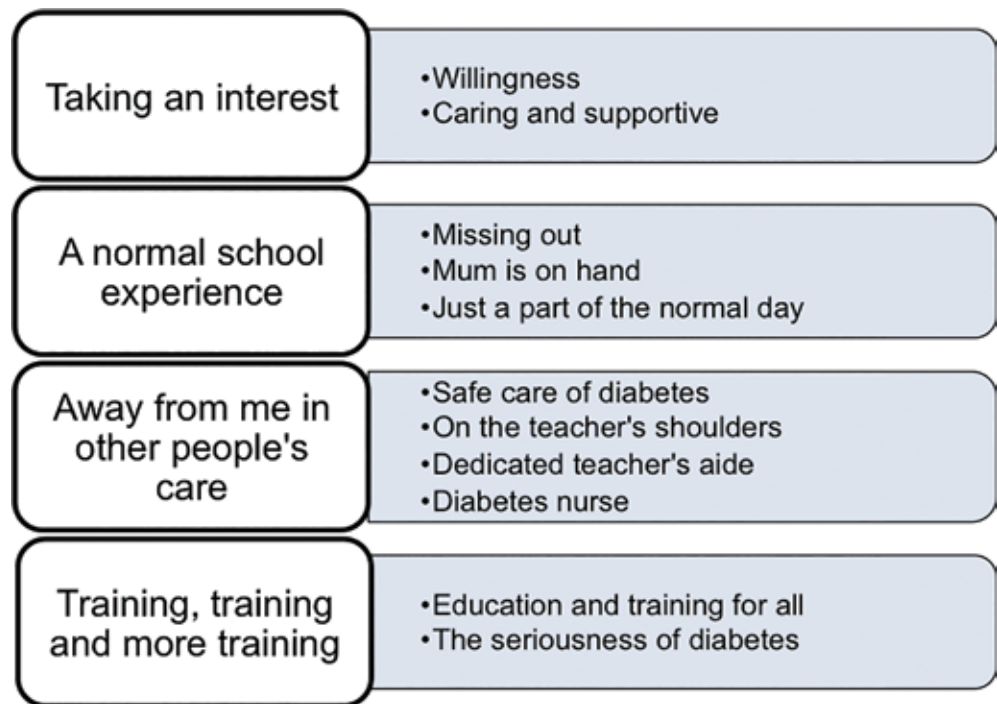
'...it's not fair that a six year old has to inject herself as no one in the school will.' Parent 44
(Year 2 child)

Caring & supportive

Despite the concerns outlined above, there were parents who expressed a feeling of comfort when schools were caring and supportive of their child's diabetes. Accommodating school environments created a sense of safety for their child. Communication and working in partnership were also valued qualities.

'I'm extremely happy with the

Figure 1: Themes and sub-themes from the diabetes at school qualitative data



cooperation of the whole staff of the school, actively participating in the education given and actually taking an interest. They are always happy to make time to talk with us if there are any concerns or potential issues. They have made transition to school so much easier.' Parent 8
(Year 1 child)

Theme 2 – A 'normal' school experience

Missing out

There were many stories from parents detailing the school experiences that their child had missed out on. Children often missed sporting activities or experienced disruptions due to changes in blood glucose levels. Some parents reported that their child had to be collected from school due to unstable blood glucose levels and lack of full staff support.

'I've been told that treating my son's hypos takes up too much staff time, so I will need to start collecting him from school if he has more than 2 hypos in a day.'
Parent 61 (Year 2 child)

Another parent reported missing

entire days of school.

'If her teacher is not there, she has to stay home as no one else has been shown how to do sugar tests or knows how to look for signs (hypoglycaemia).' Parent 1
(Kindergarten child)

Other children were unable to participate in excursions away from the school if a parent couldn't attend to administer insulin.

'It requires someone able to work the pump to accompany him... if they're away ... he misses out or the parents have to take a day off to be there.' Parent 42
(Kindergarten child)

Another common issue was the importance of inclusion at meal times and the impact diabetes had on various school activities involving food.

'He was singled out and put in a different area of play at lunch time on the first day of school as he wasn't eating his lunch fast enough.' Parent 33
(Kindergarten child)

One mother experienced great sorrow when her child missed out on the normal transition to independence when starting primary school. Her grief was evident in the following account:

'As a mother I cried when my son started school, not because I was leaving him like all the other mothers, but because I can't just leave my son at school and let him learn his way. I have to be at the school for meals to do finger pricks and bolus the food into the pump. I feel like he misses out on the whole starting school and being independent part that every other child gets to have.' Parent 42 (Kindergarten child)

Mum is on hand

Mothers described the amount of time, dedication, planning and sacrifice that was required on their behalf to ensure that their child participated in all school activities. Parents, but particularly mothers often attended special school occasions for safety reasons and due to the lack of structure involved in these activities. Mothers often supplied food for school activities to ensure it would cater for their child's needs and to encourage inclusion in social events.

Many mothers provided education and training for school staff, which took a considerable amount of their time. Some mothers were unable to maintain employment due to the never ending demands of diabetes care, as the following mother explains;

'There are no difficulties because Mum is on hand to manage anything out of routine. Mum is also on hand each day to receive phone calls (which there are many) and able to go to school when needed. However it's worth noting that this Mum had to give up her job in order to be available to manage these events and the day-to-day management.' Parent 45 (Year 2 child)

Just part of the normal day

Creating an inclusive school environment with integration of diabetes care into normal classroom routines was very important to parents. There were a number of reports of schools that had managed to achieve this. Parents were very upset when schools did not support integration of diabetes care for their child. Leaving the classroom for routine care or missing time with peers at break times was not considered leading a 'normal' life.

Theme 3 – Away from me, in other people's care

Safe care of diabetes

Parents were concerned about their child's safety at school, *'I am always worried about how my child is going away from me in other people's care.'* Parent 28 (Year 2 child)

Some parents reported lack of provision or supervision of blood glucose testing. Parents worried about low blood glucose levels (hypo's) and often wanted extra testing to be done, just in case. Ensuring that there was easy access to hypo treatment throughout the school was equally important.

The lack of school staff that were available to care for diabetes was also an area of great concern for parents, as often their child's safety was compromised. A number of parents attended school and excursions to ensure that their child was safe.

'I'm concerned that he may fall under the radar especially when the regular class teacher is absent.' Parent 7 (Year 2 child)

Communication between parents and the school was beneficial for the development of a safe environment for the child. The exchange of information provided support and reassurance to both parents and school staff.

On the teacher's shoulders

Parents expressed the burden of diabetes care on class teachers. Often teachers were given full responsibility with limited support from other school staff. Teachers were expected to manage their usual teaching duties and diabetes care.

'...we feel that it is entirely up to us and his individual teacher to monitor his diabetes. When we aren't at school it is all on his teacher's shoulders and she has no support.' Parent 55 (Year 2 child)

Dedicated teacher's aide

Parents conveyed the need for teacher's aide involvement in their child's diabetes care. teacher's aides often reduced the burden on parents, class teachers and children. Parents felt that a teacher's aide who was dedicated fully to the child with diabetes rather than shared amongst others, would provide consistency and safety. Additional teacher's aide time was also requested to increase participation in school activities.

Supply of funding for a teacher's aide was often problematic. It appears that funding was limited in most schools and was not guaranteed to continue throughout the child's schooling. Not knowing if this care would continue was stressful for parents. A consistent approach across Australian states/territories and school types was lacking.

Diabetes nurse

Some parents wanted a specialist nurse or diabetes educator at school and excursions. Parents indicated that nurses have a higher level of diabetes knowledge and therefore would provide better care for their child at school. Some parents wanted someone to provide full-time diabetes care throughout the school day and excursions.

Theme 4 - Training, training and more training!

Education & training for all

A large number of parents felt that diabetes education for school staff should be mandatory. Mandatory training would ensure that all staff received education, rather than just a select few. Parents often associated increased education with improved understanding and better diabetes care for their child. Parents expressed difficulty organising education for reluctant schools, therefore mandatory education would relieve this pressure. Mandatory education that is similar to anaphylaxis training would also provide consistency of educators and promote the seriousness of diabetes.

Retraining was also very important to ensure currency of knowledge.

Parents suggested that the government should provide more support to health and education departments for school diabetes education. Most parents requested that education be provided by a diabetes educator.

The main topic areas that parents wanted schools to be educated about were: how to perform blood glucose testing and insulin administration, recognition and treatment of hypoglycaemia, food issues, managing sport and excursions and the difference between type 1 and type 2 diabetes.

The seriousness of diabetes

Some parents stated that the school didn't understand the seriousness of type 1 diabetes. This lack of awareness often impacted on the level of assistance that was provided for diabetes care.

'I don't believe they understand how serious the illness can be. The Principal was her carer one day and didn't test BGL for 4.5hrs, said she looked fine though.' Parent 60 (Year 2 child)

Diabetes education

A large percentage (77%) of parents reported that their child's school had received diabetes education. There were a number of different approaches for school diabetes education reported by parents (Figure 2).

Parents reported that school education was predominately provided by the diabetes educator from a local diabetes service or the parent (Figure 3).

In the majority of schools, the education was provided in partnership: diabetes educator and parent. In terms of the school level attended, a higher percentage of diabetes educator involvement was reported for younger children in Kindergarten (81%), than Year 1 (66%) or Year 2 (76%).

Parents in the study rated a higher level of satisfaction when the school had received education. Fifty parents reported that their child's school received diabetes education and thirteen parents reported no education. A Mann-Whitney U test revealed a significant difference in the level of parental satisfaction with support for diabetes care ($U = 148.5, z = -3.01, p = .002, r = .27$) when the school received diabetes education ($Md = 6$) compared to lack of education ($Md = 4$).

Diabetes care plan

Almost all parents (98%) reported that their child had a written diabetes care plan

Figure 2: The methods and resources used to provide school diabetes education

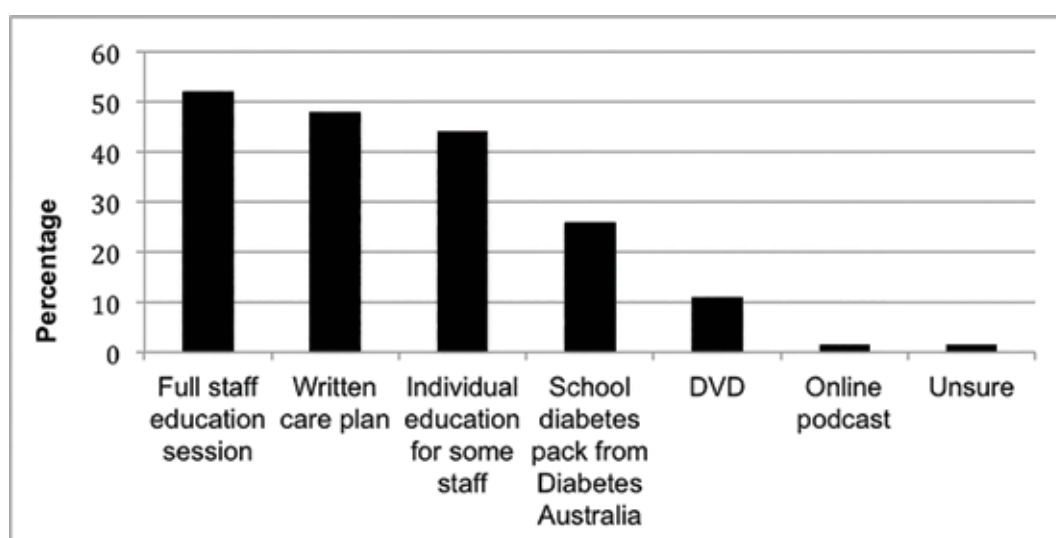
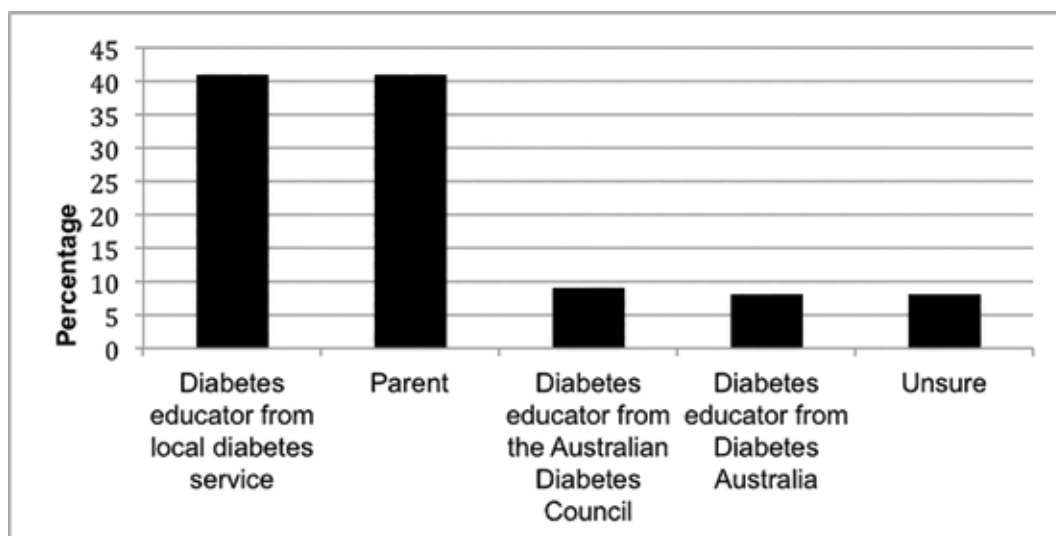


Figure 3: The person who provided school diabetes education



for school. The care plan was developed most frequently by the parent and a health professional (54%). The health care professionals involved in the development of the diabetes school care plan included: diabetes educators (predominately), doctors and general nurses. A number of care plans (29%) were developed without health professionals.

Discussion

Parents expressed concern about the difficulties children experienced with participation in school activities. A number of other studies also reported this: missing school due to diabetes¹⁵, issues with school camp, sport and excursions.^{5,12} Safety for children at school was also a concern. Many parents expressed the importance of adult assistance during fluctuating BGLs and easy access to hypo treatment. Often there was a lack of experienced, knowledgeable school staff that understood the seriousness of type 1 diabetes. This was reported in other research studies.^{8,12,16}

Approximately half of the parents in the study reported that their child had not experienced difficulty participating in school activities due to

diabetes. However, parents then expressed the amount of time that was required on their behalf to ensure that their child did participate in all activities. Similarly, Amillategui et al⁵ reported that 44% of parents made changes to their employment to attend to the needs of their child at school. This was also the finding for Lange, Jackson, Deeb¹⁵ who found that 46% of parents had experienced disruptions in their employment and 31% had missed work completely due to the inadequacy of school support.

Many parents expressed the burden of diabetes care on class teachers. Often teachers were given full responsibility with limited support from other school staff. Likewise, teachers in the study by Hill, Hollis¹⁷ expressed that too much of their instructional time was lost taking care of students' health needs on a daily basis. When a school nurse was present, teachers spent less time on health issues and teachers felt that the children were safer. School personnel also expressed concern about potential liability, as they were often performing tasks that a Registered Nurse would usually undertake. Similarly, Schwartz et al¹⁸ found that school personnel

were concerned about potential liability. Further research is required to determine the most appropriate school staff for assistance with diabetes care.

The two main strategies suggested by parents for improving diabetes management at school were education of school personnel and allocation of appropriate school staff (nurses and teacher's aides). Other research also supported this finding.^{5,6,12,15,16} Although staff in a large number of schools had received education, parents felt that it should be mandatory. This concept was also mentioned in the Middlehurst, Morrison¹² study. Mandatory training would ensure that all staff received education, rather than just a select few. Parents associated increased education with improved staff understanding and better diabetes care for their child. Retraining was also very important to ensure currency of knowledge. Recently, compliance with asthma and anaphylaxis procedures has become mandatory for Australian schools.¹⁹⁻²¹

Many schools have also been 'asthma friendly' for a number of years; staff have participated in education and training, the school has the necessary equipment, information posters are displayed

and asthma policies are in place.²² Unfortunately type 1 diabetes has yet to reach the same level of awareness as these two conditions.

The additional strategy for improving care in schools is the allocation of a nurse or teacher's aide. It was felt that a specialist nurse or diabetes educator has a higher level of diabetes knowledge and therefore would provide better care for children with diabetes. However, school nurses are not readily available in most Australian schools. Another option for school staff support are teacher's aides. Teacher's aides often reduce the burden on parents, class teachers and children. A teacher's aide that is dedicated fully to the child with diabetes rather than shared amongst others, would provide consistency and safety at school. Funding for teacher's aides was limited in most schools and was not guaranteed to continue throughout the child's schooling. A consistent approach across

Australian states/territories and school types was lacking, which was very stressful for parents as not all children received the same level of support at school.

Limitations

There were various limitations that should be considered when interpreting the findings of this study. The small sample size and the challenges associated with accessing participants through social media such as Facebook, restricted generalisability to the larger population. The sample is also biased due to the requirement for respondents to have access to a computer and Internet connection and the ability to read and write English to participate in the study.

Implications for diabetes educators

In order for the child to be safe whilst attending school, the appropriate level of education,

staffing and ongoing support is required. Diabetes services are ideally positioned to support schools, however awareness of this role needs to be highlighted at a national level to influence resource allocation in terms of staffing. Appropriate school personnel for diabetes support also relies on a suitable level of funding, so that a collaborative approach can be adopted rather than individual teachers taking on care. Ideally a consistent approach across school types and Australian states/territories would improve continuity and equity for children. To ensure that there is ongoing progress in improving the school experience for children with diabetes, further data collection is required to explore these issues in detail.

References:



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