

The school experiences of children and adolescents with type 1 diabetes in Western Australia

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Children and adolescents with type 1 diabetes (T1D) spend a significant portion of their day at school. It is therefore important that schools provide a safe and flexible environment for disease management and psychosocial support. Little is known of the school experiences of children and adolescents with T1D in Western Australia. The aim of this research was to describe the mental health and school experiences of children and adolescents with T1D attending mainstream schools in Western Australia. Using an online questionnaire, 92 parents of children and adolescents with T1D were surveyed. The results suggest elevated levels of emotional difficulties among school students with T1D and variable levels of support from school staff to assist these students to manage their diabetes at school. Increasing teacher knowledge to provide more individualised support and enhancing the quality of communication between parents and school staff may be useful strategies to support the physical and emotional needs of children and adolescents with T1D at school.

Introduction

Type 1 diabetes (T1D) is one of the most common chronic diseases of childhood. In Australia, it was estimated that over 6000 children and adolescents aged 0 to 14 years were living with T1D in 2013, with approximately 1,100 new diagnoses for this age group per year (AIHW, 2014). The best practice care regimen for individuals with T1D recommends intensive insulin therapy with either insulin injections or an insulin pump, and regular blood glucose testing throughout the day. As children and adolescents spend a significant portion of their day at school, schools play an essential role in providing a safe and flexible environment for diabetes management, and supporting the psychosocial health of young people with T1D. Limited school support has been shown to result in inadequate T1D management, leading to poor metabolic control and an increased risk of long-term complications (Marks, Wilson & Crisp, 2013).

Students with T1D require the same access to educational opportunities and school-related activities as their peers. These include a medically safe environment with appropriately trained staff and permission to self-care or monitor their blood glucose as needed (Lange, Jackson & Deeb, 2009). In addition to practical support, students with T1D may require additional support and resources to deal with the challenges and uncertainty of living with a chronic condition (Nabors, Lehmkuhl, Christos & Andreone, 2003). In 2009, an international survey found that diabetes care in schools around the world was inconsistent and the needs of students with T1D were regularly not met (Lange, Jackson & Deeb, 2009). This similar lack of consistency in diabetes management has been demonstrated in Australian schools (Marks, Wilson & Crisp, 2013).

Poor or inconsistent management of T1D can also result in poor school attendance, under-achievement at school and interpersonal issues (Persson, Dahlquist, Gerdtham & Carlsson, 2013), potentially resulting in significant consequences for the physical, social and mental health of children and adolescents with T1D. Despite this, there remains a lack of understanding of the school experiences of young people with T1D in Australia. We know of no Australian or Western Australian study that has captured a broad picture of school experiences of children and adolescents with T1D to better understand the potential environmental impacts of the school on the academic, physical, social and mental health of this population.

In Western Australia, schools are guided by the *Disability Discrimination Act 1992*, *Disability Standards for Education 2005* and the *Students' Health Care Policy relevant to each education sector* to ensure that all children and adolescents with T1D have the same opportunities and choices as other students. For example, the school principal must arrange the necessary training to enable staff to support the health of their students. When a school-aged individual is diagnosed with T1D in Western Australia, diabetes liaison teachers from the School of Special Educational Needs: Medical & Mental Health contact the school to provide support and resources to develop an individualised T1D management plan with parents. It is unknown to what extent the available resources are utilised or the effectiveness of actions taken by schools to support students with T1D. This research aimed to describe the mental health and the school experiences of children and adolescents with T1D attending mainstream schools in Western Australia. The research employs a predominately quantitative approach to address the aim, incorporating some open-ended questioning to provide a more in-depth description of students' school experiences.

Method

Participants

The diabetes clinic at Princess Margaret Hospital sees 858 children aged 6 to 18 years. Parents were invited to participate if they had a child aged 6 to 18 years who has been diagnosed with T1D and is currently attending a mainstream school in Western Australia. A total of 145 self-identified parents or guardians (henceforth the term 'parents' is used)

of a child diagnosed with T1D entered the online survey, 92 of whom consented and completed the online survey. Therefore, analyses were conducted on 92 participants.

Procedure

Participants were recruited through newsletter advertisements to families registered on the Western Australian Children's Diabetes Database and advertising postcards provided in the state-wide clinics serviced by the Diabetes Service at Princess Margaret Hospital for Children. Participants consented to complete a survey accessed via a web link that was live between March and August 2016. Participants received detailed information about the study before deciding whether to participate and were unable to proceed with the survey without providing their consent. The online survey took approximately 20-30 minutes to complete. Respondents were required to complete the survey in one sitting.

Measures

The survey questions comprised both open-ended and multiple response questions designed to measure the following.

Socio-demographic variables

Data were collected on the socio-demographic characteristics of the child and family. These included parent gender, postal code, place of birth and combined family income. Child gender, place of birth and current year level at school data were also collected.

Diabetes specific variables

A series of questions were developed in consultation with clinicians, diabetes educators, liaison teachers, parents and support groups to characterise onset of T1D, treatment regime and diabetes management, and understand the impact of T1D on school-related social activities, such as sport, school camps and leadership roles. Examples of questions include: "How often has your child been late or missed part of recess/lunch with their friends because of managing their diabetes?", "It is known that some children may miss out on school camps because of their diabetes. How often does this happen to your child? Why has this happened?" A full list of these questions is available in Appendix 1.

Mental health

The *Strengths and Difficulties Questionnaire* (SDQ), Parent Report extended version for children (4 to 10 years) and for youth (11 to 17 years) (Goodman, 2001), was used as a brief behavioural screening questionnaire. This questionnaire has 25 items divided between five scales: Emotional symptoms, Conduct problems, Hyperactivity/inattention, Peer relationship problems and Prosocial behaviour. The extended version has an impact supplement that indexes chronicity, distress, social impairment and burden to others, if the respondent feels the young person they care for has a problem. The SDQ identifies individuals with a psychiatric diagnosis with a specificity of 94.6% (95% CI: 94.1-95.1%) and a sensitivity of 63.3% (95% CI: 59.7-66.9%) (Goodman, Ford, Simmons, Gatward & Meltzer, 2003). The reliabilities for the five SDQ subscales, total difficulties and impact

scales range from Cronbach alpha = 0.59 (N=1359) to alpha = 0.80 (N=1359), indicating moderate to strong internal reliability (Hawes & Dadds, 2004).

Data analyses

Closed questions in the survey were analysed descriptively and independent groups t-tests and ANOVA were used to compare groups. Sample means on the SDQ were compared to Australian norms developed for the SDQ by Mellor (2005) to explore differences in mental health between youth with T1D and the general Australian population. Effect sizes were calculated using Cohen's d with 95% confidence intervals. Open-ended questions were analysed using text segment referencing, wherein distinct ideas were tagged by code names.

Results

The results of the closed and open-ended questions are presented together under broad themes. Themes developed through text-segment referencing of the open-ended questions are presented as subheadings describing school experiences.

92% of the parent respondents were mothers, and 69% of the parents were Australian born. The characteristics of the children whose parents completed the survey are presented in Table 1. Children were equally matched on gender and attendance at a primary or secondary school.

Table 1: Demographic characteristics of children whose parents completed the survey

Item		Mean	SD
Age (years)		11.72	3.24
Age at diagnosis (years)		6.99	3.52
		N*	%
Female gender		44	47.8
Child country of birth	Australia	80	87
	Other	11	13
Location	Perth Metropolitan	65	70.65
	Rural	27	29.34
School year	Primary school	45	48.9
	Secondary school	46	50
Treatment type	Insulin pump	52	56.5
	Insulin injection	40	43.5
* Total number of respondents may vary due to missing data			

Mental health

Subscale scores for the SDQ are presented in Table 2. Emotional symptoms, conduct problems, hyperactivity/inattention, peer problems and total problems were above Australian normative data (Mellor, 2005), but only statistically significantly higher for

emotional symptoms and total problems. The Cohen's effect size for emotional symptoms was 0.34, a small to medium effect size (95% CI of .219 to .468). The Cohen's effect size for total problems was 0.19, a small effect size (95% CI of .068 to .315).

Table 2: Mean and SD for sample and Australian normative data on the Strengths and Difficulties Scale (SDQ)

Subscale	Sample M (SD)	Aust. norms (N=917) M (SD)	p-value	Cohen's effect size (d)
Emotional symptoms	2.85 (2.35)	2.1 (2.0)	<0.001*	0.34
Conduct problems	1.79 (1.70)	1.5 (1.6)	0.102	
Hyperactivity/inattention	3.5 (2.54)	3.1 (2.4)	0.132	
Peer relationship problems	1.65 (1.94)	1.6 (1.9)	0.811	
Pro-social behaviour	8.13 (1.86)	8.3 (1.7)	0.368	
Total problems	9.74 (9.61)	8.2 (6.1)	0.031*	0.19

* t-test $p < 0.05$

Further analyses were conducted to investigate the effect of age and gender on emotional symptoms and total problems. Students were divided into four age groups: lower primary (Preprimary to Year 3; ages range from 5 to 9); upper primary (Years 4 to 6; ages range from 9 to 12); lower secondary (Years 7 to 9; ages range from 12 to 15); and upper secondary (Years 10 to 12; ages range from 15 to 18). An analysis of variance showed that the effect of age on emotional symptoms was significant: $F(3, 86) = 3.245$; $p = .026$. Emotional symptoms were highest for the lower primary group ($M = 3.62$) and the upper secondary groups ($M = 3.85$). The effect of age on total problems was not significant. The effect of gender was not significant on emotion symptoms or total problems for the study sample.

42% of the respondents indicated their child has difficulties with emotions, concentration, behaviour or being able to get along with other people. Some parents expressed concern about the high levels of anxiety experienced by their children:

Since diagnosis he carries a lot of worries as he fully understands how serious diabetes is.

We are often concerned by [child's name] anxiety issues, nervous habits and lack of confidence...

There is an underlying anxiety to her in all things she does... like she has to prove herself because of the diabetes.

Although the conduct problem score for this sample was not significantly higher than Australian normative scores, comments made by participants described the externalising behaviours of their children related to T1D diagnosis or mentioned the behaviours related to 'highs' (hypoglycaemia) or 'lows' (hyperglycaemia):

He is just more angry with his parents since diagnosis and he often won't do what he is asked or ignores us...

My son is generally kind hearted but his behaviour can be affected by highs and lows, which can make his behaviour more difficult.

School experiences

Participants were asked to rate how comfortable their child felt managing diabetes at school. 55% of participants reported their child felt comfortable using their diabetes equipment in the classroom and 67% felt comfortable about their peers seeing them use their equipment (see Table 3). Close to 70% of participants reported their child felt comfortable getting help from school staff when he or she was feeling unwell.

Table 3: Child's experiences managing T1D in school

Item	Closed responses	N	%
Where does your child feel comfortable using equipment during school time?	In the classroom	50	55.5
	In the office	24	26.2
	In the playground	27	29.4
	Other	25	25.1
Does your child feel comfortable about their classmates seeing them use the equipment?	Yes	62	67.4
	No	30	32.6
Who does your child feel comfortable getting help from if unwell?	Ed Asst./other school staff	62	69.7
	School nurse	31	33.8
	Friends	55	60.0
	Siblings/relatives	20	21.9
	Other	10	11.0
	Feels like there is no-one	4	4.3

Severe hypoglycaemia

Data collected regarding severe hypoglycaemic events, defined as a coma or convulsion, showed that 11 children had incidences of severe hypoglycaemia in the 12 months prior to this survey, and half of these occurred in school. 45% of the participants said their child would not notify the teacher if they were feeling low. Reasons given for not telling the teacher included not wanting to draw attention or fear of being excluded from activities:

She hides all lows until they are obvious due to fear of being excluded. She doesn't want to interrupt or miss out on an activity.

Other parents reported their children were fearful of a negative response or lack of trust between the child and teacher:

She's had a couple of teachers who she has perceived as being annoyed by her having a hypo.

She feels the teacher doesn't trust her that she is low and thinks she is just trying to get out of class.

A lack of teacher knowledge about hypoglycaemia was also identified as an issue:

Even once he has explained it (glycaemic episodes), they (teachers) don't understand how serious it is.

However, not all participants experienced problems related to seeking help for hypoglycaemia, with some saying their child had little or no difficulty reporting this to their teachers.

Attendance and participation at school

Parents reported an average of 13.82 (SD = 17.0) days of missed school in the last year, with 19.8% of these students absent for more than 20 days. The average number of school days missed because of T1D was 9.3 (SD=10.4), with 14% of students absent for more than 20 days because of their T1D, and over half of these aged between 7 and 9 years. The Western Australian clinical care standards recommend at least four visits per year for T1D care. 30% of parents reported their children often or very often missed out or were late for meal breaks because of T1D management. 53% of parents reported their child missed out on sport because of T1D and approximately 9% indicated their child often or very often missed out on going to camps. Reasons given for their child missing out on camps included:

The school is not confident in caring for my son on excursions without parental support.

[Child's name] was only allowed to attend if either my husband or I went also.

Reasons given for their child missing out on sport included:

Time of day of sport session generally causes a low so she has to cease.

On occasion the teacher is unsure what action to take and asks my child to sit out from sport, thinking that is the safest choice.

Communication

In the open-ended questions, some of the participants identified issues associated with communication between the child and teacher, and the school and parent/s. Some participants suggested this lack of communication was due to children or adolescents not wanting to draw attention to themselves and feel different, such as this quote:

She doesn't like drawing attention to herself, especially in relation to her diabetes.

A lack of communication between the teacher and child was also explained in part by the physiological effects of low BGL. One parent commented that when busy with a task, her son '*doesn't recognise the filters to speak up*' when BGL is low. Another participant identified

the issue with communication as being particularly worrying when their child's cognition became impaired when BGL was low. Other parents commented on the need for better communication between the school and home, and particularly related to missed work due to school absence:

... I don't get enough communication from the teachers as to what she should catch up on when she has missed out on school.

However, not all comments were about a lack of communication:

The teachers are very communicative and will call me if unsure.

Support

When asked to discuss school support, several parents commented that their child's school was very supportive. For example:

The school has personally undertaken the support for her outside of the education guidelines.

However, 42% of participants indicated school support for their child with T1D was inadequate. The most common reason provided for this lack of support was teachers' lack of knowledge:

...I have endless issues trying to make the school understand how important certain things are around my daughter's illness.

Participants were concerned about actions that resulted from a lack of knowledge:

... her year 1 teacher... even took her glucose away from her thinking she was eating them like lollies...

While some of the participants identified lack of knowledge as the reason why support was inadequate, others identified teacher disinterest, disorganisation and grumpiness. School support was suggested to be dependent on the individual teacher:

If they (the teachers) have a good attitude to T1D it makes a huge positive difference to the school experience.

This year [my child] has had a very supportive teacher who cared for all her students as 'whole people' and has been very good at supporting our daughter with all her needs.

Other participants described the inability of their child to seek help as a reason for this inadequate support. For example:

[Child's name] is a very quiet girl and finds it hard to express herself. Not letting teachers know how she feels does worry me the most.

Participants mentioned the need for a school nurse on site for at least some of the school day and were concerned that additional staff support was only provided to children until the age of 7 years.

Several parents in the survey referred to the difficulties experienced when their child transitioned from primary to secondary school. This transition period was identified as one in which extra support was required and where a lack of understanding or communication was more likely to occur because of student movement between classes in secondary school. One parent commented:

Transition to high school with different teachers and lots of new classmates has been difficult... We have arrangements for him to have his phone and message me (his) BGLs but teachers question him using his phone and tell him he should be able to do it on his own.

Discussion

This study aimed to describe the mental health and school experiences of children and adolescents living with T1D who are in mainstream education in Western Australia. Results showed that in children with T1D, scores for emotional symptoms and overall psychopathology were significantly above the Australian norms.

These findings confirm previous research which demonstrated that emotional issues are significant in this paediatric group (Bernstein, Stockwell, Gallagher, Rosenthal & Soren, 2013; Dantzer, Swendsen, Maurice-Tison & Salamon, 2003; Zenlea et al., 2014). Research has shown that as many as one in seven adolescents with T1D meet the clinical cut off for depression (Hood et al., 2006), and that significant anxiety is present for between 9 and 19% of the adolescent population with T1D (Goldston et al., 1997; Rechenberg, Whittemore & Grey, 2017). Australian general population data showed that 5% of adolescents experienced depression and 7% of adolescents experienced an anxiety disorder (Lawrence et. al., 2015).

We found that the age of the child was significantly associated with emotional symptoms, with upper secondary (ages 15 to 18) and lower primary (ages 5 to 9) students experiencing higher levels. Much of the research on psychological wellbeing and T1D has been conducted with the adolescent age group but this research has not differentiated between younger and older adolescents. Our findings are somewhat unexpected as upper secondary adolescents are often considered to be more settled emotionally than their younger counterparts. However, this age group are completing secondary education and therefore may be experiencing more school-related stress. The elevated emotional symptoms in the lower primary students may be due to their more recent diagnosis. In contrast to previous research, no significant association was found between gender and emotional symptoms in our study. A ten-year prospective study from diagnosis of T1D, for example, found that adolescents were at high risk for various psychiatric diagnoses and that females were more likely than males to receive a diagnosis (Delamater, 2000).

However, the differences may be due to our study being cross-sectional while the other was longitudinal.

More than half of the participants reported their children experienced difficulties telling their teacher when they were feeling the effects of low BGL. Our research showed that communication between students with T1D and teachers is complicated by several factors, including the physiological aspects of low BGL, the individual needs of students, student responses to having T1D and teacher attitudes. Communication difficulties could be addressed by enhancing self-advocacy and communication skills of students and training school staff to better understand the importance of recognising and managing the early warning signs of hypoglycaemia (Clarke, Jones, Rewers, Dunger & Klingensmith, 2009; Marks, Wilson & Crisp, 2013). School psychologists could also provide functional communication training to students with T1D and to staff and reinforce ways to appropriately communicate medical needs (Kucera & Sullivan, 2011). Involving each student with T1D in the development of their individualised communication plan is likely to assist in T1D management and improve the ongoing relationship between the parents of children with T1D and the school staff. Research is needed to determine the effectiveness of interventions that help students communicate their medical needs during school time.

An average of nine days of school were missed per year by students because of T1D, and 14% missed more than 20 days a year. Students who are absent from school for 20 days or more per year are considered at educational risk (Office of the Auditor General Western Australia, 2015), as regular school attendance is correlated with children's positive self-esteem, healthy peer relationships, and academic progress (Weitzman, 1986). In a recent study undertaken in Western Australia, school attendance in students with T1D was 3% lower than their peers (Cooper, McNamara, de Klerk, Davis & Jones, 2016). For children with a chronic condition, school absenteeism may occur because of the condition itself or psychological factors (e.g. anxiety or depression) that relate to their condition (Spurrier et al., 2000). With current management strategies, near normal school attendance is a reasonable goal for all children with T1D (Glaab, Brown & Daneman, 2005).

This study did not include questions about how much class time is missed due to diabetes management. However, 57% of students in this study felt comfortable using their T1D equipment in the classroom while approximately a third often or very often missed or were late for lunch or breaks. Given school inflexibility is correlated with poor metabolic control of T1D (Newbould, Francis & Smith, 2007), schools need to enable students to manage their diabetes effectively and ensure that school life does not obstruct their illness management (Hayes-Bohn, Neumark-Sztainer, Mellin & Patterson, 2004; Schwartz, Denham, Heh, Wapner & Shubrook, 2010). Future research should explore what contributes to students with T1D feeling sufficiently comfortable to conduct management tasks in the classroom.

The majority of participants commented on the supportive nature of their child's school, whereas 43% felt the support for their T1D child at school was inadequate. Support from

school personnel for children and adolescents with T1D can be affected by various factors including teachers feeling that they are expected to do too much (Lange, Jackson & Deeb, 2009), concern with the amount of time and attention students with T1D require (Olsen, Seidler, Goodman, Gaelic & Nordgren, 2004), and worry about potential liability (Hill & Hollis, 2012). Research has found that schools have declined visits from diabetes educators because they feel they have sufficient knowledge (MacMillan et al., 2014). This view fails to account for the highly individualised nature of T1D and differences in the assistance each child may require at school. For example, there can be significant differences between what students with T1D see as stressful and supportive behaviours by teachers (Nabors, Lehmkuhl, Christos & Andreone, 2003). An individualised approach, developed through communication between the teacher and student, may help to align teacher behaviours to the psychosocial needs of the student.

Wagner and colleagues (2006) found that educating school staff in diabetes management improved glycaemic control of children with T1D. Improving management of T1D at younger ages may enhance management during later adolescence, given the difficulty children report they experience managing their T1D as they move into adolescence (Cafazzo, Casselman, Hamming, Katzman & Palmert, 2012; Kovacs, Charron-Prochownik & Obrosky, 1995). These difficulties may be exacerbated as young people with T1D move from primary school to secondary school. Research has highlighted the vulnerability of adolescents during this period with glycaemic control worsening between the ages of 8 to 18 years of age (Clements et al., 2016) and deterioration in psychosocial measures such as quality of life (Insabella, Grey, Knafl & Tamborlane, 2007). Transition to secondary school is a time when effective communication between the school and the family is vital. Consistent with previous research findings, parents in our study identified a lack of communication between the school and the home as an issue affecting their child's school experience (Lewis, Powers, Goodenough & Poth, 2003; Nabors, Troillet, Nash & Masiulis, 2005).

Providing teachers with information about T1D and its potential impact in the classroom may also help to support students with T1D who are experiencing difficulties in class (Wodrich & Cunningham, 2008). Educating peers may also prove beneficial to students with T1D. Wagner et al. (2006) found that having a "diabetic buddy" or student who assisted the student with their T1D and was educated to recognise signs of hypoglycaemia improved diabetes management and quality of life of the student with T1D. Evidence from various studies suggests that peer interventions improve people with T1D's health behaviour, metabolic control and quality of life (Fisher et al., 2012).

This research is limited by the small self-selected sample, restricting the generalisability of the findings. Data was collected from parents rather than the child with T1D; adolescents may be more inclined to share their thoughts with their peers than their parents. Finally, the use of an online survey may have excluded some potential respondents unable to gain access or unfamiliar with this technology, although it is likely this group will be small. This study did not investigate whether the choices made by parents in relation to their child's diabetes care were influenced by the parent's perceived support at the school. It would be valuable to understand this aspect of diabetes care in a future study.

Conclusion and future research

This research provided evidence of elevated emotional symptoms in children and adolescents with T1D in Western Australia. The data suggest school support for students with T1D to manage their disease is variable and often dependent on the caring nature of individual teachers. Some concern was expressed by parents of poor teacher knowledge of T1D, the impact of the transition to secondary school on their children's management of their T1D and emotional wellbeing, and the lack of communication between school and home. Communication between students with T1D and teachers must also improve so that student medical and psychosocial needs can be attended to.

Further research is needed to determine what type of school staff training is needed to improve their knowledge and communication with parents, and develop skills to provide more tailored support to meet the physical and emotional needs of children and adolescents with T1D at school. Future research also needs to engage with young people with T1D to understand from their perspective what actions schools need to take to enable them to manage their diabetes effectively and communicate their needs to others.

References

- AIHW (Australian Institute of Health and Welfare) (2015). *Prevalence of type 1 diabetes among children aged 0-14 in Australia*. Diabetes series no. 24. Cat. no. CVD 70. Canberra: AIHW. <https://www.aihw.gov.au/reports/diabetes/type1-diabetes-among-children-aged-0-14-2013/contents/table-of-contents>
- Bernstein, C. M., Stockwell, M. S., Gallagher, M. P., Rosenthal, S. L. & Soren, K. (2013). Mental health issues in adolescents and young adults with type 1 diabetes: Prevalence and impact on glycemic control. *Clinical Pediatrics*, 52(1), 10-15. <https://doi.org/10.1177/0009922812459950>
- Cafazzo, J. A., Casselman, M., Hamming, N., Katzman, D. K. & Palmert, M. R. (2012). Design of an mHealth app for the self-management of adolescent type 1 diabetes: A pilot study. *Journal of Medical Internet Research*, 14(3). <https://doi.org/10.2196/jmir.2058>
- Clarke, W., Jones, T., Rewers, A., Dunger, D. & Klingensmith, G. J. (2009). Assessment and management of hypoglycemia in children and adolescents with diabetes. *Pediatric Diabetes*, 10(S12), 134-145. <https://doi.org/10.1111/j.1399-5448.2009.00583.x>
- Clements, M. A., Foster, N. C., Maahs, D. M., Schatz, D. A., Olson, B. A., Tsalikian, E., Lee, J. M., Burt-Solorzano, C. M., Tamborlane, W. V., Chen, V., Miller, K. M. & Beck, R. W. (2016). Hemoglobin A1c (HbA1c) changes over time among adolescent and young adult participants in the T1D exchange clinic registry. *Pediatric Diabetes*, 17(5), 327-336. <https://doi.org/10.1111/pedi.12295>
- Cooper, M. N., McNamara, K. A., de Klerk, N. H., Davis, E. A. & Jones, T. W. (2016). School performance in children with type 1 diabetes: A contemporary population-based study. *Pediatric Diabetes*, 17(2), 101-111. <https://doi.org/10.1111/pedi.12243>
- Dantzer, C., Swendsen, J., Maurice-Tison, S. & Salamon, R. (2003). Anxiety and depression in juvenile diabetes: A critical review. *Clinical Psychology Review*, 23(6), 787-800. [https://doi.org/10.1016/S0272-7358\(03\)00069-2](https://doi.org/10.1016/S0272-7358(03)00069-2)

- Delamater, A. M. (2000). Quality of life in youths with diabetes. *Diabetes Spectrum*, 13, 42-46. <http://journal.diabetes.org/diabetesspectrum/00v13n1/pg42.htm>
- Fisher, E. B., Boothroyd, R. I., Coufal, M. M., Baumann, L. C., Mbanya, J. C., Rotheram-Borus, M. J., Sanguanprasit, B. & Tanasugarn, C. (2012). Peer support for self-management of diabetes improved outcomes in international settings. *Health Affairs*, 31(1), 130-139. <https://doi.org/10.1377/hlthaff.2011.0914>
- Glaab, L. A., Brown, R. & Daneman, D. (2005). School attendance in children with type 1 diabetes. *Diabetic Medicine*, 22(4), 421-426. <https://doi.org/10.1111/j.1464-5491.2005.01441.x>
- Goldston, D. B., Kelley, A. E., Reboussin, D. M., Daniel, S. S., Smith, J. A., Schwartz, R. P. & Hill, C. (1997). Suicidal ideation and behavior and noncompliance with the medical regimen among diabetic adolescents. *Journal of the American Academy of Child & Adolescent Psychiatry*, 36(11), 1528-1536. [https://doi.org/10.1016/S0890-8567\(09\)66561-8](https://doi.org/10.1016/S0890-8567(09)66561-8)
- Goodman, R. (2001). Psychometric properties of the Strengths and Difficulties Questionnaire. *Journal of the American Academy of Child & Adolescent Psychiatry*, 40(11), 1337-1345. <https://doi.org/10.1097/00004583-200111000-00015>
- Goodman, R., Ford, T., Simmons, H., Gatward, R. & Meltzer, H. (2003). Using the Strengths and Difficulties Questionnaire (SDQ) to screen for child psychiatric disorders in a community sample. *International Review of Psychiatry*, 15(1-2), 166-172. <https://doi.org/10.1080/0954026021000046128>
- Hawes, D. J. & Dadds, M. R. (2004). Australian data and psychometric properties of the Strengths and Difficulties Questionnaire. *Australian and New Zealand Journal of Psychiatry*, 38(8), 644-651. <https://doi.org/10.1080/j.1440-1614.2004.01427.x>
- Hayes-Bohn, R., Neumark-Sztainer, D., Mellin, A. & Patterson, J. (2004). Adolescent and parent assessments of diabetes mellitus management at school. *Journal of School Health*, 74(5), 166-169. <https://doi.org/10.1111/j.1746-1561.2004.tb08215.x>
- Hill, N. J. & Hollis, M. (2012). Teacher time spent on student health issues and school nurse presence. *The Journal of School Nursing*, 28(3), 181-186. <https://doi.org/10.1177/1059840511429684>
- Hood, K. H., Huestis, S., Maher, A., Butler, D., Volkening, L. & Laffel, L. M. B. (2006). Depressive symptoms in children and adolescents with type 1 diabetes. *Diabetes Care*, 29(6), 1389-1389. <https://doi.org/10.2337/dc06-0087>
- Insabella, G., Grey, M., Knafl, G. K. & Tamborlane, W. V. (2007). The transition to young adulthood in youth with type 1 diabetes on intensive treatment. *Pediatric Diabetes*, 8, 228-234. <https://doi.org/10.1111/j.1399-5448.2007.00266.x>
- Kucera, M. & Sullivan, A. L. (2011). The educational implications of type 1 diabetes mellitus: A review of research and recommendations for school psychological practice. *Psychology in the Schools*, 48(6), 587-603. <https://doi.org/10.1002/pits.20573>
- Kovacs, M., Charron-Prochownik, D. & Obrosky, D. S. (1995). A longitudinal study of biomedical and psychosocial predictors of multiple hospitalizations among young people with insulin-dependent diabetes mellitus. *Diabetic Medicine*, 12(2), 142-148. <https://doi.org/10.1111/j.1464-5491.1995.tb00445.x>

- Lange, K., Jackson, C., & Deeb, L. (2009). Diabetes care in schools – the disturbing facts. *Pediatric Diabetes*, 10(s13), 28-36. <https://doi.org/10.1111/j.1399-5448.2009.00613.x>
- Lawrence, D., Johnson, S., Hafekost, J., Boterhoven De Haan, K., Sawyer, M., Ainley, J., Zubrick, S. R. (2015). *The mental health of children and adolescents. Report on the second Australian Child and Adolescent Survey of Mental Health and Wellbeing*. Department of Health, Canberra. <http://www.health.gov.au/internet/main/publishing.nsf/Content/mental-pubs-m-child2>
- Lewis, D. W., Powers, P. A., Goodenough, M. F. & Poth, M. A. (2003). Inadequacy of in-school support for diabetic children. *Diabetes Technology & Therapeutics*, 5(1), 45-56. <https://doi.org/10.1089/152091503763816463>
- MacMillan, F., Kirk, A., Mutrie, N., Matthews, L., Robertson, K. & Saunders, D. H. (2014). A systematic review of physical activity and sedentary behavior intervention studies in youth with type 1 diabetes: Study characteristics, intervention design, and efficacy. *Pediatric Diabetes*, 15(3), 175-189. <https://doi.org/10.1111/pedi.12060>
- Marks, A., Wilson, V. & Crisp, J. (2013). The management of type 1 diabetes in primary school: Review of the literature. *Issues in Comprehensive Pediatric Nursing*, 36(1-2), 98-119. <https://doi.org/10.3109/01460862.2013.782079>
- Mellor, D. (2005). Normative data for the Strengths and Difficulties Questionnaire in Australia. *Australian Psychologist*, 40(3), 215-222. <https://doi.org/10.1080/00050060500243475>
- Nabors, L., Lehmkuhl, H., Christos, N. & Andreone, T. L. (2003). Children with diabetes: Perceptions of supports for self-management at school. *Journal of School Health*, 73(6), 216-221. <https://doi.org/10.1111/j.1746-1561.2003.tb06563.x>
- Nabors, L., Troillet, A., Nash, T. & Masiulis, B. (2005). School nurse perceptions of barriers and support for children with diabetes. *Journal of School Health*, 75(4), 119-124. <https://doi.org/10.1111/j.1746-1561.2005.tb06655.x>
- Newbould, J., Francis, S. & Smith, F. (2007). Young people's experiences of managing asthma and diabetes at school. *Archives of Disease in Childhood*, 92(12), 1077-1081. <https://doi.org/10.1136/adc.2006.110536>
- Office of the Auditor General Western Australia (2015). Western Australian auditor general's report follow-on: Managing student attendance in Western Australian public schools. Perth, p.7. <https://audit.wa.gov.au/reports-and-publications/reports/follow-managing-student-attendance-western-australian-public-schools/>
- Olson, A. L., Seidler, A. B., Goodman, D., Gaelic, S. & Nordgren, R. (2004). School professionals' perceptions about the impact of chronic illness in the classroom. *Archives of Pediatrics & Adolescent Medicine*, 158(1), 53-58. <https://doi.org/10.1001/archpedi.158.1.53>
- Persson, S., Dahlquist, G., Gerdtham, U-G. & Carlsson, K. (2013). Impact of childhood-onset type 1 diabetes on schooling: A population-based register study. *Diabetologia*, 56(6), 1254-1262. <https://doi.org/10.1007/s00125-013-2870-8>
- Rechenberg, K., Whittemore, R. & Grey, M. (2017). Anxiety in youth with type 1 diabetes. *Journal of Pediatric Nursing*, 32, 64-71. <https://doi.org/10.1016/j.pedn.2016.08.007>

- Schwartz, F. L., Denham, S., Heh, V., Wapner, A. & Shubrook, J. (2010). Experiences of children and adolescents with type 1 diabetes in school: Survey of children, parents, and schools. *Diabetes Spectrum*, 23(1), 47-55. <https://doi.org/10.2337/diaspect.23.1.47>
- Spurrier, N. J., Sawyer, M. G., Staugas, R., Martin, A. J., Kennedy, D. & Streiner, D. L. (2000). Association between parental perception of children's vulnerability to illness and management of children's asthma. *Pediatric Pulmonology*, 29(2), 88-93. [https://doi.org/10.1002/\(SICI\)1099-0496\(200002\)29:2%3C88::AID-PPUL2%3E3.0.CO;2-D](https://doi.org/10.1002/(SICI)1099-0496(200002)29:2%3C88::AID-PPUL2%3E3.0.CO;2-D)
- Wagner, J., Heapy, A., James, A. & Abbott, G. (2006). Brief report: glycemic control, quality of life, and school experiences among students with diabetes. *Journal of Pediatric Psychology*, 31(8), 764-769. <https://doi.org/10.1093/jpepsy/ksj082>
- Weitzman, M. (1986). School absence rates as outcome measures in studies of children with chronic illness. *Journal of Chronic Diseases*, 39(10), 799-808. [https://doi.org/10.1016/0021-9681\(86\)90082-2](https://doi.org/10.1016/0021-9681(86)90082-2)
- Wodrich, D. L. & Cunningham, M. M. (2008). School-based tertiary and targeted interventions for students with chronic medical conditions: Examples from type 1 diabetes mellitus and epilepsy. *Psychology in the Schools*, 45(1), 52-62. <https://doi.org/10.1002/pits.20278>
- Zenlea, I. S., Mednick, L., Rein, J., Quinn, M., Wolfsdorf, J. & Rhodes, E. T. (2014). Routine behavioral and mental health screening in young children with type 1 diabetes mellitus. *Pediatric Diabetes*, 15(5), 384-388. <https://doi.org/10.1111/pedi.12099>

Appendix 1: Diabetes specific questions

Questions	
1	At what age was your child diagnosed with diabetes?
2	Do you or anyone else in your child's immediate family have Type1 Diabetes? Who?
3	What is your child's treatment?
<i>If child uses pump:</i>	
3.1	How old was your child when they started using a pump?
3.2	Does the beeping of your child's pump bother them at school?
3.3	Is your child able to manage all aspects of their pump at school without adult assistance? If not, in which areas does your child require help?
4	In the last 12 months, has your child has episodes of severe hypoglycaemia? If yes, where did these take place?
5	Where does your child feel most comfortable using their diabetes equipment during school times?
6	Does your child feel comfortable about their classmates seeing them use their diabetes equipment at school?
7	In what school year did you feel that your child was competent to manage their own diabetes at school?
8	Has your child ever found it difficult to tell their teacher or other staff at school that they are feeling 'low'?
9	Does your child feel that there is someone who can help them if they feel unwell at school? Who is this person?
10	How often has your child been late or missed part of recess/lunch with their friends because of managing their diabetes?
11	Thinking back to the last school year, excluding school holidays, how many days was your child absent from school specifically because of their diabetes, which includes hospitalisation, appointments, treatment or sick days?
12	Does your child's diabetes limit them in participating in voluntary school activities such as leadership, volunteering for an activity or contributing to class discussions?
13	It is known that some children may miss out on sports at school because of their diabetes. How often does this happen to your child? Why has this happened?
14	It is known that some children may miss out on school camps because of their diabetes. How often does this happen to your child? Why has this happened?
15	It is known that some children may miss out on school excursions because of their diabetes. How often does this happen to your child? Why has this happened?
16	Because of their diabetes, how often has your child been unwilling or unable to participate in extracurricular activities such as music, arts or drama activities?
17	Does your child's diabetes result in difficulties in your child's ability to make or maintain friendships?

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<http://www.iier.org.au/iier28/fried.pdf>