

Unsafe at School: Advocating for children with type 1 diabetes

Recent research has confirmed the deleterious effects that glucose extremes have on a child's learning, yet BC still has no province-wide standard of care for diabetic students.

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Type 1 diabetes (T1D) is a chronic, life-threatening autoimmune disorder that affects children of all ages. Before the discovery of insulin, T1D was fatal. Today children with T1D face a lifetime of insulin injections and require daily monitoring and treatment to keep blood glucose levels as close to normal as possible.

Unsafe at School is a group of parents concerned about the lack of support in BC schools for children with type 1 diabetes. Lila Yewchuk is a pediatric radiologist at BC Children's Hospital in Vancouver and a clinical instructor in the Department of Radiology at the University of British Columbia. John Paul Morrison is a technology consultant and children's rights advocate committed to helping children with diabetes receive the support they require in school. Scott Yewchuk is a teacher of English and physical education at Semiahmoo Secondary School in Surrey, BC.

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Although there is an abundance of promising research, the cause of T1D is unknown and there is currently no cure.

Worldwide, T1D affects millions of adults and at least 440 000 children under the age of 14, with 70 000 children newly diagnosed each year.¹ More than 300 000 Canadians live with type 1 diabetes.¹ Its incidence is increasing by 3% to 5% annually, with the greatest rise occurring in children aged 5 to 9.¹ In Ontario alone, the incidence of T1D increased by 48% between 1992 and 2002.² In British Columbia in 2004, the prevalence of T1D was estimated to be 0.15%, or 1477 children aged 0 to 18.³ According to researchers, incidence is expected to double in children younger than 5 by 2020.⁴

The goal in diabetes management is to optimize blood glucose control using hemoglobin A1c targets—a more precise measurement of blood glucose that tracks changes over 3 to 4 months. The aim is to avoid hyperglycemia (high blood glucose) and its well-documented, long-term microvascular consequences (including heart attack, stroke, kidney failure, blindness, amputation) while minimizing hypogly-

cemia (low blood glucose). Encouragingly, recent studies reveal that a 1% reduction in A1c lowers the risk of microvascular complications by 40%.⁴

Glucose extremes in children with T1D

In adults with T1D, the detrimental effect of acute glucose extremes on motor function and cognition is well documented.⁵ Until recently, however, few studies were undertaken to examine the effects of acute blood glucose fluctuations in children, likely because of a reluctance to induce extreme glucose levels, and possible neurological insults, in younger patients with developing brains. However, glucose fluctuations more extreme than those induced in studies occur routinely outside of the laboratory; these naturally occurring episodes of acute hypo- and hyperglycemia during daily routine have been shown to cause cognitive-motor disruptions in school-aged children.⁶

Recent research is uncovering the deleterious effects that glucose extremes have on a child's learning. Repeated hypoglycemia has been found to reduce spatial intelligence and delayed recall in children with T1D.^{6,7}

In these same children, increased exposure to hyperglycemia reduces verbal intelligence and slows mental efficiency.⁷ Hyperglycemia, not hypoglycemia, is “associated with adverse effects on the brain polyol pathway activity, neuronal structural changes, and impaired long-term spatial memory. This finding suggests that the hyperglycemic component of diabetes mellitus has a greater adverse effect on brain functioning than does intermittent hypoglycemia.”⁸⁻¹⁰ This is echoed by the Canadian Diabetes Association (CDA) statement: “studies have found chronic hyperglycemia in young children [is] associated with poorer cognitive performance.”¹¹

Correcting high blood glucose is therefore essential for a child’s long-term health and learning needs.

Managing T1D in school-aged children

The Canadian Diabetes Association’s 2008 clinical practice guidelines describe insulin therapy as the mainstay of medical management of type 1 diabetes and emphasize tight glycemic control for patients with T1D.¹¹ The guidelines make special mention of the pediatric population living with T1D: “regardless of the insulin regimen used, all children should be treated to meet glycemic targets.”¹¹

A statement from the American Diabetes Association (ADA)¹² also stresses the need to manage diabetes in children aged 6 to 12, which is described as a “particularly challenging” age group:

Many require insulin administration while at school, which demands flexibility and close communications between the parents, the health care team, and school personnel.¹³ The lack of abstract thinking in most children of this age limits management choices and dictates that parents or other adults make most of the treatment decisions. While children in

this age group may be more able to recognize and self-treat hypoglycemia, close adult supervision is still required... The ability of most children of this age to recognize, report, and seek treatment for hypoglycemia, combined with an absence of insulin resistance and psychological issues associated with puberty, makes this age group perhaps the most amenable to intensive glucose control. An A1c goal of $\leq 8\%$... is recommended.¹²

While the Canadian Diabetes Association also recommends an A1c goal of $< 8\%$ in 6- to 12-year-old children, the International Society for Pediatric and Adolescent Diabetes recommends $< 7.5\%$ for all age groups.^{11,14} In all cases, children should have their A1c targets determined individually.

For young Canadian children with T1D, receiving assistance with insulin administration while at school is rare, meaning that hyperglycemia can go untreated. This increases the risk for long-term chronic complications of the disease as well as for neurocognitive learning impairments that may appear immediately.⁶

Canada’s contribution to T1D management

In 1922, Canadian surgeon Frederick Banting and his colleagues discovered insulin, which led to one of the most important health care advances of the 20th century. Since that time, Canada has been a leading country in the area of diabetes research.¹⁵ The first continuous glucose monitor (CGM), a sensor and transmitting device used to communicate with the insulin pump, was developed in Toronto in the mid 1970s. In conjunction with the US, Canada conducted the ground-breaking Diabetes Control and Complications Trial (DCCT), a comprehensive 10-year study ending in 1993 that clearly demonstrated the importance of glycemic control in preventing micro-

vascular complications of T1D. This control was attained through intensive insulin therapy (more frequent insulin dosing), not conventional treatment (twice-daily insulin dosing).¹⁶ This trial has been referred to as “the study that forever changed the nature of treatment of T1D”¹⁷ by revealing the need for better management.

It is through intensive insulin therapies, such as the insulin pump and multiple daily insulin injections, that many children with T1D now experience the best glycemic control. When insulin is administered at a low level all day long by either of these methods, it is possible to do as the DCCT recommends: Improve glycemic control with the “reproduction of physiological insulin secretion.”¹⁶ The 2010 landmark STAR 3 trial, a 1-year multicentre randomized controlled trial that compared the efficacy of sensor-augmented pump therapy with that of multiple daily insulin injections in 485 adults and children with type 1 diabetes, concluded that “in both adults and children with inadequately controlled type 1 diabetes, sensor-augmented pump therapy resulted in significant improvement in [(A1c)] levels, as compared with injection therapy.”¹⁸ STAR 3 is the first study that confirms sensor-augmented insulin pump therapy provides superior glucose control for children and adolescents, an age group that is particularly challenging to treat because of the social and physiological changes caused by growth and maturation. In STAR 3, nearly 44% of pediatric patients using sensor-augmented insulin pump therapy achieved the American Diabetes Association’s age-specific glucose control targets, compared with only 20% of patients in the multiple daily injection group.¹⁸ It is the longest and largest diabetes device trial of its kind, redefining what should be the standard of care for diabetes management. “For the first time, with the sensor-augmented insulin pump, adults,

Continued on page 234

Continued from page 233

children and teens had a sustained improvement in A1c levels, which can greatly reduce the risk of complications from diabetes.”¹⁹

While both the CDA and ADA promote optimal glycemic control in diabetes, only American children receive the support they need at school.²⁰ The American Diabetes Association initiated the Safe at School campaign, which resulted in a statement of principles to ensure children with T1D are guaranteed freedom from discrimination and access to medically necessary support while at school. Recognizing that “diabetes must be managed 24 hours a day, 7 days a week,” this support includes the administration of insulin and glucagon (a life-saving medicine used to treat emergency hypoglycemic reactions) and school assistance for young children not able to care for themselves.²¹ Meanwhile, Canada has the fourth highest incidence of T1D, ranking ahead of Norway, the United Kingdom, and the US,²² and yet to date, no Canadian diabetes organization has actively endorsed the Safe at School principles.

Although Canada is on the cutting edge of diabetes research and has made astounding contributions toward improving diabetes care, and although the CDA continues to lobby at the provincial and territorial levels for legislative change regarding safety at school,²⁰ children with T1D still do not receive the medical treatment they require while at school. It is common to find Canadian children on traditional insulin therapies and not on newer intensive regimens just so that they can attend public school. Traditional regimens have fewer insulin injections and do not require a lunch-time insulin bolus; the result of this is convenience for school personnel. But this means children must fit into the school, instead of the school meeting their care needs. The insulin strategies currently promoted by Canadian schools (twice-daily dosing) “rarely

achieve optimal glycemic control because... they do not provide physiological or flexible insulin replacement... and may increase the risk of hypoglycemia.”¹⁶

Given Canada’s high incidence of T1D and the country’s legacy as a world innovator in diabetes treatment, it is both ironic and tragic that Canadian policy has not kept pace with medical recommendations to ensure children receive care essential to them while at school.

The cost of inadequate care at school

If children with T1D do not receive proper medical support during school hours, the impact of this substandard care can reach beyond the child to the family, the classroom, and society. Families can suffer hardship as one parent is required to leave the workforce to attend to the child at school. Classrooms can be disrupted by the regular visits that diabetes care requires, and teachers can be distracted by the need to monitor the safety of the diabetic child. In addition, the cost to the health care system is substantial. Diabetes and its complications cost the Canadian economy more than \$17.4 billion a year, with type 1 diabetes being the leading cause of adult blindness, stroke, heart disease, nerve damage, and amputation.¹ In addition, diabetic nephropathy occurs in 20% to 40% of patients.²³ For those diabetics with kidney disease, the average cost of dialysis treatment is \$50 000 a year. The one-time cost of a kidney transplant in BC is approximately \$20 000, with an additional yearly cost of about \$6000 for antirejection medications.²⁴ Proper glycemic control, something not independently achievable in young children, is proven to reduce or eliminate these complications.

The right to reasonable accommodation

Apart from the medical implications, there are legal implications should a

diabetic student be harmed or die because of insufficient care at school. Although children with T1D are considered disabled by the federal government, and classified by the BC Ministry of Education as “physically disabled, chronic health impaired” (Level 2 D),²⁵ these children do not always receive the accommodation they need. Until policy change occurs and a better standard of care is set, children with T1D will continue to face discrimination. Schools must provide appropriate medical treatment for each diabetic child to achieve glycemic target goals regardless of what insulin regimen is used. The health, safety, educational potential, and emotional well-being of these children depends on it.

Under the Canadian Charter of Rights and Freedoms, every citizen, including those with disabilities, has the right to equal protection and benefit without discrimination.²⁶ In the case of female firefighter Tawney Meiorin, the Supreme Court of Canada outlined steps to eliminate discriminatory conditions and satisfy the “duty to accommodate.”²⁷ In another case involving a 9-year-old boy with autism, *Hewko v. BC*, Madame Justice Koenigsberg stated that “reasonable accommodation is an integral part of the [school’s] duty to consult”²⁸ and found that the Abbotsford School District did not “meaningfully consult” with the boy’s family. Reasonable accommodation, as demonstrated in this case, involves providing a standard of care at school that reflects the care provided at home to ensure a “consistent educational program” for the child.²⁸

For children with T1D, a “consistent educational program” would have staff trained in diabetes care to complement the care that the children receive at home. However, this is presently not the case. Current provincial Nursing Support Services (NSS) policy asserts that the care children with T1D need to safely attend school, namely the provision of insulin and

glucagon administration, cannot be provided safely by an education aide. While this policy may be the result of licensure concerns, the larger question raised is: Does such a policy directly or indirectly negatively affect children with T1D in a way prohibited in the Canadian Human Rights Act?²⁹ Another case involving disabilities and the duty to accommodate, the Grismer case, suggests it is reasonable to ask if the argument that aides cannot “safely” care for a child with T1D has a bona fide justification, especially in light of the fact that some BC school districts currently permit staff to be trained in the administration of insulin and glucagon. Has the policy put forth by the NSS taken into account how these services could be provided safely, or is this belief based on “impressionistic assumptions”?³⁰

For students with T1D, the present NSS care plan policy does not consider the negative impact on learning or health that results when aides cannot give insulin promptly to treat hyperglycemia. The current policy is unreasonable in that it forces families with young diabetic children to attend their children at school regularly, and if this is not possible, to choose an insulin regimen for their children that they might not choose otherwise. The potential loss of glycemic control and, consequently, “instructional control,”²⁸ raises the question asked in Grismer: Must all students “meet a single policy standard, or could varying standards be adopted”³⁰ to meet the diverse needs of students? If varying standards can be adopted, then all children with type 1 diabetes could be accommodated at school and see cognitive and health benefits that would ultimately allow them to be more receptive to learning.

In March 2010, Canada’s Parliament ratified the United Nations Convention on the Rights of Persons with Disabilities. All provinces and territories are now bound by the convention, which among other rights ensures that

“effective individualized support measures are provided in environments that maximize academic and social development, consistent with the goal of full inclusion.”³¹

Barriers to care

Being a student with type 1 diabetes in a BC school brings with it many risks. For those too young to self-manage, the risks are even greater. Currently, there is no province-wide standard of care for diabetic students and therefore no province-wide safety plan to ensure their well-being. Although the School Act includes general principles regarding care for children with health designations, and NSS has guidelines for training school personnel to deliver care in elementary schools, care is delivered inconsistently and limited provisions are made for those unable to self-manage.

As a result, the care that children with T1D currently receive depends on five things:

- Which school district they are in.
- Which school within the district they attend.
- The nursing support available for that school.
- The principal in charge of that school.
- Whether the parents can advocate effectively for their child.

Overall, children receive vastly different care, with many receiving none. Most serious is the province-wide denial of the two critical components of diabetes care: insulin and glucagon administration. Consequently, parents often fear for the safety of their children while at school.

Current NSS guidelines do not reflect the seriousness of the impact diabetes can have on children’s health and learning. Compounding this problem, the policy for health designations in schools falls under three ministries: Health, Education, and Children and Family Development. In addition to these challenges, BC’s endocrinologists do not agree on school care, with some concerned that supporting in-

sulin therapy and glucagon administration at the school level will directly tax their clinical resources. Consequently, parents who want intensive therapies, such as an insulin pump, must prove they have the means to personally support a child at school. Otherwise, they must wait several years until a child can self-manage—years when irreversible damage may occur.

Another barrier to care involves concerns for the liability of those administering insulin to children, and the belief that insulin therapy and glucagon injection are “too dangerous” for school personnel. Although aides provide medical support for students with physical disabilities and administer other injectable medications such as epinephrine, a life-saving injection for severe allergic reactions, the perception is that diabetes management is “too difficult.” In fact, insulin administration is a skill that can be easily taught to school personnel; the cost is negligible as extra funding is provided for the care of diabetic children. Glucagon administration, a skill parents typically learn in one teaching session lasting 10 to 15 minutes, can also be taught.

A possible solution

In an effort to improve support at school, a small number of BC families have already effected change for their children and proven that a new standard of care is possible. In five school districts, six students aged 6 to 8 now have working care plans that were negotiated independently. In these plans, insulin therapy is administered by an aide trained by a nurse who is a certified diabetes educator. The aide is covered under current liability insurance provided to CUPE members. Management is clearly delineated with phone support from the parent. The result is that students have greater independence, classes have fewer disruptions, parents can remain in the workforce, and students have the best

Continued on page 236

Continued from page 235

possible conditions for health and learning.

This solution could be a province-wide one, since funding is already attached to students with diabetes, and the number of students requiring aides to administer insulin is relatively small—likely only 300 of the 600 children aged 5 to 12 on insulin pumps (written communication from Dr Daniel Metzger, endocrinologist at BC Children's Hospital, and Dr Sue Stock, endocrinologist at Lions Gate Hospital, 22 February 2012).

A policy that (1) allows school personnel to be trained to administer insulin and glucagon, and (2) requires the NSS to hire or train nurses who are certified diabetes educators, would give school districts the capacity to properly support diabetic students. If this is not possible, using outside agencies for medical care, an existing practice in BC schools, could meet this need.

In the past, children diagnosed with T1D lived highly regimented lives. They used “assigned fixed doses of insulin and had to follow a fixed meal schedule to fit the insulin regime.”¹⁶ However, as shown by the DCCT, glycemic control was rarely optimal using these traditional therapies. With the advent of methods that reproduce physiological insulin secretion, those living with type 1 diabetes today can have better quality of life and improved glucose control, through insulin therapies that fit their individual needs.

If schools will accommodate individual needs, then young children—who have the greatest number of years to live with diabetes and incur its complications—can live longer, healthier lives. Ultimately, improving the care that school-aged children with T1D receive in Canada will result in a healthier and more prosperous nation.

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BCMA insurance: Defining “earned income”

Your earned income is a factor in determining how much coverage you are eligible to receive when you apply for disability insurance, and it is also used in calculating your entitlement to disability benefits at the time of claim. Earned income is calculated differently for insurance purposes than it is for income tax purposes.

Our disability insurer (Sun Life Financial) has well-established procedures in place to calculate earned income, which take into consideration the amount paid to you by your professional corporation (salary and bonus) and the net income or loss of the professional corporation, which is attributable to you. This calculation assumes that the performance of your professional services is the sole source of revenue to the corporation. If you change from a sole practitioner to an incorporated practice with no change in expenses it will not alter your earned income for the purposes of disability insurance.

What about corporate dividends paid to a physician?

When calculating earned income for disability insurance, dividends are not considered earned income since they are paid from the professional

corporation’s retained earnings. Dividends are just the distribution of the net income of the professional corporation that has already been included as income to you. See the **Table** for a sample calculation.

Earned income for the Physicians’ Disability Insurance plan (PDI)

To determine your eligible monthly PDI benefit, both your practice type and your earned income are considered. Earned income is calculated annually as of 1 April and includes your prior calendar year earnings, consisting of fee-for-service billings, sessional payments, or non-salaried income under a service contract.

The information provided here is not legal or financial advice; you should consult your attorney or accountant with any questions about professional corporations.

For a complimentary review of your insurance coverage by a non-commissioned BCMA insurance advisor, please contact Ms Julie Kwan at 604 638-8745 or 1 800 665-2262 ext. 8745 or e-mail jkwan@bcma.bc.ca.

—Sinden Malinowski
Manager, Insurance

Table. Sample calculation of earned income.

Income for insurance purposes vs. income for tax purposes	Year 1	Year 2
A Corporate income before owner compensation and tax.	150 000	150 000
B Physician’s draw (salary plus bonus).	100 000	100 000
C Net corporate income before tax.	50 000	50 000
D Physician’s actual dividends from retained earnings.	—	20 000
Earned income for insurance purposes (B plus C)	150 000	150 000
Physician’s income for tax purposes (B plus D)	100 000	120 000

Pulsimeter continued on page 252