NOTHING TO “SUGARCOAT”: EIGHT ELEMENTARY SCHOOL
TEACHERS’ PERSPECTIVES OF PROMOTING DIABETES SELF-CARE IN
THEIR CLASSROOMS

by

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ABSTRACT

School-aged children with diabetes face the need to develop self-care skills while at school and in relation to other educational, parental, and health care agents. This thesis offers a qualitative picture of how eight elementary teachers perceived their caregiving role and corresponding experiences relating to the development of self-care in students with diabetes mellitus (DM) in two provinces: Ontario and New Brunswick.

Participants were purposefully recruited from a School District in a mid-sized city in New Brunswick (N = 4) and two Boards of Education in a mid-sized Ontario city (N = 4). Eight teachers who had at least previous experience in caring for a student with diabetes at school participated in a 90-minute, one-on-one, in-depth interview. Employing a Husserlian phenomenological research design and using an iteration of inductive, thematic analysis, the main themes arising from the interviews encompassed: roles and responsibilities, communication, inclusionary practices, and coping with care.

Educational, parental, and health care agents in relation with students with diabetes encompass a range of roles and responsibilities at school. With the adoption of official duties of care, these care agents must communicate with each other to circulate health information quickly and effectively and to develop health literacy. However, the movements of health information reflect the implicit motivations of care agents to navigate the school environment according to medical, social, and biopsychosocial notions of disability and forms of inclusive education. As a result, care agents of students with diabetes must choose approaches, steps, and strategies in their practice to help students and themselves cope with diabetes care.
ACKNOWLEDGING THE PROCESS OF RESEARCHER SELF-CARE

Roughly two years ago, I entered into conversation with Dr. John Freeman for the first time to explore what it might be like to pursue personal growth as a researcher at Queen’s University. At that time, my interests were groomed from sustained inquiry within the tradition of humanities scholarship. I had little idea about the spectrum of educational research and how such diversity within the educational research tradition could prove resourceful in addressing several lingering questions I had. Little did I know then that my initial meeting with Dr. Freeman would turn into an educationally transformative journey with him and through Queen’s Faculty of Education. These acknowledgments aim to recognize and appreciate those who have supported me throughout this process, but my gratitude to these people extends far beyond the space given to them here.

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Through each of your embodied examples, I have learned that self-care is an ongoing personal commitment never to tire.

My heartfelt sentiments to all!
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PROLOGUE

I fondly recall my Grade 1 teacher. She had blonde, wispy hair, attentive eyes, along with a calm and reassuring demeanour. She made me feel that diabetes was not a limitation to my schooling, but an opportunity to enrich understanding about human life as a whole and to grow along with others in their diversity, too. If I could go back in time and ask Mrs. F questions about how she felt in the process of caring for me through my experience of pre- and post-diagnosis during the school year, the need to understand her perspective would contribute towards some degree of personal resolution on the matter and would offer an enriching perspective for many others who share in the everyday struggles to care for diabetes. Unfortunately, that option is no longer available, so, in this thesis, I have turned to other teachers to tell their stories.
CHAPTER 1: INTRODUCTION

As an individual who lives with Type 1 diabetes mellitus (DM), I have been touched by the experience of a medically-dependent chronic illness, and further intimately linked to the chronicled nature of the diabetes histories of others. Whether these chronicles relate to my own life with diabetes; to the diabetes of children I have come to teach and to care for over the years as an educator; or to the diabetes of children for whom people have cared in their everyday lives, these chronicles are, at bottom, representations of encounters. Some caregivers have told me about their ongoing struggles with the care, while others have remarked about their fond memories of accomplishments as a caregiver. These individuals have shared their stories about what makes the caring experience sometimes discomforting, at times manageable, and, in other contexts, uplifting.

I have entered into this study with a long history of living with diabetes marked by deeply psychological trials and tribulations, while also seeing the need to understand the bigger picture of how the family, education, and health systems work and interact with one another to help children with diabetes navigate in their school environments. I have organized my experience in graduate school to construct a systematic and in-depth inquiry aimed to address personal biases that have blocked me from seeing a different side to the story of diabetes care. Through a pilot study and the practice of reflective journalling and debriefing, I have attempted to understand my own biases, but have learned in the process that caregiving is never a singular endeavour nor is it limited to contexts of health care. Diabetes care involves both self and others.
Purpose of the Study

The purpose of this study was to understand how elementary teachers perceived their caregiving role and corresponding experiences relating to the development of self-care in students with diabetes mellitus (DM) in two provinces: Ontario and New Brunswick. I have selected Ontario and New Brunswick as focal provinces for this study because each province offers a contrasting model for diabetes care at school, according to the respective provisions of School Health Support Services (SHSS) provincial policy.

The guiding research questions in this inquiry were:

- What factors and experiences shape teachers’ interactions with students with diabetes in the development of self-care?
- According to the interviewed teachers, how do other stakeholders (e.g., students with diabetes, their parents, other school personnel, and health care professionals) contribute to teachers’ abilities to support the challenge of teaching children with diabetes to develop self-care?
- How do teachers understand students’ narratives of their chronic illness and integrate these understandings into their support for self-care?
- What texts (e.g., policy documents, curriculum documents, medical documents, training resources, medical technologies) do teachers report that they encounter and make meaning from to inform their practice of teaching children to care for their diabetes in the school setting?

These research questions were used to structure my interview questions for the study. As such, they provided my initial ideas about what I might find. My analyses, however, while reflecting these questions due to their use in the interview, were primarily informed...
by the participants’ own understandings as shown in the four themes used in the results chapters and the discussion.

Definitions of Key Terms

Several terms used in this study were and are still commonly practiced in the fields of health care, educational philosophy, and educational programs and services. In that everyday words often carry a multiplicity of meanings connected to specific places and times (Creswell, 2009), I have defined four terms as they are used throughout this study: (i) diabetes mellitus; (ii) hyperglycemia; (iii) hypoglycemia; and (iv) school health support services.

Diabetes Mellitus (DM)

The World Health Organization (WHO, 2014) defines diabetes mellitus (DM) as “a chronic disease, which occurs when the pancreas does not produce enough insulin, or when the body cannot effectively use the insulin it produces.” The two most prevalent types of DM are Type 1 and Type 2. Whereas Type 1 DM (T1DM) is characterized by a lack of insulin production, T2DM is caused by the body’s ineffective use of insulin. T1DM develops most frequently in children and adolescents, but it may set in later in life (Rock, 2003). Children under 10 years of age, teenagers, and adults in their 20s and 30s are increasingly being diagnosed for T2DM (Fagot-Campagna et al., 2000).

Hyper- and Hypoglycemia

The term hyperglycemia is used to refer to a diabetes-related syndrome that results from insulin deficiency or interference with its action (insulin resistance), or both. It describes high blood sugar levels, which produce polyuria (frequent urination), polydipsia (increased thirst), and polyphagia (increased hunger). Frequent and
excessively long durations of hyperglycemia lead to elevated levels of Hemoglobin (HbA$_{1c}$ $\geq$ 7.0%; Canadian Diabetes [CDA], 2013). Conversely, the term hypoglycemia designates a diabetes-related syndrome that occurs when there is an abnormally diminished content of glucose in the blood. Its principal problems arise from an inadequate supply of glucose to the brain, resulting in impairment of function (neuroglycopenia).

**School Health Support Services (SHSS)**

The term *school health support services* (SHSS) is used to designate the provision of educational services for school children with health support needs. The SHSS is an interdisciplinary health care program that enters into the context of education through the agency of multiple stakeholders (e.g., children with DM, parents, teachers, school administrators, and health personnel) with the aim of serving the interests of children with health support needs and the broader community.

**Context of Diabetes Care in School**

Diabetes self-care is a complex learned behaviour that individuals with diabetes mellitus (DM) develop in partnership with others in their daily lives (Vallis, Higgens-Bowser, Scott, Murray, & Edwards, 2004). Self-care refers to the actions people with diabetes take to maintain life, health, and well-being (Orem, 2001). An essential part of children’s self-care is self-management, which involves following a day-to-day regimen and sharing responsibility for diabetes-care tasks and decision-making with informed caregivers (Schmitt, Wodrich, & Lazar, 2010).

For elementary school-aged children with DM, self-care is typically focused on their ability to perform daily tasks in the classroom similar to those of their peers (Kelo,
Martikainen, & Eriksson, 2011). Some children additionally learn to practice diabetes-related skills, including blood glucose monitoring, insulin and diet management, and hypoglycemia treatment (Amillategui, Ramón Calle, Alvarez, Cardiel, & Barrio, 2007; Amillategui, Mora, Ramón Calle, & Giralt, 2009). While Kindergarten and Grade 1 school-aged children (ages 4 to 6) for the most part do not possess the cognitive skills and physical dexterity to practice self-care (Desrocher & Rovet, 2004), Grade 2 through to Grade 8 school-aged children (ages 7 to 14) generally exhibit the ability to participate in treatment decisions, planning around everyday activities, and learning of target blood glucose levels while under the supervision of an adult caregiver (Halvorson, Yasuda, Carpenter, & Kaiserman, 2005), as well as showing increased concerns for self-image, having autonomy, and spending time with peers (Palmer et al., 2004). Regardless of age, when children manage their diabetes in the school setting, they tend to have improved academic performance and social inclusion (Kovacs, Goldston, & Iyengar, 1992; Sandberg & Barrick, 1995).

The Canadian Diabetes Association (CDA; 1998, 2003, 2008, 2013) continues to make specific recommendations for the transfer of responsibility for treatment management, so that elementary school-aged children can assume more self-care tasks with significant assistance in making management decisions. In keeping with these recommendations, in June 2008, the New Brunswick Department of Education (NBDE) released a comprehensive guide for diabetes management at school, *The Handbook for Type 1 Diabetes* (NBDE, 2008). This guide expanded on many of the CDA recommendations. Furthermore, diabetes care at school in New Brunswick is deemed an “essential service” (NBDE, 2008), meaning that all teachers in New Brunswick’s public
education system must practice an ethic of care consistent with the standards of practice for school health support services (SHSS) outlined in NBDE’s (1999) Policy 704.

While students with allergic reactions have been recognized by Ontario educational policymakers (e.g., Sabrina’s Law), similar measures have not been put into place for students with other chronic conditions, such as diabetes. In 2010, a private member’s bill that proposed to set out various rights for pupils with diabetes to care for their disorder at school was introduced in the Ontario legislature. While the bill did not reach the status of law, parliamentarians supported its expressed call for schools to adopt special caring practices consistent with diabetic children’s need to incorporate frequent glucose monitoring, meal planning, and insulin injections into their everyday school routines (Legislative Assembly of Ontario, 2010).

Despite the province not having a comprehensive care policy exclusively for diabetes at school, Ontario has a long history of public commitment to the administration of medical health services in the public education system for students with health support needs. As a result of Policy Program Memorandum No. 81 (PPM81; 1984), three branches of government—Ministries of Health, Education, and Community and Social Services—joined together to enact medical health provisions for direct therapy and nursing services, consultative services (e.g., the training of educators and families), and the administration of related medical supplies, including the injection of medication when and where necessary. The Ontario Ministry of Health and Long-term Care assumed responsibility for assisting school boards in the training and direction of school board staff on therapy programs related to developing a diabetes self-care regimen at school. However, Ontario Boards of Education were and are still entitled to develop their own
policies regarding the provisions of SHSS, specifically to allow for local determination of
the medical health services provided to address students with health needs.

The use of the School Health Support Services (SHSS) for educating students
with DM to develop self-care holds the potential to assist these students (Deloitte, 2010),
but school personnel are often undertrained in and misunderstand the provision of
medical services (Mackay, Sutherland, & Pochini, 2013; Mazur-Mosiewicz, Pierson, &
McIntosh, 2009). While some school personnel have interpreted school-based medical
services as a measure designed to address students’ medical needs (e.g., injection of
medication, catheterization, stoma care, postural drainage, suctioning, and tube feeding;
Deloitte, 2010), others have understood such services as a vehicle to support children’s
broader health and developmental needs (Ryan, Jones, & Weitzman, 1996). Given these
unique provincial contexts, there is a need to study the experiences of teachers in
promoting self-care among their students in these two provinces.
CHAPTER 2: THEORETICAL FRAMEWORK

With approximately 20% of North American students having some recognized health support needs (Forrest, Bevans, Riley, Crespo, & Louis, 2011), local families, schools, and health systems have undergone significant changes in the ways they act and interact with one another, through mobilizing resources and adjusting practices in light of policy shifts and in response to the perceived health needs of these children (Woodward-Lopez, Ikeda, & Crawford, 2000). Models of disability (medical model, social model, biopsychosocial model) frame understanding of diabetes care in school.

Medical Model

The medical model is an ideological health schema that considers all disability as “problems” (Falvo, 2014, p. 1), a physiological impairment that arises due to damage or some disease process (Llewellyn & Hogan, 2000), which needs to be cured or fixed (Smart, 2009). Accordingly, the medical profession is considered the unquestionable authoritative agent (Falvo, 2014), equipped with the tools to cure, alter, or manage the disorder, disease, or health impairment, while the individual is approached as the passive and compliant beneficiary of medical care (Johnston, 1996).

The medical model has inspired terms like diagnosis, disease, and pathology (Ferguson, 2002), while the practices of defining and managing the health condition looks for solutions that erase the impairment the impaired person faces, thereby returning the individual to normal (Longmore, 1995). The implicit philosophy of the medical model has always been the motivation towards normalcy, based on the prevailing values, norms, and beliefs of the time. In the case of someone deviating from the normal, he or
she is so naturally “handicapped” by virtue of some anomaly inside him or her, with the medical practitioner as the responsible caretaker in society who tries to make the individual acceptable in the face of society (Tremain, 2005).

Through care practices that further the meanings of the medical model, the word “diabetes” inevitably carries with it a notion of social incapacitation that often envelopes an individual’s social identity. Saying someone is “diabetic,” for example, or referring to perceived health behaviours with the intention of equating personal identity with disease reflects an understanding of disability that favours correspondence to the medical model. In line with these language practices, lay views on illness remain sustainably influenced by the medical model (Bury, 2005). In addition, contemporary health professionals tend to employ methods and terms of language use that reflect notions of disease in the person, thus placing patients into hierarchical power relations that put precedent on protocols of care and legitimating space for the search for a cure (Petrie & Weinman, 1997). With respect to the school, many elementary students are exposed to ideas of disability and disease as something to be feared (Haller, Sanci, Sawyer, & Patton, 2008); some of these students have encountered medically-inspired illness representations through health promotion initiatives (Mechanic & Hansell, 1987), while others learned about the perceived need to be safe from certain risky, disease-inducing behaviours from the applications of science (Haller et al., 2008).

**Social Model**

The *social model* of disability represents a divergence from viewing disability medically as an abnormal state of affairs, the source of which lies within the human body. Conceiving social and environmental conditions as sources to the construction of
disability, the social model is oriented towards actions that seek out equality (Falvo, 2014). The conception of the individual in this framework sheds any association with being problematized as in needing a cure; the social order is placed under scrutiny and is the target of experimentation in the hope to find an environment that proves accessible, useful, and non-stigmatizing to the individuals who have become disabled under the forces of social constructions (Anastasiou & Kauffman, 2013). The social model views the agency of the individual not in terms of bodily restrictions or physical limitations (medical model) but through society’s lack of attention and accommodation to the health needs of individuals. For example, the physical and social environments in which school-aged children with diabetes live, work, and play can either enhance their ability to perform or exaggerate a form of social oppression (disability). As a result, these same social and physical environments are understood as powerful agents that act to shape the extent and type of functioning permissible to these children (Falvo, 2014).

Proponents of the social model argue that our Western, capitalistic society constructs childhood as a period of dependency of limited duration that involves predictable progress toward an independent, economically productive, adulthood (Oliver, 1989). Children with disabilities who do not conform to these expectations are viewed as social misfits in their own right (Garland-Thomson, 2011), or more generally as a social problem (Priestley, 2003). Several studies have validated these perceptions through self-administered questionnaires, asking participating caregivers about their caregiving functions for youth with disabilities. Green (2007) has shown that many professionals and members of the public hold health beliefs that associate grief and sadness with the everyday lives of parents, particularly mothers. Using a mixed-methods approach
surveying 81 mothers of children with disabilities, Green discovered that the burden of caregiving is more related to societal rejection and social stigma, along with the sheer challenge of navigating a poorly coordinated and often non-responsive service system, than to direct caregiving and adjustment issues surrounding the child’s disability. In the medical model, in contrast, parents who hold positive attitudes toward raising a child with a disability are often pathologized as being unrealistic, failing to accept their “tragic” circumstances, or being “in denial” of their children’s problems (Barnett, Clements, Kaplan-Estrin, & Fialka, 2003; Ferguson, 2001).

The practitioner with a preference towards the social model is likely to make adjustments to the environment surrounding the patient, so as to moderate the effects of having the experience of disability (Lukemeyer, Meyers, & Smeeding, 2000). In advocating for these measures, caregivers of children with disability face the likelihood of incurring excessive financial costs in the form of specialised medical and therapeutic services, necessary equipment, and home or vehicle modifications (Lukemeyer, Meyers, & Smeeding, 2000; Parish & Cloud, 2006). One way that caregivers advance the social model of disability without incurring these environmentally-based burdens is through modifying the use of language (Cousins, 2013). Rather than treating the individuals as a reflection of their disease, practitioners may locate the individuals first and in association with their health condition; so Robert with diabetes as opposed to he’s diabetic.

Like the medical model, the social model has received its share of critics. Some perceive the social model legitimating an unnecessary bias directed towards the environment as the sole progenitor of impairment and disability (McClimens & Taylor, 2003). Anastasiou and Kauffman (2011) have raised objections over how the social
model problematizes the architecture of socially-constructed conditions, claiming that social constructionists only replace the biological determinism of the medical model with cultural determinism. Accordingly, practitioners of the social model approach the world with “a problem and fix it” orientation, which, in so doing, associates individuals with the products of intervention. Rather than labels and protocols of medical care being used to stigmatize individuals, adjustments made to pre-existing environments may function in a similar way. Lastly, invisible disabilities, including certain mental health disorders, allergens, and diabetes, tend to be questioned as legitimate disabilities within the social model (Krieger, 2001), since the emergence of certain bodily reactions, such as hypoglycemia, fevers, and episodes of distress, are temporal in nature and persist only indefinitely (Kundrat & Nussbaum, 2003). Physical disabilities, however, have received substantially more recognition, as architectural interventions, such as ramps, elevators, and adjustable seating, have improved access for many individuals and likewise benefited the public at large (Shakespeare, 2006).

**Biopsychosocial Model**

Neither the medical nor the social model of disability adequately represents the experience of disability (Duncan, 2013), so the biopsychosocial model was developed in response (Falvo, 2014). Instead of an unequal distribution of value assigned to health data, the biopsychosocial model places equal status to the clinical data emanating from the biologic (medical model) and social (social model) spheres, and introduces a third sphere of data (psychological) that captures the experience in the interactions between the other two (Gatchel & Turk, 2008). It reorients perceptions of disability to include both internal and external factors in the formation of an individual’s ability to function.
Disability is thus seen along a continuum of individual and cultural factors that work synergistically to produce the experience of disablement (Falvo, 2014).

The biopsychosocial model is based on the work of ecological systems theory (EST; Engel, 2012). According to EST, individuals are presumed as active agents who constantly shape, and are shaped by, their environments (Lounsbury & Mitchell, 2009). EST contributes to the biopsychosocial model in helping to formulate insights on how human behaviour works according to an interactionist relationship between self and the environment (Lounsbury & Mitchell, 2009). It also favours the role of perception in the study of how human motivation operates in the context of complex, evolving, interdependent ecosystems (Glass & McAtee, 2006). Using phenomenology to collect data about the experience in a classroom (Bronfenbrenner, 1999) could reveal possible underlying factors involved in how some practitioners prefer to act in one way while another chooses to behave otherwise, while occupying the same space (Lounsbury & Mitchell, 2009).

With growing recognition worldwide that disability is a complex construction of both individual and cultural factors (Hutchinson, 2010), the World Health Organization (WHO, 2001) formulated the International Classification of Functioning, Disability, and Health. This model identifies disability broadly as a health condition, co-mediated by body functions, activity, and participation, which in turn reflect and interact with environmental and personal factors.

The uses of the ICIDH-2 are varied. Some see the model providing the means to clarify team roles and enhance empirical reasoning (Tempest & McIntyre, 2006); reconcile humanism (mind) and science (body) to understand the breadth of human
clinical experience (Stucki, 2005); serve as a catalyst for research (Hutchinson, 2010); and provide a comprehensive framework for collaborations involving legislative, political, health, and educational policy (WHO, 2001).

With respect to use of the ICIDH-2 in understanding diabetes, Sanmartin and Gilmour (2008) reported on the findings of the national 2005 Canadian Community Health Survey (CCHS). Almost three-quarters of respondents living with diabetes reported having had their HbA1c checked by a health care professional at least once in the year before the survey, and those who had had the test were close to meeting the recommended frequency of every three months. The majority of diabetic respondents were also meeting the recommendation for eye examinations, but only half had the recommended annual foot examination. Roughly half the diabetic population (49%) reported that they or a family member had checked their glucose level at least once every day. The authors concluded that the collected health data provided a first-hand look at the health care practices shaping the experience of chronic disability for Canadians living with diabetes and illuminated perspectives on the cultural and personal factors that influenced the reception of appropriate care.

The biopsychosocial (BPS) model is not without its detractors. Llewellyn and Hogan (2000) claimed that the use of the model is limited to modes of discovery-based research since it is not prescriptive in design. Other critics have pointed out that the BPS model provides limited practical use in everyday settings (Álvarez, Pagani, & Meucci, 2012), since the model elicits no formal means for designing and evaluating the complexity of clinical and educational choices presumed within it (Sadler & Hulgus, 1992). The BPS model implicitly subscribes to the belief that all factors associated with
disability formation originate from an intentional or deliberate set of mechanisms (Álvarez, Pagani, & Meucci, 2012). For those living with mental health disorders, the BPS model therefore falls short of adequately explaining the formation of behaviours that seemingly lie outside of intentionally driven behaviour, individually or culturally formulated (McLaren, 1998).

**Wagner’s Chronic Care Model (CCM)**

This study drew upon Wagner’s Chronic Care Model (CCM; 1998), a biopsychosocial model, to guide the interpretation of the research data representing the perspectives of New Brunswick and Ontario elementary teachers. The CCM (see Figure 1 and Appendix A) is an ecologically minded, evidence-based care delivery model that is based on three foundational assumptions:

(i) Chronic health conditions are forms of disability that require the production of a continuous healing relationship;

(ii) Health delivery for chronic health conditions like diabetes, asthma, and cystic fibrosis, among others, requires the creation of a fundamental care unit comprised of a prepared, proactive, practice team delivering care to an informed, activated patient;

(iii) Care delivery operates at the intersection of community, health, and family care provider systems to provide support for the ongoing improvement in the practice of care among all care agents involved.

The CCM is widely used in the treatment of chronic diseases across North America (Murcko, Donie, Endsley, & Cooper, 2006), having its basis of justification to address the root causes of the well-articulated gap between the “health care we have and
the care we could have” (Institute of Medicine, 2001, p. 1). It has also been used to inform the development of chronic disease management in public service organizations, such as health care and education. For example, Ontario and New Brunswick teachers employed in the public education system have access to resource booklets that have illustrated versions of Wagner’s CCM (see Ontario Ministry of Health and Long-Term Care [OMHLTC], 2008; New Brunswick Department of Health [NBDH], 2011). The CCM is a multifaceted, complex, interdependent framework to improve health care delivery (Cabana & Jee, 2004; Griffin, 1998). It recognizes that the conventional acute health care delivery model must change to meet the needs of those with chronic illness within a system that is more inclusive and addresses health care from prevention to advanced management.

I used this model when I was first thinking about the purpose, the research questions, and the interview questions of the study, which considered both resources and policies and organization of health care. Second, I kept in mind the four components (self-management support, delivery system design, decision support, and clinical information systems), while analyzing the data. In the end, I used different terminology for each of these components: inclusionary practices for self-management support, roles and responsibilities for delivery system design, coping with care for decision support, and communication for clinical information systems. These terms reflected my participants’ language more appropriately.
Figure 1. The Chronic Care Model. Adapted from Wagner (1998).
CHAPTER 3: LITERATURE REVIEW

Diabetes is a very human condition. Even to those of us with many years of clinical practice in diabetes, the infinite diversity of individual response to diabetes is a constant source of amazement but also professional enhancement. … Diabetes and its consequences have a fundamental physical basis, but these are deeply intertwined with complex psychosocial issues. Such interrelationships are considerable, sometimes subtle; sometimes overwhelming (Shaw, 2000, pp. ix-x).

Educational, parental, and health care agents in relation with students with diabetes encompass a range of roles and responsibilities at school (Gelfand et al., 2004). To fulfill these roles and responsibilities, care agents must communicate with each other to circulate health information among them and to develop health literacy for all caregivers (Nguyen, Mason, Sanders, Yazandi, & Heptulla, 2008). However, the movements of health information reflect the inclusionary practices of care agents to navigate the school environment according to medical, social, and biopsychosocial notions of disability (Woodward-Lopez, Ikeda, & Crawford, 2000). As a result, care agents of students with diabetes must choose approaches, steps, and strategies in their practice to help students and themselves cope with diabetes care (Snoek & Skinner, 2000).

Roles and Responsibilities

Diabetes care in the school setting requires the creation of a complex caring partnership struck among multiple stakeholders (see Richard & Shea, 2011, for a review). Clinicians have described the “importance of the community in chronic disease management” (Bobo, Kaup, McCarty, & Carlson, 2011, p. 172), where care providers utilize an understanding of self-care, coping with illness, and chronic disease management to guide the provision of health services catering to the needs of children.
with diabetes (see Erickson, Splett, Mullett, & Heiman, 2006). Echoing these suggestions is systematic review literature (e.g., Compas, Jaser, Dunn, & Rodriguez, 2012; Kelo, Martikainen, & Eriksson, 2011; Richard & Shea, 2011) that stresses the collaborative nature of care involved in addressing the health needs of young people with diabetes.

Working together, the educational, parental, and health care agents form “the diabetes management team” (Craig, Glastras, & Donaghue, 2007, p. 19), a circle of care practitioners brought together to implement the provisions of the child’s health-care and education plans, along with providing the necessary assistance in the school setting, when and where appropriate (Wood & Kaufman, 2012).

**Students**

There is strong evidence to support the link between the habituation of self-care behaviours supportive to sustained glycaemic control and the reduction of long-term complications of diabetes. The most crucial studies providing this link are the *Stockholm Diabetes Intervention Study* (Reichard et al., 1988) and the *Diabetes Control and Complications Trial* (DCCT; 1993). These landmark clinical trials conducted among an adolescent and adult population of diabetic patients independently established that improvement in the control of metabolic abnormalities decreases the risk of the development of complications responsible for severe and chronic disabilities associated with the disease, such as blindness and renal failure (Zajac, Shrestha, Patel, & Poretsky, 2010). Such results provide a very strong incentive to initiate the practice of self-care starting at a young age (Wagner, Heapy, James, & Abbott, 2006).

Children with diabetes, however, continue to face challenges in the formation of self-care in their everyday settings. At school, some children desire more flexibility from
their teachers in making allowances to test blood sugar levels and to treat their diabetes
when and where needed (Lin, Mu, & Lee, 2008; Nabors, Lehmkuhl, Christos, &
Andreone, 2003). Others require more involvement from teachers, nurses, and peers with
respect to their self-care (Herrman, 2006; Nabors et al., 2003). Outside the classroom,
participating in school athletics, such as after-school sports, is often challenging for
students with diabetes (Nabors et al., 2003). Treatment supplies are typically not
available for students to access on their own, and the teachers in charge often do not
possess enough knowledge of diabetes to remind children about testing and balancing rest
and snacks (Nabors et al., 2003); and to recognize the onset of hypoglycemia (Lehmkuhl
& Nabors, 2008).

Children living with other chronic health conditions similarly share in the
experience of difficulty encountered by students with diabetes in the formation of self-
care at school. Newbould, Francis, and Smith (2008) conducted a qualitative case study,
sampling 43 young people (8 to 15 years) with asthma and 26 with diabetes, as well as
138 parents. Both groups of young people had to first ask for permission to access stored
medication before addressing immediate health needs. Furthermore, in the administration
of medications at school, Clay, Farris, McCarthy, Kelly, and Howarth (2008) found that
the most common problem reported by parent-child dyads of children with diabetes (N =
75) was the children forgetting a dose and running out of medication (other children in
the study had asthma or ADHD). Children with more self-responsibility for medications
were less likely to report medication errors.

Other studies offer a clear picture of the relationships constructed between
children’s roles and responsibilities and perceived school experiences. Through a
descriptive, non-experimental study, Wagner, Heapy, James, and Abbott (2006) investigated the relationships among diabetes control and quality of life (QoL) in children with diabetes. Fifty-eight children with Type 1 diabetes (T1D) and their parents were interviewed about the child’s school experiences. Children who had greater flexibility in performing diabetes care tasks at school had significantly better diabetes control and higher QoL scores compared to children who reported less flexibility. Nearly one third (31%) of the children noted that peers provided help as a diabetes “buddy.” Buddies recognized hypoglycemia, alerted staff, prompted self-care, buffered teasing, and escorted the student to the nurse. In addition, children whose parents reported that school personnel received diabetes training showed significantly better diabetes control than those whose parents reported untrained school personnel.

Poor glycemic control (that is, poor self-care and diabetes management) has a deleterious effect on effective school functioning. Using a cross-sectional approach to evaluate current academic performance of children with diabetes compared to two control groups (siblings and matched classmates), McCarthy, Lindgren, Mengeling, Tsalikian, and Engvall (2002) found that poorer academic performance tended to occur in children with poorer diabetic control. Children with diabetes had significantly more school absences than their siblings and more behavioural problems. McCarthy and her associates concluded that their study provides evidence of the need for careful monitoring to ensure that episodes of hypoglycemia associated with seizures do not adversely affect learning.
Parents and/or Guardians

Family cohesion is a key mediator in the development of self-care among young children (Christie & Barnard, 2012). Parents who construct with their child a nurturing environment sustained through taking an active role in facilitating warmth, support, understanding, and healthy limit-setting are more likely to transfer self-care responsibility to their child and at a younger age than those parents who do not take such an active role (Halvorson, Yasuda, Carpenter, & Kaiserman, 2005).

Parents tend to expect their responsibilities for diabetes management to be shared with school personnel (Ginsburg et al., 2005), with some even requesting the school health team to uphold special care expectations that recognize the unique health challenges encountered by their child (Nurmi & Stieber-Roger, 2012). Some parents report dissatisfaction with the management of their child’s diabetes at school (Skelley et al., 2013), citing a lack of equitable and culturally appropriate care for these students within the public education system. Data from Spain suggest that 44% of parents had to adapt their working time arrangements to provide school support for their children (Amillategui, Mora, Ramón Calle, & Giralt, 2009).

Parents generally attribute their dissatisfaction with the caregiving functions at school to a number of factors, including inadequate educational policies (Nurmi & Stieber-Roger, 2012), disproportionate care being leveraged reflecting disparate understandings of health (Caballero, 2010), and school caregivers having a poor understanding of developmental milestones related to the child’s ethnic orientation and maturity level (Institute of Medicine, 2002). A Diabetes UK (2009) survey examined the provision of diabetes care in primary schools and found that, if children were unable to
administer their own insulin, 70% of schools expected a parent to come and give the injection. Parents object to these types of expectations (Skelley et al., 2013), leading them to question the knowledge school staff hold in the provision of medical procedures (Nurmi & Stieber-Roger, 2012), and raising criticisms about the school placing strictures over access to regular snacking and monitoring of blood glucose concentrations, which were freely encouraged at home (Jacquez et al., 2008). As a result, some parents assume an advocacy role in relation to the school health care team (Nurmi & Stieber-Roger, 2012). While a few parents have successfully petitioned school boards to revamp policies to include provisions for the administration of glucagon injections by school personnel (Hellem & Clarke, 2007), others have adversarial relationships with school personnel in disagreeing about the care for children with diabetes at school (Jacquez et al., 2008).

**Health Professionals**

In several countries, the school nurse is widely recognized as the most important person to assist students with metabolic control in school settings (National Diabetes Education Program, 2014). In addition to servicing students with diabetes, the school nurse’s role in elementary settings typically includes population-focused assessment, program development, and supervision of unlicensed assistive personnel (UAP). They typically provide routine and emergency nursing services, and monitoring of all students; they are often the impetus for the student’s family and school staff to access their primary health care provider (Kirchofer, Telljohann, Price, Dake, & Ritchie, 2007; Lear, 2007). For uninsured students without a primary care provider, the school nurse may be their only access to pediatric health care.
Nguyen, Mason, Sanders, Yazdani, and Heptulla (2008) conducted a randomized control trial of 34 elementary school-aged children. The 18 students receiving regular supervision on glucose monitoring and insulin-dose adjustment by school nurses had significantly better glycemic control than the 16 students (N = 16; 14.0 +/- 1.8 years old) who independently managed their own care at school. Additionally, school nurses may positively affect the academic success and well-being of students with diabetes (Lightfoot & Bines, 2000; Patrick & Silverstein, 2007; Silverstein & Patrick, 2007).

Despite the evidence in favour of having health personnel on school premises, there has been a decline in the number of schools staffed with licenced health personnel. While the recommended school nurse to student ratio is 1:750 for optimal care during the school day (Vail, 2004), the current ratio at 1:1,350 represents nearly a doubling of the student population for every nurse, with less than half of the North American schools meeting the recommended school nurse-to-student ratio (Brener, Wheeler, Wolfe, Vernon-Smiley, & Caldart-Olson, 2007). Factors involved in the shortage of on-site school nurses include escalating budgetary cuts (Lear, 2007; Tetuan & Akagi, 2004); school health programs emphasizing health promotion and illness prevention, and wellness not being widely perceived as an essential service (Lear, 2007); the use of UAP, including lay volunteers, teachers, educational paraprofessionals, school secretaries, school administrators, and health aides for lower-cost health services (Tetuan & Akagi, 2004); and UAPs often utilized in substitution of unavailable licensed health professionals (Gursky & Ryser, 2007).

Even when nurses are present in schools, some have only moderate confidence in their ability to provide diabetes care for the students (Fisher, 2006), while others express
concerns about a lack of access to information about diabetes care and time constraints on
the provision of appropriate support and care to the students in need (Joshi, Komlodi, &
Arora, 2008). Wang and Volker (2013) used a Husserlian phenomenological approach to
qualitatively understand through semi-structured, in-depth interviews five experienced
Taiwanese school nurses’ experience of caring for students with diabetes. Wang and
Volker discovered four interrelated themes that portrayed the experiences of school
nurses caring for their students: (a) I try to put myself in the parents’ and students’ shoes,
(b) I am not a diabetes expert, (c) managing diabetes requires teamwork, and (d) caring
for students with diabetes is a struggle with practical limitations. In summary, the school
nurses encountered many challenges as they implemented their roles and responsibilities
in caring for students with diabetes.

Similarly, but more broad in scope, Marshall, Gidman, and Callery (2013)
examined the role of pediatric diabetes nurse specialists (N = 45) and children’s
community nurses (N = 2) in supporting the intensive insulin management regimens of
children with diabetes in educational settings using focus groups (n = 8) and individual
telephone interviews (n = 8). The nurses experienced challenges in balancing the varied
roles they played in diabetes management in school settings, including advocating for
children with diabetes and training school personnel. The role was complicated by
ambiguity between requirements for reasonable adjustment for disabilities and policies to
leave schools freedom to determine how they met children’s needs. Furthermore, nurses
identified the need to establish partnerships with schools to support children, but believed
the legal and policy framework was woefully inadequate. In the absence of enforceable
standards, nurses sought to negotiate diabetes care on a case-by-case basis with individual schools.

**School Personnel**

Teachers, educational support staff, secretaries, bus drivers, and custodians are typical examples of the cohort of school personnel who are currently faced with increasing demands within the school environment (Lightfoot, Mukherjee, & Sloper, 2001), as they are expected to fulfill duty of care obligations in the presence of a vulnerable population of students, of which some live with medical health conditions (Hellems & Clarke, 2007; Olsen, Seidler, Goodman, Gaelic, & Nordgren, 2004).

School personnel tend to have reservations about working with students having chronic medical needs. These reservations include: fear of how to respond to a medical emergency (Johnson, Lubker, & Fowler, 1988), the illness’ impact on academic performance (Olsen et al., 2004), extra demands placed on them, and the additional time and attention to chronically ill students outside teachers’ regular terms of employment (McCarthy, Williams, & Eidhal, 1996). In the Commonwealth countries, such as Canada, the United Kingdom, and Australia, there is no legal duty that requires school staff to administer medications (MacKay, Sutherland, & Pochini, 2013), although some support staff, such as educational paraprofessionals and secretarial personnel, may have such a role in their contracts of employment (Marshall, Gidman, & Callery, 2013).

Teacher knowledge of the areas critical to the safety of children with diabetes is generally sub-optimal (Gesteland, Sims, & Lindsay, 1989; Jarrett, Hillam, Bartsch, & Lindsay, 1993; Siminerio & Koerbel, 2000; Vanelli et al., 1999). Nonetheless, professional development about a disease that affects a small number of students may be
difficult for school systems to realistically pursue (Faro, Ingersoll, Fiore, & Ippolito, 2005). Some school personnel may resist formalized educational efforts, believing that the knowledge they have obtained from personal or family experience with adults with diabetes or with other younger relatives is sufficient (Norris et al., 2002).

In their UK qualitative study exploring the concerns of elementary school staff (N = 22) and multidisciplinary health-care professionals (MHCP; N = 5) working with children with Type 1 diabetes and their parents, Boden and colleagues (2012) discovered that teachers expressed concerns about being responsible for children with diabetes in class. Teachers spoke of constant surveillance whether in the classroom, in the playground, or when supervising children with diabetes off-site on school trips. In some cases, teachers felt that their day-to-day conduct became structured around constant ‘checking up’ and ‘chasing’ of children, making sure that they were aware of the necessary regimen and of the emergency drill that would take place if their health deteriorated. In contrast, MHCPs felt that support services would improve by using community-based dieticians and including psychological input into the diabetes team. Formal training was thought to validate the role of the teacher as ‘qualified carer’. One suggestion was to upgrade teachers with first-hand experience of diabetes management to the role of ‘diabetes expert’. The MHCPs envisioned experienced teachers having the means to bridge the gap between school staff and MHCPs, liaising and feeding back informatively to both parties about the roles and responsibilities expected of them.

**Communication**

Communication among students, parents, health professionals, and school personnel involves an organized schema of social support to facilitate the mobilization of
health information across participating caregivers (Smaldone & Lawlor, 2009). Formal and informal sources of information circulate in context (Cunningham & Wodrich, 2006; Eyong, Anah, Asindi, & Ubi, 2012), building knowledge about the possible strengths and limitations of the students with DM (Logan, Coakly, & Scharff, 2007). In particular, social communication networks and health literacy are critical components of a communication strategy for students with diabetes (e.g., Hardin & Banaji, 1993; Nguyen, Mason, Sanders, Yazdani, & Heptulla, 2008; Schultz & Kopec, 2003).

Social Communication Networks

Social communications networks encompass exchanges among individuals within a community, in this case, with respect to self-care and diabetes management for the student with diabetes. These communications can be done face-to-face, through writing, over the phone, and electronically. Research has examined how students with diabetes engage in social communication networks to support their diabetes care (Cammarata et al., 2009; Smaldone & Lawlor, 2009; Swift, 2007). School provides one of the best arenas for meeting a child’s needs in areas of socialization, achieving success, and youth with diabetes self-identifying as important members of society (Anderson, 2004). Participating in school is thus a powerful tool in the development of communication practices, with language-users having the means to carve for themselves a measure of global self-worth and opportunities for self-mastery and self-esteem building that are not readily achieved elsewhere (National Institute for Health and Care Excellence, 2008).

Supportive school climates embrace communications that promote health and wellness, safety, and students’ sense of dignity. Embedded discursive practices in the formation of learning, problem-solving, and decision-making processes (Hardin &
Banaji, 1993) impact diabetes self-care with tangible outcomes, such as glycemic control (Nguyen, Mason, Sanders, Yazdani, & Heptulla, 2008); perceived quality of life (Chisholm et al., 2011); and perceived school-based experiences of addressing health needs (Wang, Brown, & Horner, 2013).

Of special importance may be communications with peers. The communication dynamics between peers and students with chronic illnesses can be seen through three lenses (La Greca, Bearman, & Moore, 2002): (i) the role of peers and close friends as a source of support; (ii) friends’ influence on treatment adherence; and (iii) peers’ and friends’ impact on health-promoting and health-risk behaviours. While children with medical conditions like diabetes may encounter stigmatizing relationships with others and experience peer difficulties (La Greca et al., 2002), social support from friends and classmates, such as through “buddy” systems and co-presenters, appears to facilitate youngsters’ disease adaptation and may help with the lifestyle aspects of treatment regimens.

Technology may be changing the way communication about diabetes is conducted. Murphy, Rayman, and Skinner (2006) reviewed 168 psycho-educational interventions and randomized control trials (RCTs) from 1999-2005, of which some reported on the results of using contemporary technologies to introduce social communication networks into the realm of digital medias and to mobilize self-care education across distances, including continuous blood glucose monitoring (Nordfeldt, Ängarne-Lindberg, Nordwall, & Krevers, 2013), text messaging (Franklin, Waller, Pagliari, & Greene, 2003), and telephone contacts or telemedicine care (Liesenfeld, Renner, Neese, & Hepp, 2000). One of these reviewed studies—Howells and associates
involved negotiated telephone support showing significant improvement in self-efficacy but not in HbA1c. The frequency and duration of telephone contact seemed to be of more importance than the (educational) content of the conversation.

Health Literacy

Health literacy is a set of cognitive-based communication skills and knowledge with respect to health-related topics (Nutbeam, 2008). Health literacy falls under the heading of communication in that it involves individuals communicating their knowledge about health (in this instance, diabetes) to other individuals and vice versa. The term “health literacy” first appeared in the medical vocabulary during the mid-1970s (Millan-Ferro & Caballero, 2009) but has become commonplace since (Berkman, Davis, & McCormack, 2010) with the term now in everyday usage (e.g., Nielsen-Bohlman, Panzer, & Kindig, 2004; United States Department of Health and Human Services, 2014). In their systematic review of health literacy research, Al Sayah, Williams, and Johnson (2012) identified existing research employing the term as a skill-based construct threaded through four main components: (i) functional; (ii) interactive; (iii) critical; and (iv) numerical. Functional skills encompass the ability to read and understand written text, locate and interpret information in documents, and write or complete forms (Berkman et al., 2010). While interactive skills denote the ability to speak and listen effectively and communicate about health-related information (Nutbeam, 2008), critical skills, otherwise known as navigational skills (Pulgarón et al., 2014), concern the ability to navigate the health care system and make appropriate health decisions. Lastly, numerical skills refer to the ability to use numeric information for tasks, such as interpreting medication dosages and food labels (Berkman et al., 2010; Nutbeam, 2008).
Low levels of health literacy are more prevalent in minority populations (Schultz & Kopec, 2003); among persons with English as a second language (Schultz & Kopec, 2003); for people from low-income households and with low levels of education (American Medical Association, 1999); and for elderly individuals and those with a compromised health status—the same populations that carry the greatest burden of chronic conditions (Sudore et al., 2006). These associations suggest those school-aged children with diabetes who live in a low-income environment; and/or use English as a second language; and/or live as a member of a minority population are placed at significantly greater risk for having low health literacy compared to other children with diabetes.

The literature illustrates a substantial number of existing studies (N > 2100) examining health literacy through use of non-experimental research designs (Al Sayah et al., 2012), with the preferred platform of data collection being observational methods supported through a cross-sectional apparatus. In their cross-sectional study that examined the relationship between parental health literacy (HL), diabetes-related numeracy, and parental perceived diabetes self-efficacy on glycemic control in a sample of young children with Type 1 diabetes, Pulgarón and her associates (2014) recruited 70 primary caregivers of children (aged 3 to 9 years) to participate in a self-report survey administered at a diabetes outpatient clinic. Parental diabetes-related numeracy, but not reading skills, were inversely correlated with the child’s glycemic control (HbA₁c). Parental perceived diabetes self-efficacy was also negatively correlated to their child’s HbA₁c. Both remained significant in multiple regression analyses.
While clinical health outcomes continue to significantly propel the direction of health literacy research (Moon, Cheng, Patel, Baumhaft, & Scheidt, 1998; Tang, Pang, Chan, Yeung, & Yeung, 2008), perpetuating the notion of health literacy as a construct reflecting actions residing within the individual (Cutler & Lleras-Muney, 2006), a concentration of research has recently emerged in the areas of healthy literacy through patient-provider interactions (Hassan & Heptulla, 2010). This process has shifted attention towards understanding health literacy as the exchange of health information between caregivers and the care-given (Rothman et al., 2009), concentrating on verbal communications through interpersonal contact (Harrington & Vallerio, 2014), not only within designated health settings per se but in the broader contexts of life (Peerson & Saunders, 2009).

Following this reasoning, Ishikawa and others (2009) showed that higher health literacy levels were associated with perceived better patient–physician communication and, furthermore, that higher health literacy was associated with perceived better information exchange between patients and their physicians. Using the NVS (Newest Vital Sign) screening tool, Morrison and her colleagues (2014) attempted to determine the association between low caregiver health literacy and child emergency department (ED) use, both the number and urgency of ED calls. Low caregiver health literacy was a significant independent predictor of higher ED contact and increased the odds of a non-urgent index ED visitation.

Similarly, the widespread use of the Internet has offered health literacy researchers another avenue to investigate information-exchange encounters in the production of health literacy. Both Sarkar and associates (2010) and Mayberry, Kripalani,
Rothman, and Osborn (2011) examined digital media use for promoting health literacy. The studies provided minimal evidence that higher health literacy was correlated with more frequent use of computer and Internet-based training programs.

**Inclusionary Practices**

DeLuca (2013) has pointed out those educational movements to inclusion overall have carried a number of different disciplinary conceptions that blockade efforts to encompass a more interdisciplinary approach to the construction of addressing diversity in educational spaces. With respect to addressing students with or without disabilities, DeLuca has further argued that these efforts have involved the mobilization of inclusive conceptions ranging from normative orientations [e.g., “to limit the influence of the illness on the life as much as possible” (Öhman, Sönderberg, & Lundman, 2003, p. 531)] to transgressive approaches [e.g., “the imperative for greater social justice” (Thomas & Vaughan, 2004, p. 1)]. In using these interventionist measures, educators have simultaneously reconstructed relationships of power in the likeness of the medical (normative), social (transgressive), and biopsychosocial models (integrative—normative and transgressive) of disability (Garrick Duhaney & Salend, 2000; Worche  

Like other Canadian elementary students with chronic health conditions, those with diabetes mostly attend mainstream schools (Hutchinson, 2010). Inclusive education in Canada is a matter of legal provision (Bennett, Dworet, & Weber, 2013), having its basis of justification found in the Canadian Charter of Rights and Freedoms. With education in Canada being a matter of provincial jurisdiction (MacKay, Sutherland, &
Pochini, 2013), educational systems in each province and territory have developed models of inclusive education through policy and practice initiatives that augment the terms of inclusion governed at the federal level (Hutchinson, 2010).

Despite widespread adoption of inclusion into the arena of provincial and territorial educational policy, inclusion at the classroom level largely remains expressed through special education interventions rather than through measures that recognize the broader contexts of inclusion (e.g., DeLuca, 2013; Vlachou, 2004). Furthermore, curriculum practitioners both domestically and internationally have reported confusion about what constitutes inclusive schooling (e.g., Gérin-Lajoie, 2008; McGhie-Richmond, Irvine, Loreman, & Lupart, 2013), and have relayed frustration with the challenge to construct inclusion through addressing the health needs of students who require medical provisions of care (e.g., Jackson, 2013). Consequently, Jackson (2013) claimed that, while educators who teach students with chronic illness are primed with the motive to construct opportunities of developing inclusion for them, these educators often face ambiguity concerning the nature and impact of the medical conditions these students present, which positions the educators to experience levels of doubt as to the construction of inclusionary interventions for these student populations. These kinds of doubts may negatively influence how educators work with these students.

One of the primary factors that contributes to the need for inclusive education for students with chronic health conditions is the requirement for specialized health care and access to medical services while participating at school (Jackson, 2013). Educational systems have responded to the expressed need for the provisions of medical care through constructing an integrative model of inclusion (Ashman & Elkins, 2011), whereby school
and specialized health caregivers associate themselves to the student with health needs by addressing his or her deficits in cognitive, physical, or behavioural domains and through the terms of available accommodations and modifications (Thomas & Vaughan, 2004). Like other students with health needs, making schooling accessible for school-aged children with diabetes sets them up to partake in school re-entry programs that typically unfold according to pre-defined steps or health measures (Alderfer & Rourke, 2014). At the same time as these medically-dependent students enter into the school community, the combination of health service delivery and educational programming that encircles them inevitably constructs a socially distinguishing boundary in the context of mainstream schooling (DeLuca, 2013). Consequently, educators look for ways to reduce or eliminate the imposed interactional gap that has arisen between students with health support needs and other participating school stakeholders who stand outside of that immediate caregiving circle. Educators who face this position have the option to construct a culture of social acceptance (Hutchinson, Freeman, & Berg, 2004), using pedagogical tools in the process to deconstruct misconceptions, attitudinal barriers, and other stigmatizing forces that can negatively shape and impact the school experience for all involved (Bennett, Dworet, & Weber, 2013).

Research in the fields of special education and pediatric development among school-aged children consistently shows remarkable similarities in the available approaches educators, parents, and health practitioners have independently taken in addressing the health needs of children in their care. Teachers, parents, and health professionals who demonstrate warm and caring behaviours are more likely to witness higher levels of self-efficacy among young people to develop self-care compared to those
professionals who do not follow such an approach (Faulkner & Chang, 2007; Mahoney, Lord, & Carryl, 2005). In addition, offering emotional support to and practicing open communication with young people with diabetes helps to disintegrate existing barriers to actively seeking out self-care development (Davidson, Penny, Muller, & Grey, 2004; Mukherjee, Lightfoot, & Sloper, 2000). Overall, the experiential dimension involved in the construction of inclusive education for elementary school-aged children with diabetes holds the key to unlocking existing barriers that delimit understanding how pedagogy, policy, and theory interact to influence the motivation of the students and care agents for students with DM (Ginsburg et al., 2005; Schwartz, Denham, Heh, Wapner, & Shubrook, 2010).

**Coping with Care**

Diabetes care at school is precipitated by a number of interweaving factors, including advancements in health care practices for people living with chronic illness (Wagner et al., 2001), progressive emergence of scientific knowledge on the nature of diabetes and on the long-term impact of unregulated glycemic control (Zajac, Shrestha, Patel, & Poretsky, 2010), amendments in educational policies recognizing the exceptional health needs of chronically ill students (Wilt & Foley, 2011), and the mobilization of knowledge on diabetes management through digital and traditional forms of correspondence among health and educational stakeholders (Holtz & Lauckner, 2012).

To participate in the normal, everyday school routines, children with chronic illness (especially those having diabetes, asthma, or obesity) are inextricably faced with the challenge to act publicly about managing their illness, while being social in addressing the demands of a typical school day (Kaffenberger, 2006; Prevatt, Heffer, &
Lowe, 2000; Van Cleave, Gortmaker, & Perrin, 2010). In such a context, further evidence is nonetheless needed on the approaches, strategies, and steps of communication involved in the processes of self-care.

**Approaches**

The prevailing orientation school systems have taken for students with chronic health conditions like cancer, HIV/AIDS, and diabetes is through adopting a re-entry approach (Prevatt, Heffer, & Lowe, 2000). In re-entry, schooling systems seek to construct a learning environment that allows children with chronic illness the chance to reintegrate into the school community and to participate as if there is a strong likelihood of them returning to their pre-disease-onset lives (Canter & Roberts, 2012).

Existing re-entry programs have typically incorporated ecological service models into their health service delivery framework (Farmer & Peterson, 1995), which holistically considers the interaction of the child, family, hospital, school, and community in dealing with school health issues (Bobo, Kaup, McCarty, & Parker Carlson, 2011; DuPaul, Power, & Shapiro, 2009; Wagner et al., 2001). Although some evidence exists on the benefits of ecologically minded service models as demonstrated in the self-reported perceptions of survivors, their healthy peers, and school personnel (Prevatt et al., 2000), there is no summative indication that school re-entry programs organized for purposes of recognizing the child holistically are effective or that a specific type of intervention is more effective than others (Canter & Roberts, 2012).

Nevertheless, reintegration into the school community has been reported as a critical factor in the effort to address educational and psychosocial needs of these students (Houlahan, 1991; Kliebenstein & Broome, 1999; Sexson & Madan-Swain,
1995). It is a gradual process elapsed through the engagements of parents, health care providers, school personnel, and the student with the chronic illness, who each enter into dialogue with one another (Smith, Taylor, Newbould, & Keady, 2008), either anew or proceeding from a previous year’s iteration (Marks, Wilson, & Crisp, 2013).

With respect to re-entry programs, some studies illustrate an entrenched pattern of chronically ill children having difficulty returning to school after diagnosis or prolonged hospitalizations (Baskin, Saylor, Furey, Finch Jr., & Carek, 1983; Sexson & Madan-Swain, 1993; Worchel-Prevatt et al., 1998), while others show promise in the effectiveness of these sorts of school health programs. For example, Katz and colleagues (Katz, Rubenstein, Hubert, & Blew, 1989; Katz & Varni, 1992) twice conducted an empirical investigation of effectiveness of re-integration programs for students with chronic illness. Pre- and post-measures showed an increase in the intervention group children on self-rated social competence and teacher-rated school behaviours. In addition, Canter and Roberts (2012) have lent further credence to the proposition that health re-entry programs, despite differences in the provisions of health service delivery, generally lead to improvements in physical and emotional wellbeing of chronically ill students. Canter and Roberts have interpreted their findings as evidence for the effectiveness of communications in school re-entry interventions.

**Steps**

Re-entry programs generally encompass five main steps or stages carried out throughout the typical school year: (i) build a connected, collaborative family-school-hospital reintegration team; (ii) assess the specific needs and resources of the child, family, and school; (iii) identify appropriate mechanisms for intervention and develop
tailored plans; (iv) prepare school personnel to reintegrate the child with chronic illness; and (v) prepare classmates for the child’s return (Alderfer & Rourke, 2014).

Assembling members to form a school reintegration program for students with diabetes can be challenging. Some teachers have expressed being very concerned due to lack of knowledge about the disease (Abdel Gawwad, 2008), are unsure about realistic expectations (Wodrich, Hasan, & Parent, 2011), and worry about being able to handle medically invasive and emergency procedures (Duggan, Medway, & Bunke, 2004). Likewise, parents may feel guilty about their child’s medical condition and react with over-protectiveness and unrealistic fears (Henning & Fritz, 1983; Lawson, 1977). Prior to the assessment of the child’s actual health needs, students with chronic health conditions typically cope with the knowledge that they are a source of worry and financial strain for the family and must deal with ambiguities regarding the future (Farell & Hutter, 1980).

Knowledge is paramount to the success of the reintegration team. Knowledge is related to length of employment as a teacher (Birbeck, Chomba, Atadzhanov, Mbewe, & Haworth, 2006), prior experience of supporting pupils with chronic health conditions (Bishop & Slevin 2004), and previous personal experience of having to address chronic health conditions (Tahirovic & Toromanovic 2007). In one study, while teachers of children with special education needs (N = 54) felt more knowledgeable about the perceived health and academic needs of students with chronic health conditions, these same teachers did not as a whole feel any more confident than mainstream teachers in meeting the academic needs of these pupils (Nabors, Little, Akin-Little, & Iobst, 2008).

Subsequent to the initial stage of most re-entry programs is the assessment stage of reintegration. Some teachers show difficulty expressing concerns about their capacity
to meet pupils’ needs with families (Robinson & Summers, 2012). Teachers often find useful resources outside of the school environment to gather health information relevant to their perceived caregiving needs, including surfing the Internet, scanning hospital brochures, and striking conversations with parents or relatives who may have had or have had previous experience with the pupil’s chronic condition (Bishop & Boag, 2006; Thacker, Verma, Ji, Thacker, & Mishra, 2008). Although teachers may use resources outside of the school or rely on parents to provide information about their child’s illness (Robinson & Summers, 2012; Thacker et al., 2008), teachers might prefer to receive information about chronic health conditions from a licensed medical professional to ameliorate misconceptions regarding these students’ care (Shiu, 2004).

Exploring or examining the process to select appropriate tools to develop customized health plans (step three) has been understudied compared to the other steps. Individualized health plans (IHPs) are intended to record valuable information on the student's specific health care procedure or physical management area (Getch, Bhukhanwala, & Neuharth-Pritchett, 2007). These tools ask participating caregivers to contribute general information, while also asking them to chart out more specific information like how to handle routine health care procedures, physical management techniques, and medical emergencies. In addition to these expressed procedures, collaboration in the process of constructing the health plan is construed as purposeful actions centred on establishing goals for care and intervention, documenting contact information, and addressing any outstanding concerns (Zombek, 2002).

Past academic coursework and in-service training may prepare caregivers in executing caregiving functions for the school year (step four). Boden and colleagues
(2012) collected focus group data from elementary school teachers. Teachers were generally very apprehensive about their preparedness to care for children with medically-invasive chronic health conditions; were fearful of making mistakes because they lacked the confidence to execute specialized health care functions, such as medical administration and making sense of health data; and were worried about the ability of children to practice self-care. Similarly, less than one-fourth of elementary and middle school teachers surveyed (23%) in a sample of 52 felt confident that their school could safely handle a medical emergency related to diabetes (Pinelli et al., 2011). More than half the 480 educators surveyed by Clay, Cortina, Harper, Cocco, and Drotar (2004) reported having no academic training for addressing chronic health conditions (59%), with 64% reporting having participated in no on-the-job training.

Finally, welcoming students with diabetes back into the classroom in the company of their peers formally represents the last step in the process of most re-entry programs. It also presents an occasion that marks the beginning of the rest of the school year for those caregivers involved in diabetes care. Returning children who have recently been diagnosed, similar to others diagnosed with a chronic health condition, bring their journey of grieving whatever their travels, potentially lasting for the rest of their lives (Guthrie, Bartsocas, Jarosz-Chabot, & Konstantinova, 2003).

Most children return to pre-diagnosis emotional levels (acceptance) within seven to nine months (Shiffrin, 2001); however, a number of children experience long-term adjustment difficulties (e.g., levels of denial, anger, and depression; Northam, Anderson, Adler, Werther, & Warne, 1996). Upon return to the school, younger children (Kindergarten to Grade 2) tend to display feelings of separation anxiety from their
parents (Shiffrin, 2001), while older children (Grades 3-8) are more likely to fear stigmatization or teasing from peers, which may evolve into social phobias as time continues (Cammarata et al., 2009). Some children with diabetes hold additional impairments in cognitive functioning, especially in children diagnosed before they are four and who have experienced several episodes of hypoglycemia (Ryan et al., 1990). These children have shown the need for additional assistance from school caregivers to help them with planning and organizing health behaviours; for the most part, they have a more difficult time adjusting from home to school life (Cammarata et al., 2009).

**Strategies**

The pediatric diabetes education literature provides scant evidence with respect to behavioural intervention strategies designed to support children with Type 1 diabetes (T1D) in their pursuit of glycemic control within school settings. However, Lasecki, Olympia, Clark, Jenson, and Heathfield (2008) examined the usefulness of a specific behavioural intervention (mystery motivator) for four patients ages 8-12 under two variations of behavioural consultation to improve treatment compliance for T1D: *behavioural consultation* (BC)\(^1\) and *conjoint behavioural consultation* (CBC)\(^2\). The authors used an intermittent reward procedure to reinforce individualized target

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\(^1\) Behavioural consultation (BC) involves an indirect service delivery approach, typically with a parent or teacher as the consultee. Conceived by Bergan and Kratochwill (1990), BC involves indirect service delivery to a student through a consultee, such as a parent or teacher, by a consultant (e.g., school psychologist, school administrator, or counsellor). Therefore, BC involves only at most three participants: consultant, consultee, and client.

\(^2\) The CBC model is a variant of BC. Although it uses an indirect form of service delivery (with distinct stages for problem identification, analysis, etc.), it makes use of a broader range of consultees. For example, parents, teachers, and other support staff from schools work with a consultant to address problem health and/or academic behaviours. These individuals form an alliance to provide assistance in the environments where children are having difficulty. Working with a consultant, multiple consultees share responsibility for developing and implementing the intervention (e.g., School Health Support Services) and evaluating its effectiveness (Sheridan & Kratochwill, 1992; Sheridan, Kratochwill, & Bergan, 1996).
behaviours associated with treatment noncompliance. All participants were found to have made gains in appropriate blood glucose levels and self-management behaviours, but improvements were the greatest for the CBC condition in which multiple consultees, including teachers, parents, and medical professionals, worked with the school psychologist.

Other less interventionist measures, such as *direct supervision*, tend to increase children’s glycemic control and their concordance with an established medical health plan. Nyugen and colleagues (2008) trained school nurses how to provide diabetes care through direct supervision of self-care behaviours, including blood glucose monitoring and insulin injections, for students with poorly controlled T1D (HbA1c ≥ 9%). In comparison to the control group (N = 18), the intervention group (N = 18) demonstrated evidence of improved HbA1c levels (reduction by 1.9%), suggesting that health professionals or others in the line of health caregiving duties can assist children with poorly controlled blood sugars in making positive headway in their management of glycemic control.

Outside of group-facilitated and individually led interventions used to assist children in their self-care, researchers have explored the use of pedagogical interactions taking place between individual caregivers and the care-given. One such technique—*motivational interviewing*—has evidenced some beneficial results for supporting positive behavioural change in children who demonstrate ambivalence or avoidance towards diabetes self-care (Kucera & Sullivan, 2011). Defined as “a particular way of helping clients recognise and do something about their current or potential problems” (Rubak, Sandbæk, Lauritzen, & Christensen, 2005, p. 305), motivational interviewing is a
technique that relies upon identifying and mobilizing the client's intrinsic values and
goals to stimulate behaviour change (Emmons & Rollnick, 2001) through open
questioning, reflective listening, agenda setting, summarizing, and discussing, which is
meant to facilitate positive behavioural change (Kucera & Sullivan, 2011).

In a meta-analysis of the pediatric chronic care literature on motivational
interviewing (N = 37), Gayes and Steele (2014) discovered that the effectiveness of MI in
pediatric domains was moderated by factors such as practitioner background, health
domain, and the type of chronic health condition targeted by the intervention. The overall
effect size was slightly higher than a small effect size and also slightly higher than what
has been typically found in the adult substance users literature. Effect sizes varied by
health condition with the largest overall effect sizes attributed to Type 1 diabetes, asthma,
and calcium intake, suggesting that MI can be a useful and appropriate intervention for
targeting child health behaviour changes.

Not entirely unlike motivational interviewing is the use of behaviour contracting
and behaviour modification protocols, with or without reinforcement contingencies.
Through these strategies, educators of children with diabetes orient themselves to
students by teaching them self-management and coping strategies, all of which
technically find their derivation external to the particular children in question and to their
own goals and intrinsic values. Halvorson and colleagues (2005) showed the use of
behavioural contracting coupled with reinforcement strategies to be an effective means of
improvement in treatment adherence, while Wysocki (2006) determined that teaching
elementary students how to manage their diabetes with more autonomy through
behaviour modification protocols, such as reviewing glucose meters with memory recall
or data logbooks or charts displaying patterns of glycemic behaviour, resulted in an increase of glycemic control in home and educational settings.

Other pedagogical strategies have been tried for children with chronic health care needs. Howe and colleagues (2005) showed that telephone case management—featuring periodic conversations between caregiver and client involving the exchange of health information followed by recommendations for practice and after that positive reinforcement—was effective in increasing patient concordance with his or her existing health plan among 13 children aged 9 to 15, compared with 28 peers who received only training or case management. However, Nordfeldt and associates (2013) demonstrated that educating children by telephone over 6 months led to no significant effects on behaviour. Similarly, Nunn, King, Smart, and Anderson (2006) showed that caregiver monitoring over the telephone alone proved unsuccessful in leading to changes in treatment adherence for children with diabetes.

**Peer support** and **mentorship models** typically work through social network members offering emotional, appraisal, and informational assistance to the individual with chronic illness (Dennis, 2003); the quality of that assistance tends to be largely owing to experiential knowledge (Heisler, 2007). While previous peer support interventions have been highly variable in format (e.g., small groups, one-to-one in-person or through telephone, and web-based chat rooms), amount of mentor training, and group composition (e.g., homogenous or mixed, with or without disease and disease type; Embuldeniya et al., 2013), they have in the main proven beneficial in complementing the intermittent supervision or involvement of caregivers in the service to support self-care management (Newman, Steed, & Mulligan, 2004).
Applied to the school context, peer support and mentorships are typically forged through positive relations with classmates or close associates embarking on a shared experience with another student, usually someone with similar values, interests, and tastes in curricular and extra-curricular activities (Schwartz, Rhodes, Chan, & Herrera, 2011). In the case of students with chronic illnesses, usually the formation of peer support circles have occurred after some initial input by the classroom teacher, such as having a classroom meeting or descriptive presentation to model problem-solving strategies and reflections on best and poor practices (La Greca et al., 2003). For example, Greco, Shroff, Pendley, McDonell, and Reeves (2001) developed a group program for young people with diabetes and their best friends to encourage friends to become involved with diabetes management. After the intervention, the students with diabetes and their friends reported greater diabetes knowledge and support, while parents reported having less diabetes-related conflict with their sons or daughters.

**Interpretation of the Review Findings**

An in-depth analysis of the literature has revealed perspectives on the ways in which family, health, and educational systems have so far operated in the care of elementary students or young children with diabetes and which forms of practice have supported or inhibited the development of self-care. With respect to health and educational policy systems in the context of Ontario and New Brunswick public schools, educational and health practitioners working within such environments give tacit consent to the duties of care according to the provincial policy statements on inclusion and school health support services (SHSS). The formation of self-care should therefore be expected
to differ on account of the personal and environmental factors that make up the topology of care brought into being in the particular school setting.

While existing research has found a strong correlation between self-care ability and age of the child with diabetes, less attention has been paid to the experience of caregiving among educational practitioners in the development of self-care. This study thus enters into conversation with the existing literature with the expressed purpose to add insight into the unexplored terrain relating to the contextual factors and experiential variables that make up caregiving for children with diabetes from the perspectives of New Brunswick and Ontario elementary teachers.
CHAPTER 4: METHOD

This study explored the perceptions of elementary school teachers in the care for past and/or present students with diabetes mellitus (DM) in New Brunswick and Ontario. Building on the study by Wang and Volker (2012), this study used a Husserlian phenomenological approach to qualitatively understand how eight experienced elementary teachers (four from each province) made sense of caring for these students. Using Wagner’s (1998) Chronic Care Model as a theoretical map, the focus was on teachers’ knowledge, beliefs, and practices involved in their relationship with past and/or present students with DM.

Using a phenomenological approach was the ideal choice among several qualitative research paradigms, as this method enabled me to specialize in unveiling the multiple, intersecting threads of meaning that culminated in the teacher perspectives of school-based diabetes care. This study adopted the use of individual, in-depth, semi-structured interviews to examine the teachers’ self-perceptions and their feelings about their involvement in supporting the self-care learning process in their students. The eight interviews enabled me to enter into an understanding of the world of each teacher as experienced through the teachers’ own stories, specifically reflections of past, present, and future circumstances as envisioned in contribution to the development of self-care. The interviews assisted in articulating an intuitive vision on the complex interplay of

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3 Husserl’s phenomenological approach is a type of research method used to uncover the fact that human experience is fundamentally a layered phenomenon, one that involves an intersection of self and others’ lives (Costello, 2012). Husserl’s approach is widely used in health and social science research to examine the levels or layers of caring relationships (Miller, 2003; O’Conner, 2008; Salmon, 2012). The Ontario and New Brunswick teachers were thus approached as two distinct but interconnected groups of subjects who face the world through their experiences of care in relation to past and/or present students with DM.
diabetes management, pedagogy, and teacher identity in the performance of medical services for these students (Schwartz et al., 2010).

Phenomenological studies are based on the word “phenomenon,” which comes from the Greek *phaenesthai*, meaning “to flare up, to show itself, to appear” (Dowling, 2007; McNamara, 2005). As a researcher in the mode of phenomenological research design, I was able to relate to the participants through adopting sensitivity for the study of emergent stories as they appeared in the context of the individual interviews.

**Procedures**

**Setting**

This study took place in two medium-sized cities in New Brunswick and Ontario. In New Brunswick, one School District was approached and agreed to participate. In Ontario, two School Boards were approached and agreed to participate (a Public Board and a Catholic Board).

**New Brunswick.** Like all the other School Districts in New Brunswick, the selected District administers diabetes management services to diabetic students with health support needs according to the provisions of the School Health Support Services (SHSS) program. The specialized care made available to these students is vested under the authority of the New Brunswick Department of Education. Based on the most recent School District Annual Report, roughly 858 educators in full-time positions were employed for the 2011 school year in the Board, with a pupil/educator ratio of 14:1. From the Office of the Chief Medical Officer of Health (2011), roughly 620 New Brunswick children and adolescents were living with diagnosed diabetes, a 12% increase from 2002-03. According to these estimates, the prevalence of diagnosed diabetes in New
Brunswick’s children and adolescents has been on the rise, with an average of 78 new cases of diabetes being diagnosed on an annual basis among young New Brunswickers, aged 1 to 19 years. These statistics partially contribute towards New Brunswick having a higher percentage of individuals with physician-diagnosed diabetes (6.0%) compared to Ontario (4.8%), aged 12 years or older (Sanmartin & Gilmore, 2008).

**Ontario.** Since 1984, Ontario School Boards under the terms of Policy Program Memorandum No. 81 (PPM 81) have delivered specialized care programs and services for children with special health support needs (e.g., children with DM). These programs and services of care are operations administered under the collective directives of community, education, and health departments of governance (Ontario Ministry of Education, 1984). Ontario Boards of Education have developed formal policy guidelines that serve to extend the provisions of PPM 81 to the school setting. The policy for the Catholic Board features distinct diabetes management guidelines for which each school in the Board is held to account. All participating Board school members are obliged to share in the demands placed for diabetes management, with teachers in particular encouraged to envision themselves as integral partners in this task. Similarly, the Public Board has formulated policy surrounding the issue of diabetes management at school. This policy features an outline of the Board’s philosophy of diabetes management as well as the general operating procedures that inform their model of diabetes care at school.

According to the most recent data published in the Ontario Ministry of Education’s *Operational Review Report* (2010), 720 full-time Anglophone teachers were employed in full-time positions for the 2009-2010 school year in the Catholic Board, with a pupil/educator ratio of roughly 15:1. Based on the most recent *Director’s Annual*
Report (2013), 780 Anglophone elementary school teachers in full-time equivalent positions were employed in the Public Board for the 2012-2013 school year, with a pupil/educator ratio of approximately 16.9:1. More than 66,000 Ontarians, or approximately 0.3% of Ontario children aged 1-19 years, are estimated to live with diabetes since childhood (MOHLTC, 2014). Its incidence is increasing by 3% to 5% annually, with the greatest rise occurring in children aged 5 to 9 (Juvenile Diabetes Research Foundation [JDRF], 2011). Furthermore, the incidence of childhood diabetes increased by 48% between 1992 and 2002 (Lipscombe & Hux, 2007); estimates project these numbers to rise steadily for Ontario going forward (Public Health Agency of Canada, 2011).

Ethical Considerations

Prior to the start of this study, I completed the Course on Research Ethics (CORE). After its completion, I sought ethical clearance from the General Research Ethics Board (GREB) at Queen’s University (see Appendix B). In New Brunswick, the School District awarded ethics clearance in the 2013-2014 school year via email. In Ontario, both the Boards granted ethics clearance in the 2013-2014 school year on official letterheads. All participants provided signed, formal consent to participate in this study.

Participants

Recruitment Strategy. At the outset of this study, I used purposeful sampling (McMillan & Schumacher, 2010). The participating teachers in this study were recruited from the NB School District (N = 4), the Ontario Catholic Board (N = 2), and the Ontario Public Board (N = 2). They met the following inclusion criteria:
• teacher with qualifications to teach Kindergarten to Grade 8 (need not be all grades in this range);
• currently working or has worked in collaboration with a certified health professional, and/or social worker, and/or educational stakeholder in the context of the School Health Support Services (SHSS) program;
• delivering care or delivered care to a student with diabetes mellitus in the school setting; and
• employed at an Anglophone elementary school in one of the three School Districts/Boards.

The recruitment of participants took place over the course of two phases, starting with the NB School District; followed by the Ontario School Boards. Qualitative data collected from teachers prior to the one-on-one interview illuminated perspectives on their employment status and history, professional qualifications, and training in diabetes management. Such data helped to confirm that all teachers met the inclusion criteria for participation in the study, so that I could proceed with conducting the one-on-one interviews with them.

**NB School District.** In August 2013, I began to recruit eligible teachers on a first come, first serve (FCFS) basis immediately after having gained NB School District ethics clearance in the same month. An official representing the NB School District agreed to electronically distribute recruitment notices (see Appendix C) to principals of eligible teachers. This method proved effective in recruiting one teacher who had a student with DM currently in her classroom.
By late September, I employed the snowball sampling strategy through the assistance of another on-campus colleague, as a means to recruit the remaining three participants for my study. Such a method got me in touch with a school principal, who led me to contacts with three more teachers from three additional schools. To ensure that the contacted teachers were eligible to participate in the study, I distributed the Letters of Information (Appendix D) and Consent Forms (Appendix E) via email and asked for their participation. After talking to each one on the phone, I forwarded to the interested participants the demographic questionnaire (Appendix F) and interview guide (Appendix G) as they had requested.

For this study, the participants were four female Anglophone public elementary school teachers. One teacher—Kathleen—was a support staff specialist (Kindergarten to Grade 5) at her school, while the others—Susan (Kindergarten), Rachelle (Kindergarten), and Casandra (Grade 5)—were classroom teachers. Every teacher had at least 5 years of teaching experience but not more than 14 years, within which each had worked with at least another educational stakeholder in the SHSS program during that timeframe. Every teacher had had at least one student with DM formerly in her care, while only one, Rachelle, additionally had a student with DM presently in her classroom.

**Ontario School Boards.** Encountering the same types of recruitment difficulties in Ontario, I followed a similar two-phase recruitment protocol: first, email recruitment followed by snowball sampling. By late March 2014, I completed the recruitment process in Ontario and had thereby concluded the second phase of my overall recruitment strategy for this study.
The participants were Anglophone elementary public school teachers. Two
teachers—Tim and Paul—were representatives of the Catholic School Board, while two
others—Greg and Lacy—were from the Public School Board. Greg and Paul had each a
combined grades classroom (Grade 1/2, Grade 5/6), whereas Lacy (Grade 1) and Tim
(Grade 2) had single grade classrooms. Every teacher had at least 5 years of teaching
experience but not more than 14 years. Every teacher currently had a student with DM in
his or her care and worked with at least one other educational stakeholder in addressing
the health needs of the student in the context of the SHSS program. Only one teacher,
Greg, had had a former student with DM in his care, in addition to having one this year.

Data Collection

Data were collected through individual, audio-taped, semi-structured, in-depth
interviews in New Brunswick and Ontario. At the request of each participant, the
interviews took place in a comfortable setting at school or off-site at a nearby quiet
location. Field notes were taken during the course of the interview session (Wolfinger,
2002); furthermore, each session was audio-recorded through the use of two digital
recording devices.

The interviews were designed to capture the “layers or levels of sense” (Costello,
2012, p. 5) teachers held as perceptions of their experience in addressing their students’
health support needs. Interview questions were delivered mostly in a set order, but with
some flexibility in the questions asked, the extent of probing, and the emphasis given to
key terms (McCracken, 1988; Rowley, 2012). Probes such as “Please say more about…,”
“What do you mean…,” and “Give an example of …” were used extensively to elicit
deeper descriptions of the teachers’ perceptions of their experiences in response to
previously addressed questions. The data collected included audio recordings of the sessions and field notes written in the course of the interviews. The type and amount of these data points are described in Tables 1 and 2.

Table 1: *Data Collected from New Brunswick Teachers*

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<th>Initial interviews</th>
<th>Audio file length in minutes</th>
<th># of transcribed pages</th>
<th># of field note pages</th>
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<tr>
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<td>13</td>
<td>6</td>
</tr>
<tr>
<td>Susan</td>
<td>90:32</td>
<td>15</td>
<td>8</td>
</tr>
<tr>
<td>Rachelle</td>
<td>89:03</td>
<td>15</td>
<td>9</td>
</tr>
<tr>
<td>Casandra</td>
<td>90:02</td>
<td>14</td>
<td>8</td>
</tr>
</tbody>
</table>

Table 2: *Data Collected from Ontario Teachers*

<table>
<thead>
<tr>
<th>Initial interviews</th>
<th>Audio file length in minutes</th>
<th># of transcribed pages</th>
<th># of field note pages</th>
</tr>
</thead>
<tbody>
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<td>14</td>
<td>7</td>
</tr>
<tr>
<td>Paul</td>
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<td>24</td>
<td>8</td>
</tr>
<tr>
<td>Tim</td>
<td>144:00</td>
<td>33</td>
<td>9</td>
</tr>
<tr>
<td>Lacy</td>
<td>151:11</td>
<td>32</td>
<td>9</td>
</tr>
</tbody>
</table>

I started each initial interview by reviewing with the participant his or her responses to the demographic questionnaire, which had been completed and submitted to me prior to the interview session. Some clarification questions were used to further probe on responses that were unclear (e.g., acronyms, colloquialisms), allowing participants to adjust their answers.

The second part of the interview consisted of five questions about the teachers’ beliefs in relation to the care for diabetes, while the third part focused on their practices. The interviews concluded with a question asking the teachers whether or not they had anything further to share that was not previously addressed. Overall, the questions covered the participants’ feelings, values, beliefs, and knowledge about their everyday “lebenswelt (life-world)” (Husserl, 1970, p. 173; see Appendix G). Focusing on these
three areas of the teachers’ perceptions of caring for the health needs of their students with diabetes helped me to place the teachers’ self-reports into several “layers and levels of sense” (Costello, 2012, p. 5), thus providing multiple, intersecting, and overlapping threads of experiential evidence.

During the interview, two digital recorders were used to record the conversation and the participants’ responses. I wrote down any observations that were made about the participant through non-verbal language; field notes were taken to help guide the performance of my interviewer role and to help me to further understand the participants during the data analysis phase. At the conclusion of the interview, I thanked the participants and provided a $25 honorarium for their participation. I reminded the teachers about the possibility of further contact from me should there emerge clarifications and/or follow-ups from the initial interviews and gave them my business card. While I contacted all the New Brunswick teachers with clarification questions about their interviews, none responded. Given the lack of response from the New Brunswick teachers and the need to complete my thesis in a timely fashion, I did not contact the Ontario teachers any further.

Data Analysis

Coding of the data took place inductively and reductively through four stages of development, consistent with Moustakas’ (1994) four-part phenomenological schema for analytical interpretation; namely, epoché, phenomenological reduction, imaginative variation, and synthesis of texture and structure. The purpose of phenomenological analysis from epoché through to synthesis of texture and structure is to “determine what an experience means for the persons who have had the experience,” so that the researcher
may “obtain comprehensive descriptions that … portray the essences of the experience” (Moustakas, 1994, p. 13).

In the early stages of my analysis, I attempted to suspend preconceived judgement (epoché) by encapsulating “taken for granted assumptions,” (Husserl, 2012, p. 58), so that I gradually but deliberately removed myself from the “natural attitude” (Husserl, 2006, p. 2). From epoché, I became concerned with initiating the practice of labelling key parts of the data (phenomenological reduction), using initial and open-coding techniques. I gradually became more and more attuned to finding emergent patterns, learning in the process how “general or universal meanings are derived” (Moustakas, 1994, p. 13). This analysis was supported through the use of focused coding labels, which helped to further describe the participant interviews and researcher-scribed notes.

From the analytical stage of phenomenological reduction, further patterns emerged and recurred as interpretation manifested through the final stage of the data-coding framework: axial/thematic coding. At the imaginative variation stage of data interpretation, I conducted several readings of the data, each time scanning the patterns to detect whether or not duplication and overlap of meaning could be detected in the data along with the corresponding set of focused codes (Moustakas, 1994).

With conducting an imaginative variation approach to the text, I tried to uncover the essences of the existential experiences of all the participants, which culminated in the synthesis of texture and structure of four constructs: (a) Roles and Responsibilities; (b) Communication; (c) Inclusionary Practices; and (d) Coping with Care. The sequence for the NB and Ontario data-coding project using the Moustakas phenomenological model is illustrated in Figure 2.
Using thick description based on selections of direct quotations from the eight participant transcriptions and key observations from the field notes (Hays & Singh, 2012), I constructed a portrayal of the data representative of the group of NB and ON participants involved in the study. Such portrayal of the data described what happened in the care for the students with DM and how that experience occurred from the perspectives of the eight teachers (McMillan & Schumacher, 2010). Throughout the write-up of the research data, the narrative representation of the data emerged,
uncovering the participants’ relationships in terms of what it was like for them to live among self and others through caring for their students with diabetes, while further revealing the data as a nested phenomenon (Moustakas, 1994), featuring spheres of intersecting and overlapping influence describing the nature of the participants’ subjectivity in such a context. Respectively, these spheres of influence include: roles and responsibilities, communication, inclusionary practices, and coping with care.

**Validation Procedures**

For this study, I sought to use phenomenological research methodology in a trustworthy manner (Moustakas, 1994). Although trustworthiness in phenomenological research involves variance as projected in both theoretical and technical concerns (Husserl, 2006), it is based on the maxim that “the researcher did everything possible to ensure that data was appropriately and ethically collected, analyzed, and reported” (Carlson, 2010, p. 1103). Three main validation procedures were used: (i) pilot study; (ii) journalling; and (iii) debriefing. These validation procedures were selected to remain congruent with the research process and to give further expression to the phenomenological research tradition overall (Finlay, 2012; Moustakas, 1994).

**Pilot Study**

Before the project was fully undertaken, I conducted a pilot study to (i) see the extent to which in-depth interviewing would be effective in the collection of participant data and (ii) test the interview protocol. It was also hoped that (iii) any other practical issues and difficulties could be discovered to see if they could be resolved before the main research began.
Two educational caregivers, Amanda (a Grade 8 teacher) and Vicky (a Grade 3/4 Educational Assistant) were recruited for the pilot study using the recruitment email (Appendix C). Each signed a Consent Form (Appendix E) to participate in the pilot study after having read the Letter of Information (Appendix D). The methods of data collecting used in this pilot were in-depth interviewing and field notes, which permitted *intra-* (that is, while the interviewing was taking place) and *post-*reflections of this pilot experience. Semi-structured interviews were conducted at the participants’ homes, their choice of location. Each interview was approximately 100 minutes in length and was recorded on a digital voice recorder as well as on an MP3 player voice recorder. In this pilot, participants offered suggestions to improve the pilot process, including clarifying interview questions; advising me on the appropriate use of probing questions; and pointing out how to make better use of field notes to aid in facilitating smoother transitions between interview questions. These suggestions were taken to the researcher’s thesis supervisor, who aided in the revision of the pilot research instruments (Demographic Questionnaire and Interview Guide; Appendices F and G) and in the refinement of data gathering in the interviewer-interviewee context (Miller, 2003).

**Journalling**

From the start of my graduate studies experience in education (September, 2012), I have kept a digital journal detailing the record of my growth as a qualitative researcher. Journalling reflexively through the NVivo software program (Version 10) has enabled me to construct an archive of my journey throughout the research process (Ahern, 1999; Tufford & Newman, 2010). I have attempted to facilitate the unveiling of “preconceived beliefs into dialogue” (Harry, Sturges, & Klingner, 2005, p. 7), so that I could render
explicit the implicit forces of researcher biases, assumptions, and aspects of my own personal background (Carlson, 2010). Through journalling, I have found that my engagements within the context of the inquiry were reflexively encountered through modes of “rigorous self-scrutiny” (McMillan & Schumacher, 2010, p. 332), as well as through keeping my implicit prejudices in check insofar as possible (Peshkin, 1988). Aspects that were explored include: my assumptions regarding demographic characteristics; my place in the power hierarchy of the research; my personal value system (Hanson, 1994); my potential role conflicts with research participants; feelings such as blame or disengagement that may have indicated presuppositions (Paterson & Groening, 1996); and my choice to write in the first person (Porter, 1993). An example of an NVivo journal entry is displayed in Figure 3.

Figure 3. Memos\Animating my research standpoint. Excerpt from EDUC 802_Curriculum of Difficulty. Dec. 6, 2012
Debriefing

After showing some difficulty with interpretation in the early stages of data analysis (January 2014), I was recommended to partition the write-up of my data analysis into submissions of sequences of paragraphs. This recommendation initiated the start of a series of debriefing-like sessions with my thesis supervisor, which manifested as critical correspondences and were predominantly exercised through email (N = 540), but also arranged over the telephone (N = 8) and conducted in-person (N = 7).

Debriefing is typically used to make the research process more transparent by motivating the researcher to document the evolution of a research study to a “disinterested peer” (Lincoln & Guba, 1985, p. 308), someone who can offer “another check outside of the designated research team” (Hays & Singh, 2012, p. 211). However, when used with integral members of research teams, such as with an experienced researcher, it can provide a trustworthy avenue to triangulate interpretations of the research data (Carlson, 2010). In acknowledgement of these considerations on the practice of debriefing, I entered into debriefing sessions with my thesis supervisor. The purpose of these sessions was to (i) elicit critical and ongoing examinations of the research data; and (ii) systematically organize constructive feedback throughout the data analysis research process. Accordingly, evidence-based adjustments to future phases of the current study were implemented emergently and coherently with the research data (Lincoln & Guba, 1985). Figure 4 shows a typical example of the refinement process used to shape a drafted document to its final form.
John Freeman <freemanj@queensu.ca>
To: Sean Cousins <spwcousins@gmail.com>

Thu, Jul 17, 2014 at 9:06 AM

Until this paragraph, I thought Kendall was female. I would like you to change his name to Ken as his being male is critical to the narrative, and I thought Kendall was a woman's name. I am also not keen on Leslie as a name because everyone I know whose name is spelled that way is a man, although I recognize Leslie can be a woman's name. Gender seems to be an important trait in these stories that you hide through using androgenous names.

John

Figure 4. Debriefing Example
CHAPTER 5: NEW BRUNSWICK RESULTS

This chapter reports on the results of data collected from New Brunswick. Through thick description of the teachers’ perspectives, four narrative accounts have been produced to represent the embodiment of care that Kathleen, Susan, Rachelle, and Casandra had in their relations with students with diabetes. Each narrative is introduced with an excerpt highlighting the experience of the teacher in her own words. Following the excerpt is a brief statement introducing the teacher from data drawn from the demographic questionnaire. The narrative then unfolds through four themes that provide a fuller account of the perspectives of the teachers: Roles and Responsibilities, Communication, Inclusionary Practices, and Coping with Care.

Kathleen

My experience is more the paper experience—behind the scenes. It’s okay not to know everything. It’s impossible. As long as the student with diabetes and the teacher feel comfortable with the plan and they act safely with the medical procedures, we can say that we’ve done our best to set everyone up on a healthy path. We’re good to go. That doesn’t mean we roll the dice once the paperwork is done. It’s never over.

Kathleen is an elementary teacher in Fredericton, with 5 to 14 years of teaching experience. She works with Kindergarten to Grade 5 students as an Education Support Staff specialist. While she has a Master’s of Education, a Bachelor of Education, and a Bachelor of Arts, she does not possess any postsecondary credentials related to diabetes.

Roles and Responsibilities

At Kathleen’s school, care for students with diabetes is typically shared among a circle of caregivers: the student with diabetes, his or her parents, and the classroom.

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4 Years of teaching experience when expressed as a range were taken from the demographic questionnaire, which asked for experience based on a range.
teacher. Kathleen has contributed to the “diabetes management and emergency plan,” a policy document that features a list of caregiver responsibilities for implementing the provision of SHSS for students with diabetes. The most important aspect of Kathleen’s role in diabetes care is “making sure that the staff is aware and comfortable with their responsibilities … in a way that enabled the students to pursue their education safely, comfortably, and proactively”; the other caregivers have typically exercised specific roles. Children with diabetes are expected to “work with their parents to feel good about communicating their needs for testing and for help when they felt another hand was needed at school.” These children’s parents “help in that education.” They need to teach their children about how to “share needs about diabetes with others.” Meanwhile, the classroom teacher has to ensure “she followed the plan and that the child was kept safe and could participate as much as possible in the life of the school.”

Meetings with parents are facilitated by Kathleen, who makes teachers aware of what obligations they hold, and how these obligations might play out in relations with the student. Teachers need to “know what the behaviour looks like when the sugars are running low.” Teachers become “proactive” to “identify earlier stages of low blood sugars” and “to get juice quickly before the low descended into more dangerous territory.” The meetings outline “what works to support the child’s safety, comfort, and self-esteem.” These three values—safety, comfort, and self-esteem—are intended to provide the teacher with the moral tools necessary to build self-care in the child, a point at which “the child can be trusted to monitor his or her diabetes.” The child is expected to eventually self-regulate “food intakes and sugar levels.” Parents stock the school with “the appropriate foods to eat” when and where necessary, all the while maintaining a
supportive home,” an environment that initiates the child into a “knowledge of their [his or her] own condition,” while also promoting “a healthy active lifestyle.”

The SHSS plan for students with diabetes acquires the signature of self-care development over the course of these students’ academic career. For example, two children with diabetes, Emily and Claire, attended school “a couple of years ago.” Both students were “diagnosed prior to coming into the school,” so when they entered Kindergarten, these children, alongside their parents, “came in to complete the plan.” At that meeting, the children were initiated into the expectation not only to “work with their parents to feel good about communicating their needs for testing” but also to ask “for help when they felt another hand was needed at school.” As the girls got older, the plan showed evidence of increasing autonomy over health management.

As the Education Support Staff specialist, Kathleen’s “job” is concerned with facilitating “awareness” of school caregiver responsibilities, while at the same time “making sure that my [her] staff feels comfortable” with these responsibilities. In the case of the diabetes care program, Kathleen’s work essentially involves “getting the information out there,” such as posting the student’s health profile in “the school staff room,” so that visitors can come to understand which students in the school require specialized care to address their health support needs.

Communication

The communication of diabetes and its management at school starts before the student enters into the teacher’s care. For students with previously identified medical conditions, Kathleen ensures that they have “received a letter to be sent home on the first day of school to make sure the plan is updated.” Although the terms of the plan may not
officially change from one school year to the next, the teacher of the student with diabetes “continues the tradition of talking with him or her and the parents to make sure that we are all on the same page.” In the event of the teacher having no prior experience in the care for a student with diabetes, Kathleen is inclined to “arrange for a parent meeting,” which essentially acts as “a communication practice,” something that “organizes everyone, the parents, the kid, and the teacher, in a caring network that starts then and lasts for the school year.”

Information about diabetes care in New Brunswick can be found online. School caregivers, such as “teachers, those in the office, and support staff,” for example, can visit “the New Brunswick Education website.” Such caregivers only need to “click on the [name of school district] portal and from that page click to a specific school.” On Kathleen’s school webpage (“an under-utilized resource”), “a portal that anyone in the district can go on to and see what we have posted,” one can navigate to find links to “medical forms,” such as “the Essential Routine Services and Emergency Plan,” the “Handbook for Type 1 Diabetes Management in Schools,” and “the medical alert bracelet application.” These forms feature “guidelines about how to fill out the medical health information” and “tips about how to practice care routines for students with health support needs.” Kathleen found out about “the portal” after her neighbour “brought attention to the plan, telling me that the school board has this plan in place.”

The communication of diabetes and its management in the classroom involves health and school caregivers contributing “a credible voice,” that is, “a language, you know, that works to bring the school up to speed.” Health caregivers, including “the public health nurse” and “nursing students from the [local university]” and school
caregivers, such as “parents” and “teachers with previous experience,” have the capacity to “lend a powerful perspective on diabetes to us [the school].” However, which caregiver Kathleen would recommend to fulfill the objective of “knowledge upgrading” regarding diabetes care “depends on the severity of the case,” meaning “whether and to what degree the child manages the diabetes.” The public health nurse would be the appropriate health caregiver to invite to the classroom when “we’re [the teachers] having issues with managing the health status of the child, like frequently responding to fainting or seeing the child has the inability to control.” The nurse would also be appropriate if “parents or teacher are in the learning stages themselves.” If “the parents or the teacher are super-versed in diabetes” and “feel comfortable in speaking,” then Kathleen would ask for these individuals to speak to the class on behalf of the child who is “able to manage but needs some help with explaining everything.”

Kathleen’s school regularly welcomes the perspective of “the [local university] nursing students,” a postsecondary internship consisting of “third and fourth year level students.” Each year, in the fall, “the third year nurses come in, underneath the supervision of their professor,” and “they talk to the classes, covering some of our health curriculum.” In the winter, “the fourth year students visit and cover a different aspect of the curriculum [health], and have more involvement in the activities.” The purpose of the visitations is to “talk about a variety of things within the health curriculum,” including “having a conversation about what it is like to live with disabilities and doing several activities with them [students].” If Kathleen “wanted them to do a classroom presentation on diabetes, they would have no problem sharing their perspective and giving a lesson on how to support the child who has it [diabetes mellitus].”
The management of diabetes at school involves, among other things, “testing for sugars” and “shots,” the results of which are “jotted down” in “a little notebook.” The notebook is a “mobile agenda,” which the teacher uses “to have the trail going”; it “kept the parents in-the-know” about “what dose was given; where it was given; who gave it; and at what time”—essentially, “where the child’s health is at.” The teacher can also use the notebook to “tell the parents” when “extra stuff” or “extra supplies” were “running low.” The notebook is furthermore a place where parents “make notes” to the teacher, who then can “see what the parents feel.” If the parents say “they may want to make a presentation or do book talks,” for example, “sometimes we will have parents come in and talk, especially when their son or daughter is very young.” In their visitation to the classroom, the parents “may either read a book about a child on diabetes or they’ll come in and share information with the kids” to make “the kids … feel comfortable.”

There are three levels of communication that need to occur: with medical professionals outside the school, among professionals within the school, and from teachers to students. For example, Kathleen and another classroom teacher once entered into conversation with a doctor, who told them that a Grade 5 male student “was having a lot of problems with his blood sugar and that the diagnosis was going to be happening.” In consequence, “we threw in a few extra gym classes just to get him to be more active. We started to monitor what he was eating, too.” As far as between-teacher communications, Kathleen “had a lot of different conversations checking in with the Kindergarten teacher when the two girls [students with diabetes] started off.” Those conversations centred on what “she [Kindergarten teacher] really had to watch,” specifically “what food they were having and helping get the child [girl with diabetes]
ready to test and clean-up.” In the case of teacher communicating with a student, the Kindergarten teacher, upon noticing the student’s “sugars were running low,” commented, “‘you [girl with diabetes] need to do this.’”

Students with diabetes are expected to “be a bit more aware of their body and what it was telling them” and to communicate this awareness to their teachers. Such “internal dialogue” allows the student to “identify how he or she is feeling.” For example, “if you’re having low blood sugars, what does your body look and feel like?” The teacher needs to understand “the child’s perspective,” a viewpoint that consists of “what it is like in getting to a point of being low or high.” To gain that understanding, Kathleen recommends the teacher to “have the kids draw that out,” so that, in turn, the teacher knows “what to look out for before it [hypoglycemia or hyperglycemia] happens.”

**Inclusionary Practices**

Diabetes management and diabetes self-care are two ways through which the health support needs of students with diabetes are addressed at Kathleen’s school. Kathleen believed that “diabetes management seems to be more of an external operation.” In that context, students are “externally driven,” relying on the teacher to tell them “to do something.” Self-care, however, is about “not relying on anything outside to spur healthy active living.” It means “having the impulse to lead a healthy active lifestyle, showing the care for blood glucose levels, eating appropriate foods, regularly exercising, and making sense of what the body is telling you” so as to understand “what you need and what your body doesn’t need.”

Students with diabetes show an orientation to self-care when “being proactive” or when making “proactive choices,” such as “taking steps in the direction of good health”
or when they “want to work on their health.” In these contexts, such students “make the management a lot easier,” so that their teacher has “a much easier go.” The two girls with diabetes—Claire and Emily—“each came from a home that was so supportive” and had “very proactive” parents. In addition, the girls “would carry on being attentive to their health needs.” The girls kept “the teacher abreast on the status of their sugars,” telling their teacher when they felt “a little low.”

However, students who show “a lack of attention to the needs of the body” typically require “more outside help,” which positions them to experience “having the teacher weighing in more, not for school learning itself but for reasons of health and safety.” One household known to Kathleen’s school “didn’t always feed their children the healthiest of food.” The Grade 5 student in that family who was about to be diagnosed with diabetes did not generally eat “healthy foods” nor did that student show an “appetite for being active.” Kathleen and her teacher colleagues encouraged the student to become “more active,” having him participate in extra gym classes. Furthermore, Kathleen’s school started to monitor the student’s eating behaviours.

At Kathleen’s school, all students, regardless of health condition, participate in lessons “based on Stephen Covey’s work - The Seven Habits for Highly Effective Children.” Teachers “strive to construct lessons that nudge the students into believing that health and learning go hand-in-hand.” Kathleen recognizes that “New Brunswick is known for being unhealthy.” Furthermore, “there are studies that show we are a very inactive province.” To address these negative outcomes and the reality of having “students with all kinds of different health needs,” teachers at Kathleen’s school used Covey’s Healthy Habits as “a motivational tool” to inspire students—with and without
diabetes—to listen to their bodies and to take action on its behalf. Such habits might be critical for students with diabetes to establish, according to Kathleen.

**Coping with Care**

Kathleen feels “a bit rushed” in the first month of the school year. During that timeframe, Kathleen is preoccupied with “putting the pieces into place for everyone,” organizing “health plans” that are built upon having “strong social and physical supports.” Kathleen has mobilized health information to inform school personnel about which students have diabetes. Such mobilization has to be done in a timely manner to construct a “safe” environment for these students and to address the teachers’ needs to feel “comfortable” with their duties of care.

Students in Grades 3, 4, and 5 at Kathleen’s school take “mindfulness training.” Once a week and for half an hour, the guidance counsellor and the classroom teacher help students increase their ability to “monitor and to self-regulate.” Similarly, last year, Kathleen taught a class of Grade 3 students with special education and health needs how to practice “self-regulation.” Drawing upon evidence-based research on the topic of “self-regulation,” Kathleen encouraged these students to believe that “you’re divided into four categories,” specifically, “Blue, Green, Yellow, and Red Zones.” According to Kathleen, “We want everyone to be in the ‘Green Zone’ when they are in school because that’s when you’re content, you’re happy, and you’re ready to learn—you’re focused.”

Children living with autism, ADHD, and learning disabilities have found the positive coping strategies taught in Kathleen’s self-regulation program “useful.” However, Kathleen feels that students with diabetes might find the teachings helpful as well, because “they would benefit from learning how to solve the problem.” These
students might show positive coping skills in making the attempt to reach the “Green Zone” and staying in that state of “school readiness” to avoid being “temporarily impaired” or not resolving some health difficulty at school. “The program tempts me to think it can work for them [students with diabetes in the learning stages].”

Susan

Time, budgets, size of classrooms—these are usually more pressing concerns; but they all take a back seat when you have a child showing up at your door, needing an injection or counting on you to make a difference in their lives.

Susan has been a certified elementary teacher for six years. She is currently teaching Kindergarten. With a Master’s of Exceptional Learners, a Bachelor of Education (with a focus in early childhood development), and a Bachelor of Arts (with a double major in English and Russian), Susan has three academic professional qualifications. She has further augmented her professional credentials with non-violent intervention crisis training. While she has no formal training on diabetes, she does have some background knowledge on blood glucose testing and dietary intake.

Roles and Responsibilities

Kevin, a 7-year-old student in Susan’s Grade 2 classroom, lived with diabetes. Right from the start, Kevin was “quite comfortable with his own condition.” Kevin’s self-care regimen “didn’t seem to affect him physically at all and it didn’t seem to affect his relationship with his peers.” When Susan first became aware of Kevin’s chronic health condition, she “knew very little about diabetes.” Kevin was her first, and continues to be the only, student whom she has ever had with diabetes. Susan had to understand “how severe [Kevin’s] management of diabetes was.” The question of “whether or not the child
[Kevin] was independent” — was an additional concern. “Some children can’t even tie their shoes … while others can’t open the yogurt container.”

Susan felt that Kevin, like every other student in her classroom, “has the right to learn,” regardless of whether he lives with “a physical or learning disability and/or health condition.” A salient feature of the caregiver role included embracing “the person first and foremost,” which meant saying “‘Kevin’” not ‘Kevin with diabetes,’” while targeting the health disability as it presented “barriers to full participation.” “When you sign up to be a classroom teacher, especially in New Brunswick … you’re signing up to really encompass inclusion.” As a teacher with several years behind her belt, Susan shapes her pedagogy around the dictum of dealing “with the cards that are played.”

Kevin’s habits for self-care functioned to offset Susan’s need to be “hands-on” with him in that Kevin “didn’t need help with insulin at school.” With his glucometer, Kevin performed checks on “his blood sugars.” Susan “never had any issues” with Kevin’s glycemic behaviour. However, Susan and Kevin experienced some deviation from the normal care routines in the context of sick-day management. When Kevin “wasn’t feeling well,” Susan kept “an extra eye on him for the day.” Kevin was able to “take on additional precautions to manage his health.” These precautions included drinking “extra water” and “testing his blood sugars more often.”

The parents of Kevin played a key role in developing Kevin’s abilities to manage his health needs at school and in the classroom. “His parents didn’t, for lack of a better term, sugar-coat anything.” The practice of “his sugars, what he needs to eat, how much insulin, his physical activity, and how to manage the information about his numbers” was not formally taught in Susan’s classroom. Throughout the process of Kevin’s self-care
development, the parents made sure that the language of instruction was “very child-appropriate.” The parents organized self-care at school by “involving him in the plan,” so “he could follow that into caring for himself.” In contrast, Susan has “had other students with other conditions that really don’t know why they are feeling that way.”

**Communication**

While Susan had lingering questions about the extent and depth of her care for Kevin, she additionally faced having to know “whether the student could communicate his health-related needs.” Susan had the obligation to “make sure that if he did need something medically he was able to express it clearly.” Susan’s relationship with Kevin had to be forged through “active and ongoing” communication, yet with the use of a language that articulated “health-related needs” in “non-medical jargon.”

Kevin’s parents did not want his diabetes “hidden” from “his classmates and his peers” and “him ostracized.” They believed in “an open relationship with all of the students.” The parents stockpiled the school with “snacks and juices,” where one set was “tucked in the classroom” and having “an extra set in the office.” If Kevin “felt that his sugars were out of whack,” he “could tell whether he needed to act on it and in what way,” such as in the case of going “ahead on his own or with a buddy” to “grab a drink of juice.” Kevin’s Grade 1 teacher said that “he was very independent,” a characterization that “confirmed a lot of what the parents had shared about their son.”

Susan talked to Kevin about his “health needs” and “what forms of support he needed to have from the school.” Susan wanted to “gauge what he [Kevin] needed from me [Susan] so that he could take care of himself.” After that conversation, Kevin had full access to “get juices and snacks, go to the washroom, and test his sugars when and where
necessary.” If Kevin “knew his body wasn’t telling him something problematic,” as in “an extreme situation,” he “was able to help regulate his own condition.” Susan relied on Kevin’s “confidence to take care of it [diabetes mellitus],” as “only he knows how he is feeling inside at that moment.”

After the meeting at the beginning of the school year, Susan and Kevin “went around” the school where they “met all of the new teachers.” Having Kevin place his diabetic supplies in the office guaranteed that “he wouldn’t need to ask for assistance because he already knew where his diabetic supplies were kept.” Kevin knew “the school was looking out for his best interests and reducing the barriers that might very well have interfered with him regulating himself or him getting back on track.”

Kevin “needed the classroom to understand about his diabetes and what he needed to do to manage that.” Grade 2 students “are at a stage when they are noticing what their peers are doing.” Having a classroom conversation about Kevin’s health needs was a “proactive dialogue … that helped build a supportive classroom community.” In having the dialogue, “the kids would then not mock and ridicule him [Kevin] for his diabetes.” The class discussed “what diabetes was; what some symptoms they might see if they see; if he’s tired, feeling faint, what to do; if he felt that way, what he would do; why he had permission to drink and eat snacks.” Susan approached the relationship between school rules and students with exceptionalities by examining “what their capabilities are.” Susan “used their capabilities to adapt, evolve, or interpret the school rules and routines so that these students are on par as much with everyone else” by considering their “emotional, social, biological, or behavioural needs.” Guidelines are then “adapted … to the child so that he sees success.”
At Susan’s school, “nobody really talks about diabetes or having to do the insulin or the sugar-checks.” Specialized training, such as “a workshop led by a medical practitioner” to share “inside and in-depth understanding of diabetes,” would be “something to gain.” Currently, if a teacher “were to have a student that needed special treatment,” that teacher would “have to seek that knowledge outside of what the district is typically providing.” However, in the case of Kevin, “his parents were really open with communication.” Susan could “ask them anything and not necessarily feel dumb.” Having “training specific to diabetes,” stressing “the different types that the children can have and the different severities” would be “especially nice to know.”

Susan’s school has had training on how to respond to allergic reactions. Although chronic health conditions like allergens are “recognized as a key health and safety priority across the province, with signs posted in the schools” and are “a topic of conversation at the start of the school year,” Susan does not perceive the teaching profession “actively engaged” in “talking about diabetes.” Furthermore, “if a child has a condition like epilepsy or asthma, that specific classroom teacher might be guided by the parents or information from the doctors, but as a whole profession we’re not being trained on multiple chronic health conditions.”

**Inclusionary Practices**

At Susan’s school, diabetes management is one way for students with diabetes to address their health support needs. Students need to be “externally looking at the outside world for assistance, answers, and support,” as students are “dependent on others” to “progress through diabetes.” Diabetes management needs to be scaffolded based on student growth: “what certain things he should avoid; what certain things help him.”
Susan was “part of that scaffolding” for Kevin, ready to provide him with “the stimulus and the external structure” when and where needed.

Self-care is “bandaged with the management aspects” and “not entirely separate” from the teacher’s involvement. It manifests from having “an internal reaction to your body.” Being diagnosed with diabetes “compromises you,” in that “the body can’t manage on its own any longer.” Self-care encompasses “the choices you make in response to the challenges,” which gives expression to “the ability to cope on a day-to-day basis.” Kevin never lost his “zest for being independent.” However, Susan recognized that Kevin, at times, needed “encouragement and reassurance,” especially in the face of “social conflict” with certain classmates.

“All children come to public school no matter their medical, behavioural, or learning diagnosis.” Teachers should become “educated and prepared to work with each child in their health condition.” However, “sometimes we’re lacking in the training to deal with specific conditions.” “There’s too much left to chance.” In Kevin's case, “if the parents hadn’t been proactive in being really open and communicative with me, I probably would have felt overwhelmed even though his specific type of diabetes was quite self-manageable.” Kevin's parents “fortunately had him primed and ready to go.”

**Coping with Care**

Susan’s friend, Carol, lives with “insulin-dependent” diabetes and did not “take it more seriously at the earlier stage.” “She kind of just slacked off; then it became something serious.” Today, Carol “lives with regret.” Carol is around the clock “taking more on herself”; she “checks in on her weight, on her diet, all the extra doctors’ appointments, the insulin, and all that.” Kevin is unlikely to travel “down that path.” For
one reason, Kevin “had such proactive, encouraging parents.” Furthermore, unlike most Grade 2 students, Kevin “was so aware of his own self,” showing the ability to “foresee the consequences” and having “the stamina and fortitude” to “never let his diabetes become out of control.” Kevin “always seemed to kind of just know not to push himself.”

Addressing Kevin’s health supports needs was “definitely a trial by fire.” Susan felt “extremely anxious” and “instantly terrified,” even entering into a bout of the “heebie-jeebies” on the thought of having a student requiring “invasive treatments,” such as having “someone inject his needles.” Susan did not want to have Kevin being “solely dependent” on her. Susan used a “resilient” approach to address the challenges she faced: “gelling with them and filling in the gaps.” Today, Susan feels that she can “do it again in the future.” “You learn from your mistakes, definitely, but don’t be afraid in being bold and asking for help. It’s the questions that go unasked that can get you into a mess. Usually, the solution can be found right in front of you.”

**Rachelle**

Care that’s needed for managing diabetes at school is really unique to the student. Like, some even have exceptional academic needs on top of that. There’s no recipe, it seems, for everyone. That being said, there’re guidelines of care that the teacher can’t forsake. The sugars need to be in a good zone; the challenge with that is being able to recognize the differences between behaviours – health and academic.

Rachelle is an elementary teacher in New Brunswick. She currently teaches Kindergarten. She has taught between 5 and 14 years. Rachelle earned her Bachelor of Education in 2007. Since then, Rachelle has acquired some understanding on diabetes self-care, having participated in two training sessions. One of these included a workshop on “professional diabetic nurse and needle training,” while the other included ongoing parent meetings. Both of these alternative training formats took place at school. Through
these sessions, Rachelle learned about a wide spectrum of diabetes management practices, including insulin action and administration, blood glucose testing, nutrition therapy, exercise, and interacting with adults and/or peers.

**Roles and Responsibilities**

In Rachelle’s teaching experience thus far, she has had two students with diabetes in her care. Last year, Rachelle had 6-year-old Robert. Robert became diagnosed with diabetes when “four and a half,” approximately “a year-and-a-half” prior to being a student in Rachelle’s classroom. Robert “also had several developmental delays and behavioural issues,” so that the school identified him as a “special needs child.” Rachelle currently teaches Lydia, who is 5 years old. Lydia is “appropriate development behaviourally and educational academic-wise.” Lydia had been diagnosed with diabetes prior to Kindergarten when “she was not quite 2.”

When Robert entered into Rachelle’s classroom, she “really didn’t know a whole lot about diabetes.” While she knew “what diabetes was with the insulin” and the corresponding need for “medication and that sort of thing,” she was generally unprepared. Likewise Rachelle “didn’t know a whole lot” about Robert as a person, “just minimal knowledge.” Robert had “transferred from another school,” having “gone to Kindergarten at a different school” before he “came to us in Grade 1.”

However, with Lydia, “this little one I have in Kindergarten, I actually met her twice before she came to school through our Kindergarten Start-up Programs.” The Kindergarten Start-Up program allows the school “to organize several opportunities” to “meet with parents and the children” as a whole before “any particular child begins schooling the following September.” Children participating at these sessions typically
“get into the classroom,” with the expectation to act like “themselves,” a role that carries the further expectation to “become familiar with their surroundings,” which is linked to the opportunity to “learn about what it is like to be in the classroom.”

Upon the realization that Robert (and subsequently Lydia in the context of the Kindergarten Start-up Program) lived with diabetes, Rachelle needed to understand several aspects of diabetes self-care. Rachelle had to “safely handle” medical technology, including using a glucometer to “test the sugars” and then to “do an injection.” Rachelle had to understand the physical handling of diabetes equipment, while also addressing the physiological components of the disease, including “what insulin does to the body,” specifically “whether it [insulin] raises or lowers,” and “blood sugars and the ranges.”

Once she had general knowledge about her students’ health needs, Rachelle became informed about how to specifically care for them. For Robert, the school organized training, inviting the “diabetic nurse and the parent [Robert’s mom] … to the school” to teach “the educational assistant and how to do the glucose testing,” including insulin dosage and administration. “The nurse and parent had empty needles so we could practice tasks like measuring for insulin and how to inject, as if we were doing it.” “I never decide on the dosage. That amount is always suggested by the parents. When the child with diabetes goes unconscious, the syringe loaded with Glucagon is preloaded and you inject it directly into the legs, through clothing.”

Rachelle had to develop a conception of diabetes as it manifested within the lives of Robert and Lydia. In the case of Robert, “his mom had him very regimented.” Rachelle had to “learn about his behaviours,” which included the need to recognize “his preferences,” such as “what he expected to eat” and “his physical cues.” “When his
sugars started to drop, he got sort of that glassy look in his eye” and “when his sugars would go high, he would start to become not really aggressive, but more active, more prone.” Robert “had to rely on others” due to “his challenges.” Rachelle acted “like a helicopter parent,” that is, someone who “had to hover about him,” due to a lack of trust in his judgement, and who “would really keep an eye to those behaviours.”

In contrast, Rachelle shares responsibilities with Lydia, her mother, and Noreen (Educational Assistant) with respect to diabetes care. Lydia’s lunch reflects the influence of “her meal plan, which has been put in place by her mom.” Lydia takes care of her own glucose testing: getting “all her stuff prepped,” then putting “her blood on the monitor … and she counts down,” and finally “she cleans up afterwards.” Rachelle’s task is to “write down the reading once the monitor shows it.” After lunch, Rachelle or Noreen reports the glucose reading over the phone to Lydia’s mom and finds out “what amount of insulin to adjust based on what she [Lydia] has eaten.” Rachelle and Noreen inject Lydia with the insulin, using a “premeasured needle,” “inject[ing] it in a different site on a rotating basis.” Finally, Rachelle and Noreen “record the information for the reading and the insulin injections” and ensure the “sharpies are put away.”

Typically, Rachelle and Noreen “test her [Lydia] twice a day unless she indicates to me that she feels shaky or if she is not quite herself.” When Lydia shows “the glassy look” or “that vacant look” and acts “lethargic” or even “a little snappy,” Rachelle or Noreen immediately responds to “give her juice to accommodate.” Lydia’s glycemic index has only “dropped a couple of times, but not too dangerous.” In contrast, should Lydia ever “go high” and starts getting “silly, almost hyperactive,” Rachelle has been
“told to take her blood sugar to see where she is.” Lydia has yet to experience extreme hyperglycemia in class.

Rachelle is not the only caregiver who offers support for diabetes care at school. Indeed, “the parents are a huge support.” Both children have received from their parents “education on it [diabetes management],” which has helped Rachelle to “make the health accommodations for these.” While “these children are not assigned an EA based on their diabetes alone,” “there are times when EAs have been involved.” In the case of Robert, “his EA quite often did his injections for him just because he had that individual support for other than for his diabetes.” The principal has been a source of support, too. The principal’s “youngest child is diabetic.” If anyone at school had “questions or concerns” or if Rachelle or some other school caregiver “needed to know how to deal with something related to diabetes,” the principal “was very good at giving us information and guidance on that.” Lastly, Robert and Lydia have provided relief to Rachelle’s duty to care for them by having the responsibility to “assist me or the EA as much as they can,” while also letting Rachelle “know when they are not feeling well.” Overall, Lydia “is more involved in her own care than he [Robert] was.”

**Communication**

Rachelle was “in touch with his [Robert’s] mom, in the morning, sharing health information and getting feedback to go forward with the medical procedures.” Robert’s mother would tell Rachelle, “This is how many carbs he is having today.” Robert’s carbohydrate consumption was “rigid,” so that the daily number did not “fluctuate too much.” Robert’s lunch featured, “every single day,” a selection consisting of “a whole wheat bread sandwich with bologna and cheese on it.” Robert might also have “an apple
or some grapes or a banana.” Robert’s mother factored the impact of physical education class on the amount of insulin her son would need to have for that school day.

This year, Rachelle is “in touch with the little girl’s mom [Lydia’s mother] just after lunch, over the phone, looking to get the same sort of information, too.” These conversations feature an exchange of health information:

   Rachelle: Today, she [Lydia] ate all her Kraft dinner, all her fish, half her celery, and all of her yoghurt.
   Lydia’s mother: Well, there was this many carbs.
   Rachelle: She had a reading of 9.6.
   Lydia’s mother: Based on her reading of 9.6 and with the amount of carbs she has eaten, today you’re going to give her 4 units [of insulin].

Rachelle used a “standard fixed chart” to calculate the insulin to give Robert. “If his glucose reading was less than 4, we would refrain from giving him insulin.” However, “if his reading was between 4 and 8, or if it was between 8 and 12, and also depending on whether he had physical education that day, we’d give him a standard fixed amount.” The chart also informed Rachelle what to do when Robert became hyperglycemic: “If he went above 20 for his reading, we first had to call the parent to get an adjustment.” In the event that Robert’s mother was not available to provide health information, “the standard fixed chart would serve as a substitute decision-making tool.” However, “that never did happen.” “We called, got it, and then we did the adjustment.”

Rachelle found it challenging “to know exactly who this child [Robert] was and what his body was telling me.” Given Robert’s aptitude for “poor school readiness,” Rachelle “insisted on checking his sugars so often so that I had an accurate baseline for him.” By approximately November, the practice of checking Robert’s blood sugars “became old hat.” By this time, Rachelle “knew what cues to look for and things like that” and “had a relationship with his parents,” so that she “contacted [Robert’s] mom
quickly and easily with any concerns.” The ongoing communication was essential to ensuring Robert’s “health and safety,” because “he had developmental delays.” Rachelle “couldn’t rely on him to come to me when he needed to.”

**Inclusionary Practices**

Caregivers involved in the practice of diabetes management at Rachelle’s school include the parents, teachers, pediatrician, the diabetic nurse, and the student with diabetes. Diabetes management is a “social concern,” involving the consideration of “what lifestyle the student is building” and “how others contribute to it.” It is “care by design,” in that “there are rules, procedures, and routines to follow.” Diabetes management “provide[s] a flotation device, like, you know, helping them keep swimming, not drowning.” In that spirit, Rachelle has worked with Robert and Lydia to construct their “safety, comfort, and balance in the health—sugars, diet, and exercise.”

Self-care is “concerned with gaining the skills—learning of numbers, interpreting results, all the administering, and doing decisions on your own.” It “goes hand-in-hand with diabetes management.” The first step of self-care at Rachelle’s school is “checking one’s own sugar levels.” This step relies on being able to “get the supplies, set up the monitor, get the pen-instrument ready, prick the finger, put the blood on the tab, and … understand what the readings mean.” The next step is to “start injecting either in the arm or stomach.” The student is concerned with “getting the insulin, the syringe, needle-clipper, needle-container; get the sugar-insulin chart; adjust the insulin based on the reading; get the dose into the needle; then inject it; and clip the needle; put it away in the box.” If students are not ready to practice this step, the teacher can “train them how to do their injections.” After this step comes the challenge of “going from the other two steps to
further learn how to carb count, and judge what’s been eaten, and all the exercise.” At this step, the student is striving to “read the labels on the foods, figure out plans, take readings, know what you’re doing with the insulin to fit the food and the exercise.”

Robert is “still learning to develop” self-care at school, although his mother indicates he “does his own sugar-testing” at home. At school, however, the school staff members “still do all the testing, all the administering, all the following of the chart.” As long as Robert is in elementary school, Rachelle predicts that he will draw upon others to “manage his health.” “He shows no signs of being driven to change; he can play the helplessness card for sure.”

Rachelle and Robert’s mother worked together to “build up a safe, inclusive, non-threatening environment” so that he could feel “appreciated as a person, not the disease.” Rachelle “laid down goals for him to get into his self-care.” Rachelle wanted Robert to “accept his diabetes” and to “show some signs of improvement with things.” Rachelle wanted him to move toward “I can do it!” from “No I won’t!” Rachelle thought that these goals were realistic for Robert developmentally: “He got into it—helping out when he could; but still, we needed to keep everything regulated to not stir the pot.”

Lydia “can already do her own sugar-testing.” “Once she gets a handle on counting, she will be able to indicate what her level is and determine how much insulin should go into the needle.” Rachelle foresees a fairly quick timeline to Lydia’s self-care: “By Grade 4 or 5, she’ll probably be doing her own readings and her own injections.” Lydia “could very easily be looking after things like packing her own lunches with minimal supervision.” Lydia is a “self-starter,” able to “set things up” and “take charge.”
Rachelle partnered with Lydia’s mother to “make the atmosphere work for her, here.” Rachelle developed the goal to have Lydia “create strong ties with the classmates.” Such a goal was concerned with “building upon her outgoing, take-charge attitude.” Rachelle wanted Lydia to feel “good about things” and to know that “everything is going to be okay.” She has seen Lydia change from being uncomfortable about her diabetes in the face of her peers to becoming confident and open about her health needs: “At the beginning, she was, come to think of it, not ready to be out there with it; now she has turned something invisible into something visible, open, caring.”

**Coping with Care**

Having school readiness means “being able to self-regulate, to manage the attention; not having health or behavioural issues get in the way of things.” Robert had a “difficult time” in reaching school readiness behaviours through self-care. Robert required Rachelle to often get him “into that zone.” Diabetes management had a more significant role in supporting Robert and making sure he was “with-it in the care” and “on top of things.” On a couple of occasions, Robert’s sugars “dropped very low,” “right around 2. Between 1.5 and 2.” The experience was “really scary.” For the remaining part of those school days, Rachelle was “just on edge,” keeping an “extra eye on him.”

Lydia’s attention span is typically five minutes, during which timeline she’s “very mother hen,” “very eager,” and “wants to interject all the time.” When Lydia is “being very quiet,” “lying down,” or “can’t sit still,” Rachelle interprets such behaviour to be “instant flags” that “something is going on.” Rachelle closely monitors Lydia to determine whether Lydia is having “just a moment” or experiencing out-of-range blood sugars. Apart from these behaviours, Lydia is “mostly in the zone; she’s on it.”
One of the main reasons Rachelle “never went into a medical field” was because she didn't like needles and “couldn’t imagine giving someone a needle.” Today, Rachelle administers “a needle every day.” Last year, Rachelle felt “very, very worried” that she was “going to make a mistake,” hurting Robert when she “gave him his injections.” Rachelle was concerned she was “going to give him too much or give him not enough.” Rachelle is “much more relaxed” this year with Lydia because “of course she is not my first.” Lydia's “mature for her age. She is very familiar with the process. She has had this disease much longer.” Lydia’s family is “more— I do not want to say comfortable— but they, I guess, are. They are more comfortable with it! It is just a part of the life. Yes. It is a disease.” Rachelle views her care for Lydia’s health needs as part of making “an accommodation for the child.”

**Casandra**

It was really an eye-opener for me. There are a lot of responsibilities as a teacher. You are not only just teaching the curriculum, but you are doing many, many other things as well. … It was demanding. It was a lot on me. I had nervousness, because this child was in my hands. I knew anything could happen and I just thought I have to be on-the-ball at all times. And I just never thought about that when I entered this career that this was what I might be dealing with.

Casandra is an elementary teacher in New Brunswick. She currently teaches Grade 5 students and had a child with diabetes (Darryl) in her care two years ago. Although she has a Bachelor of Education and a Bachelor of Arts, she does not have any postsecondary credentials related to diabetes. However, she has had several informal meetings with members of the medical community and with parents to learn about diabetes and its management.
Roles and Responsibilities

Darryl was a First Nations student who was overweight and “not a very active child.” Darryl “struggled” in most academic areas. “He was strong at math” and was “very polite and happy.” “Overall,” in Casandra’s words, “he was a joy to have in the classroom.” For the better part of the first school semester, Darryl was “a healthy kid.” He didn’t show any signs of health distress other than his “poor diet” and his continuing struggles with weight and lack of exercise.

Within a matter of weeks before the winter holidays, Darryl couldn’t manage his health any longer. He was away from school sick starting a few days prior to the end of the first semester. When class resumed in January, Darryl still didn’t show up for the first two days. Concerned about what was happening to Darryl, Casandra called his parents. Darryl was in the hospital and had been diagnosed with Type 2 diabetes. Casandra “made a visit up to the hospital to get a picture.” The news of diagnosis struck an emotional chord in Casandra, as she “didn’t catch any of the signs at the school. I felt blind.” Furthermore, she didn’t know what diabetes meant other than that people had to check their blood, pricking the finger with a “fancy pen,” and practice a strict dietary regimen.

The school administration scheduled a meeting involving the parents, Darryl, Casandra, and other staff members to initiate them into the School Health Support Services (SHSS) program. Casandra found the occasion deeply emotional, immediately feeling the weight of responsibility. “I had a lot on my shoulders.” While Darryl had the expectation to “inject himself and test his blood sugars,” Casandra had to help Darryl set up and practice his self-care regimen. She “needed to learn about how insulin works, the
relationship between diet and blood sugars,” as well as the “signs and symptoms of
diabetes,” and what information would be useful to log regarding glycemic behaviour.

Darryl’s parents provided Casandra with insight on how their role in the diabetes
management plan would contribute towards Darryl’s self-care. They told her what
selections of food Darryl ought to have; how they intended to prepare his daily lunches;
and what Darryl was supposed to do with used lancets, syringes, and test strips. Similarly,
the parents guided Casandra on learning the language of diabetes self-care. They
provided her with medical pamphlets listing key terms and medical contact information.

“The parents provided everything for me…the school was well looked after.”

Health professionals wanted Darryl to “keep track of his health behaviours at
school every day” to obtain as wide of a picture of Darryl’s everyday health routines as
possible. The parents forwarded a list of what Darryl was expected to have for food
choices and when he ought to check his blood sugar readings and take insulin. Casandra
began to question what all this information meant. Over the course of the semester,
Casandra began to understand more deeply the pressing nature of her responsibilities. “It
became quite a bit to handle.”

Every time Casandra took her class on a field trip, she needed to ensure that “the
extra bags were packed with extra juice and extra sugar pills.” During the second
semester, Casandra took her class to a nearby pool for five weeks. Darryl’s swimming in
the pool needed to be closely watched to prevent the onset of hypoglycemia; when he got
out of the pool, Casandra would ask him to test his blood sugars.

Casandra felt that her teaching was oriented to addressing social needs. Darryl was
“never alienated in the class.” School activities were designed so that “he did everything
that everybody else did.” Casandra made sure that her students understood and accepted
Darryl’s needs to perform his diabetes management plan without perceiving his routines
as abnormal or disturbing. Darryl felt intimidated about his diagnosis and did not wish to
be made the subject of humour, especially as “a new student that year.”

Although Casandra saw Darryl struggle with his health behaviours in her care a
couple of years ago, such an experience with him is not lost on her today. Casandra now
teaches “more health lessons on the importance of being physically active and eating
healthier.” She also is more alert about the health status of her students. For example, she
currently informs her teaching practice based on answers to questions like “Are they
drinking a lot? Do the students need to go to the washroom excessively?” Furthermore,
Casandra stresses the importance of learning about health and encourages her students to
be aware of detecting signs of poor health. While Darryl was her first experience at
seeing someone being diagnosed and living with diabetes, Casandra is open to the idea
that such an experience may not be the last of its kind in her care.

From the start of her involvement in supporting Darryl’s health needs a couple of
years ago to the present day, Casandra has never imagined that she ever needed to take on
the roles she did in caring for him. While she knew that entering into the profession of
teaching meant delivering a curriculum to her students, she never thought ever of
becoming something akin to a “nurse.” For Casandra, there is “a lot more to it in
becoming a teacher.” No longer did Casandra act as a teacher standing up at the front of
the classroom giving instructions, she also “became the parent and a babysitter. I became
a doctor and nurse to him. I became a coach and a counsellor.” The impact of her
experience with Darryl’s health resonates in her psyche today. Casandra is “not just a
teacher anymore.” She is, in her own words, “so much more.” “It is totally fine. I am accepting of these responsibilities. They were truly learning moments for me. I love the students for what they have.”

**Communication**

When Casandra visited the hospital to follow up on Darryl’s parents informing her that Darryl was ill, she recalled responding to questions from the nursing staff. “Did you notice that he [Darryl] was drinking a lot more?” “Did you notice that he [Darryl] happened to use the bathroom a lot more?” Casandra, searching at that time in her memory for clues, “had to say no to both of those [questions].” Darryl’s parents, meanwhile, “talked to me about what was to be done at home,” specifically, “how the family was going to change their lifestyle.”

After the winter holidays, Casandra met with Darryl and his parents at school. They discussed dietary considerations, medical treatment protocols, and safe storage of bio-hazardous materials to address Darryl’s health support needs. The hospital had provided Darryl’s parents with a contact number along with a hand-written note. A health professional, “the name and who it was, I have no idea,” expressed the desire to form a caring partnership with Casandra: “Tell the teacher to contact me!” While Casandra had the option to contact the Clinic for support, she “never did make a call.” Instead, Casandra felt “fine communicating with the parents and researching myself.”

The first major classroom celebration that took place after Darryl returned to school was Valentine’s Day. For the occasion, Casandra’s classroom decided to have a pizza party. Casandra called Darryl’s parents to inquire with them about what to do. Darryl’s parents felt that Darryl having a few slices of pizza would not hurt him.
“Adjustments were made based on that.” As time elapsed over the remainder of the school year, Casandra kept in touch with Darryl’s parents whenever she felt unsure about Darryl’s self-care needs in the context of having access to carbohydrate-rich foods, such as cookies and pizzas, because “I [Casandra] don’t feel like I should make that decision.”

Like other students who lived with some “sickness, disease, or allergy,” Darryl had his picture posted in the school staff room so that visitors could be made “aware of the kids in the school that have these issues.” In addition, health information was prepared in such a way that allowed the school staff—teachers, office personnel, and educational support—to identify that a specialized care program had been put into operation for Darryl. For example, whenever a staff person noticed “anything different” about the health behaviour of Darryl, Casandra was to be notified immediately: “Please come and see me [Casandra]. Let me know.”

Casandra’s investment into the SHSS program involved changing how she communicated with teacher colleagues about Darryl’s health status. Casandra and the physical education teacher, for example, constructed a sign language to relay observations of Darryl’s health behaviour while he exercised. Signs and symptoms of Darryl's difficulties were coded into hand and facial gestures. Furthermore, in the event of Darryl experiencing diabetic distress in the gymnasium, Casandra informed the physical education teacher how to respond appropriately. Casandra recalls having intervened several times to address hypoglycemic episodes while Darryl was physically active in gym class. “His sugars became low. He became dizzy and faint. We had to pull him out of gym class. These were difficult situations.”
When a substitute teacher visited the school in place of Casandra, he or she would find a list of step-by-step instructions to guide his or her interactions with Darryl. “Darryl wasn’t responsible enough to manage on his own. I couldn’t just say to the supply teacher, ‘Check with Darryl, he’ll just fill you in and explain it to you.’” With little trust in Darryl’s ability to self-care, Casandra drafted a “master template” lesson plan that featured detailed notes on what responsibilities the guest teacher needed to assume for the day. She also left a folder with Darryl’s profile of health needs attached to the plan.

When he returned to school from being hospitalized, Darryl pursued a “self-chosen” research project on diabetes. Casandra suggested to Darryl that “he become the expert,” so that he could share with his classmates “what diabetes was all about.” Darryl developed a PowerPoint presentation. When it came time to share the results of Darryl’s research, “the kids were amazed.” Darryl’s classmates “respected that,” thinking his overall work on the subject was “really cool.” In addition, Darryl and other students with diabetes in the school set up an information booth about diabetes. Darryl’s classmates became informed about diabetes and became more supportive to their classmate.

**Inclusionary Practices**

“Without actively working at staying healthy, keeping up with the routines and having the blood sugars at a good level … diabetes can go from good to bad.” At Casandra’s school, there are two ways through which diabetes care works: diabetes management (“a group effort”) and self-care (“caring for yourself” and “living life”). Diabetes management is about “managing the condition” through implementing “the tips given in the plan and from everyone around adding to the care.” It aims to “realize the
goals of health supports safely and proactively; it’s, kind of like, there to work, so that there’s no blocks to the learning.”

Self-care for Type 2 diabetes involves “eating healthy, having an active lifestyle, monitoring those levels, taking the right meds that you need, researching things about diabetes all the time, keeping up to date with that, knowing who you can go to when you need help and support.” Self-care elapses “over time,” “starting with the help from others and gradually taking ownership to get to doing it all yourself.” Self-care requires “persistence” and “courage,” the individual making a conscious choice to “stick to health routines” in the face of “unhealthy temptations,” such as “eating chips and pizza” or “playing Nintendo all day long.” Ultimately, having self-care means “you’re in control of caring for the diabetes—that’s the self in self-care speaking.”

Having Type 2 diabetes “changes your focus; you may have thought you can get by without changing your habits, but now look, it’s here—deal with it.” Casandra wanted Darryl to “start on getting concerned about his health” because, “ultimately,” he had “no other choice.” Darryl was “perfectly capable in changing himself”; but, for the most part, Darryl “just hung back, being like happy-go-lucky, and he withdrew, avoiding it.” Casandra “encouraged” Darryl to “take action,” believing that “he could do it [develop self-care], like get healthier and take it seriously.” Darryl remained “totally disorganized,” requiring Darryl’s parents and Casandra to “pick up the slack,” such as having to “make lots of the decisions” and “do lots of things for him.”

Casandra struggled with Darryl in his development of self-care. She knew that her probing questions were not enough to instill in him the practice of regularly checking his blood sugars. Casandra decided to set up a table for Darryl.
It had all of his kit. His whole kit filled with everything—extra wipes, extra strips. I always had extra juice boxes and pills on hand in it. His journal was kept in that little desk, too. That was his station to do his work at. He would go over there before snack time, at recess, before lunch, and before physical education, to check his levels. During these times, he would record everything. At that point he would give himself the injection of the insulin. If his sugars were really, really low, we would decide whether or not he needed juice or snack to get his levels back up.

While Casandra felt that the table provided Darryl some degree of ownership over his health, she didn’t think the unit itself unlocked Darryl’s dependence on her for assistance. Every day she would look and see disorganization. Used test strips would be seen on the floor. The sharps container appeared to be neglected, with few used lancets and syringes stored inside.

Casandra’s time spent checking up on Darryl’s health occurred mostly during transitions from one class to another. During these moments, she would ask him after gym class or during snack time questions like “What was it?” and “Did you put the number in your diary?” While Casandra occupied her attention primarily with teaching the class, she felt compelled to look after Darryl’s needs as well. “Otherwise,” according to Casandra, “he would have totally just forgotten about his own health.”

**Coping with Care**

When Darryl returned to school in January, he faced the challenge of being “in the intensive French program. It was all intensive French. This was a new thing for him as well.” Darryl needed academic help to “bring him back up to speed with everybody else.” “This was harrowing to go through, to take care of him and to set him back in things. I felt shocked … frustrated, too.” Casandra found that Darryl “was very lazy, had a very poor diet, and it seemed like he brought it on himself.”
Casandra spent “extra time” with Darryl, mostly during “recesses and lunches.” She “even offered after school stuff” because Darryl was getting “so behind in his math.” Despite these efforts, Darryl was “a marginal student I would say to begin with when he arrived. And instead of coming up, which I think he had the potential of coming up to speed, he stayed at that marginal level because of the absenteeism.” Darryl missed school “2 to 3 times a month.” Most absences were “diabetes-related,” but “the family would think nothing of taking a Friday off and going shopping.” “School came second.”

Darryl’s parents preferred a lifestyle that included being “physically inactive” and having an appetite for “eating fast food as well as eating unhealthy.” Darryl grew up in a home environment that encouraged him to adopt a passive approach to his health behaviours. His parents “did everything for him.” The hospital advised Darryl’s parents to adopt a healthier lifestyle consistent with Darryl’s health needs for Type 2 diabetes. Darryl’s parents were “on board in the beginning because the hospital pushed it [health plan for Type 2 diabetes] so much.” However, they appeared to stop “listening to it” and, in the process, placed the priority of “Darryl’s health … on the backburner.”

Now that Casandra is two years removed from her experience with Darryl, “the time is right” to “share my perspective to other teachers.” Her message is: “Always hope for things to turn out well, but just prepare,” because, as a teacher, “you can.” Furthermore, “every situation is different, of course. You never exactly know until you face the music, but you can always research lots and become familiar with the unknown—that’s what makes it known, less anxiety on you, and more manageable.” Casandra has a message for students who might be at risk for Type 2 diabetes: “Get active, engage, and put in the hard work now before the hard work is placed on you.”
CHAPTER 6: ONTARIO RESULTS

This chapter reports on the results of data collected, in this instance from Ontario. Through thick description of the teachers’ perspectives, four narrative accounts have been produced to represent the embodiment of care that Greg, Paul, Tim, and Lacy had in their relations with students with diabetes. Each narrative begins with a quotation describing the experience of the teacher in his or her own words. Following the quotation is a brief introduction about the teacher. The teachers’ stories are framed through four themes: Roles and Responsibilities, Communication, Inclusionary Practices, and Coping with Care.

Greg

I certainly felt shocked in having Ashley in the beginning—you know, like “I don’t want to do that!” In reflection, going through the journey of care with her has brought me in touch with the realization that having diabetes in the classroom essentially involves accepting three things: (1) Don’t take it lightly; (2) Get in touch with the parents right away; and (3) follow the plan as best you can. With these three things in you, all the expectations for care become very manageable.

Greg is an elementary school teacher with 6 years of teaching experience who currently teaches Grade 1 and 2. With a Bachelor of Arts and a Master of Science in Teaching, Greg has two professional qualifications. While Greg has Primary, Junior, and Intermediate (History) teaching qualifications, along with additional qualifications as a Reading Specialist and Mathematics (Primary and Junior, Part I), he has not participated in any training on diabetes.

Roles and Responsibilities

Ashley, 7, is the only student with Type 1 diabetes at Greg’s school and the only student with diabetes who has attended school “for the past six years.” Ashley has two
siblings in her family: a newborn “baby brother” and a younger brother, “two years younger, at the school” with “no serious health concerns.” Greg has had Ashley in his classroom for the past two years.

Greg first became aware of Ashley’s health support needs when she was in Senior Kindergarten. “She was at school and there was a lot of consultation.” While the school personnel all “knew there was a student with diabetes and everything,” Greg was focused on “teaching a different grade.” As a result, when Ashley enrolled into Grade 1, Greg knew “very, very little” about diabetes. He had “no previous experience either with a friend, a family member, or student having it.” Greg “understood that diabetes had something to do with blood levels … and they [people with diabetes] needed some kind of sugar-rush.” “There was a teacher and sometimes she would get low.” Greg learned that people with diabetes would occasionally experience “low sugar levels” and need to “get a chocolate bar to be better again shortly.” At that time, Greg “didn’t realize how serious diabetes could be.”

In June of Ashley’s Senior Kindergarten school year, the school organized an SHSS meeting to “get me [Greg] accustomed to her [Ashley’s] health needs” and to “go over the plan with everyone.” The “educational assistant, the mother [Janice], the child, the principal,” and Greg met together to “discuss what the plan was and what the caring for her was going to look like.” “Everyone met eye-to-eye,” collectively examining “the responsibilities listed on the entire medical plan.” During the meeting, the school principal “gave us permission to review all the medical safety procedures and background info.” Ashley’s 10-page SHSS plan, on first appearance, looked like “a medical health information package that the school had made.” Greg saw himself as a “health
respondent,” with the duty to care for Ashley when she became “impaired” and could not “solve it [hypoglycemia or hyperglycemia] on her own.” “If the student is appearing faint, pale, confused; then I need to do A, B, and C.”

Janice “took the lead,” assuming the role of “manager of the SHSS plan and everything.” Janice “ended up having the responsibility to pack the lunch, listing the carbs, taking the calls to validate our [school caregivers’] decision-making, sending in supplies, and educating us [the school] on Ashley’s needs for her care.” Every day, the nurse visits the class to perform “the reading,” administer “the insulin shot,” and log “all her [Ashley’s] medical health status information.” When Ashley’s been “too high or too low,” the nurse stays over the lunch hour and calls Janice to “give her the low-down.”

The educational assistant, Robyn, took on the role of “the go-to staff member,” assuming the responsibility to “check her [Ashley’s] sugars when the nurse wasn’t around.” Robyn “worked closely with Ashley the previous year,” so she had “a working understanding of the health routines.” Robyn has to “step up” when “a supply teacher is in for the day,” because “the supply teacher is not responsible for everything; doesn’t know the gist of the routines right off the bat.”

Greg accepts being the “buzzer,” which involves the practice to “notify the office” whenever Ashley has “a health issue.” The office arranges to have Robyn visit the classroom to “address the health situation,” while Greg continues teaching his students with “undivided attention.” If Robyn cannot visit the classroom, Greg becomes “the backup.” As the backup, Greg needs to understand “the signs and symptoms; and … how to do the reading” and to “take the torch when the responsibility to address this [hypoglycemia or hyperglycemia] falls on my shoulders.” Additionally, Ashley’s medical
safety plan has the stipulation that Greg “cannot be the only one” assuming supervision on field trips. While Robyn always joins Greg in the role of “field trip supervisor,” once Janice became a field trip supervisor and “took care of the lunch time piece.”

Developing self-care in Ashley is a responsibility that shifts according to context. During field trips, the students are “usually all enthralled,” so Greg devotes his attention to “keeping an eye on the clock” to determine “when it is time for Ashley to test and then have the snack.” However, during the school day, Greg makes sure that: a) the kids are not overly concerned about what Ashley had to do for snack, but they are focusing on their work; b) finding a safe means for them to continue what they are doing and not become off-task; c) and then sharing the health management with Ashley.

Greg has had “a few other students with other health issues over the past two years.” “Safety becomes your primary concern.” Greg “doesn’t operate” under the assumption of some “not-in-my-backyard” mentality. Rather, “I need to know that the parent knows about how she is feeling and what we’ve done to address her health needs.” Greg’s care for Ashley “doesn’t stop” when the school day is over. “Ashley needs to know that the school is looking after her in place of Mom; that contact and partnership is essential. She can then feel safe, comforted, and work on her schooling without a second thought to her wellness and safety.”

**Communication**

The communication for Ashley’s health support needs started in the context of the SHSS meeting. The terms and conditions of the SHSS plan sparked a conversation about “the need for understanding the prompts, things to look for, and how open the care had to be.” Greg wondered about what he needed to do. Janice guided the interpretation of
Ashley’s SSHS plan, “providing the information and kind of walking me through it step-by-step.” “She showed how the glucose machine worked—the buttons, the tabs; how to prick the finger; and all that stuff.” Robyn had had “training on the monitor the year before” and “a lot of first aid type of training,” so Greg “felt like a newbie.”

Since Ashley’s first day in Grade 1, Greg has communicated with Janice through “the communication logbook.” The logbook “goes home every single day” and carries “medical information.” “I write down when she has had the reading, the insulin, and her snacks—what times these were and the amounts.” If “anything out of the ordinary” occurs, Greg makes a note and “relay[s] that forward.” Janice has also used the logbook to inform Greg about “medical appointments” or “changes in the care for the day.” Occasionally, Janice writes something like, “Sorry, she can’t go on the field trip today.” Whenever the school is “running low on the supplies,” Greg “will write in the logbook,” saying something like, “We have two juices and one fruit cup left. Please bring some more.”

This year, in contrast to last year, “Ashley will raise her hand and come up to me [Greg] and say, ‘I’m feeling low. I need to do a check’ or ‘I need to take some juice.’” Greg will “still go and stand beside her but really I just need to be there to say the reading is 7.5 and you’re fine.” Should the blood glucose level be elevated, Greg checks “the sheet again to make sure we remember what to do.”

Greg and the nurse are “very open with each other,” despite him not having had “any in-depth conversation with” her. “The nurse is quite supportive in the sense that if anything is up during lunch, she’ll take care of it and provide me with the information.” Sometimes Greg asks the nurse: “So you told me she needs to have lunch earlier. What
do I do after this?” The nurse “has always answered my questions.” The nurse provides Greg “an update on all the medical health records that have been logged.”

While on lunch, sometimes Greg “would get buzzed down from the lunch supervisor, who was also the educational assistant.” Robyn would typically say that Ashley was “taking a long time to finish lunch” and “she hasn’t gone outside yet.” Greg had difficulty distinguishing based on this information whether Ashley “was shy or suffering from a low. I’d check in, ‘are you okay?’ I needed to separate those two behaviours.” When Ashley’s blood glucose level has been “really low” or “very high,” Greg “just buzzes … the office” or he’ll “write a note about what happened.” The secretary is “involved in relaying my message to the parents and facilitating the conversation with them over the phone.” Janice “would then give directions on what to do from there.” The secretary “enters into the mix every now and then.”

Greg posts “the medical safety plan … up on the board, in bold.” “It is the first thing you read” when you enter Greg’s classroom. Medical safety plans for students with health support needs are located “in the office and in each of the classrooms.” On the occasions supply teachers are in for Greg, “I have given them a low-down with a cover letter.” There is a “welcome to our class” note along with, “bang in bold: ‘This student has a serious medical condition.’” “When I am away for that day, it is not expected for the supply teacher to wield the same level of care over Ashley’s health. The information in the classroom definitely makes it more manageable for them.”

Inclusionary Practices

For Greg, diabetes management is “more a group of people managing and doing most of the work for the child.” It involves “all of those adults who are a part of the
program [SHSS] and doing things for the student.” Diabetes management is “enacted on
the child’s behalf,” reflecting the “values and goals of schooling and ideas about health as
a common concern.” “Safety, wellbeing, and having an accessible classroom—these are
the things the school has to ensure; they [school personnel] do that through the SHSS.”

Although Greg had “never heard the term [diabetes self-care] before until now,”
the concept of self-care meant something that “refers to that release of responsibility from
the shoulders of the staff to the child.” It is “about releasing the nurse, the EA, and others
from the context of taking care to do certain things” and, in that process, “putting these
same tasks on the child to do herself.” “For a small child, self-care would be that sense of
ownership,” “taking on the responsibility and being able to practice the steps.”

Ashley is expected to “understand that there are rules.” Ashley’s food choices
must remain in adherence to “what the mom had prepared.” Ashley has to “resist the urge
to have something too sugary,” as in the case of the classroom “having cake.” She must
“stick to the plan” and “practice awareness of her health needs,” such as “giving us a
heads-up,” so that “others know about how she’s [Ashley is] doing.”

At the beginning of Ashley’s Grade 1 school year, Greg had “a number of
learning goals” in his care for Ashley’s health support needs. “A lot of it … was trying to
make her not feel isolated or left out of things.” Greg knew that Ashley “had to leave
class to take her insulin shots, do the sugar readings, and be with the nurse,” but he felt
unsure about how best to “accommodate for the emotional needs that goes with the
health.” “A lot of my learning on caring for her happened through doing this here; doing
that there; listening to Mom; and listening to how she felt.”
The most significant development in Ashley’s self-care over the past two years has been “how managing the diabetes—going outside of class, doing it sometimes in the class, eating at different times than the rest of the class, all in front of peers was an issue and now it is not.” The classroom now “understands Ashley’s health routines, and they [Ashley’s classmates] don’t make a spectacle of it.” Furthermore, academically and socially, Greg has seen Ashley “grow in confidence” and present herself “more openly” because “she at one time kept it all in.”

Every spring, the school distributes “an information package from the Canadian Diabetes Association.” Ashley’s parents “asked if we would do a pledge sheet,” constructing a “fundraiser” in support of “raising awareness and contributing money to a good cause.” Ashley “wanted to go on the walk, which takes place in June, and have fun.” The classroom “helped out a bit, but mostly the money came from the teachers.” Last year, Ashley “did not make a presentation in front of the class.” However, this year “she’ll probably give a mini-presentation to each of the classes on a trip around the school.” This initiative is “good for self-care” and “makes for more awareness about the need for understanding in the management.” In Greg’s own words, “I’m a fan of it.”

Coping with Care

In the “first month or two” of Ashley’s Grade 1 year, Greg “was not stressed out, but concerned.” He “didn’t know what was going to happen here.” Although Greg had Ashley’s health support needs “on the front of my [his] mind,” such needs “were not fully spelled out in the SHSS meeting.” Greg “didn’t know what Ashley’s behaviour was going to look like” nor did he “understand the meaning of health in the care.”
Throughout his time with Ashley, Greg has “worked out a lot of the kinks to her care.” “The biggest problem last year was when the nurses were running late.” Greg and Ashley “had to wait; she’d [Ashley would] not have her mind in the school; she’d be looking at the clock; and I felt my job was to reassure her things were going to work out.” The nurses’ tardiness was “late just enough to become a worry,” such that “a degree of responsibility was shifted onto my [Greg’s] plate and I didn’t have the means to carry all that [caring for Ashley’s health support needs] out, being set up the way it was.”

Over these two years, Ashley has “developed confidence,” drawing on “the support available to her at school.” Although the nurse and educational assistant attend to the majority of Ashley’s health support needs at school, Greg occasionally gets his “hands in the mix.” Janice is “only a stone’s throw away over the telephone.” Greg has shared “ownership with Janice over the care, but it has developed into a validation procedure.” “I call just to confirm; tie up loose ends.” There have been several “bumps in the road,” such as “late arrivals by the nurse,” “lack of clarity between Ashley’s health and personality behaviours right off the bat,” and “not knowing what to do when unexpected things show up—sudden assemblies, change of plans on field trips, and having late arrivals.” The SHSS plan does not make clear how to carry “out the plans” nor how to “make adjustments when things go awry.” Despite these obstacles, Greg has “just been learning how to deal with the health and getting along together.”

Greg has had a “child who lived with Medium-chain acyl-CoA dehydrogenase (MCAD),” a female student who was “the only one in Kingston and surrounding area.” “This disease is an immune deficiency” that “had to do with feeling low sometimes.” Having Ashley and the student with MCAD has “opened my [his] eyes to different
things.” They have kept Greg “on my [his] toes,” allowing him “to be more confident about solving mini-problems.” Greg is “more adaptable to different situations,” since he has been “through these relations before and it is not something I need to get all uptight about again.” Greg has learned about the importance of “chunking my time and doing things better with children overall.”

Greg now feels “quite confident about how to deal with the care for students with diabetes and almost share information with other teachers down the line.” Greg recommends having “some guidebook on diabetes care” might be helpful to guide teachers’ efforts in “implementing the plan.” “Key activities and things to think about would be very helpful for those who have never had a child with diabetes before. … It might help settle nerves and give direction to the teacher and student.”

Paul

I’ll take full ownership for the child, but that means taking steps that the care the child receives is appropriate for his health needs. I may not be the one who performs this task or another task, but as a teacher I can pull strings to arrange someone with the qualifications who can.

Paul is currently a Grade 5/6 Catholic teacher with 5 years of teaching experience. Paul holds a Bachelor of Arts (Honours), a Bachelor of Education, and a Master’s in Literacy. He has Primary, Junior, and Intermediate (Mathematics) teaching qualifications, as well as additional qualifications in Religion (Part I) and First Aid. Paul’s training in diabetes has been limited to meetings with “family members” and “nurses.”

Roles and Responsibilities

Jared, 12, is the first student with diabetes Paul has ever had in his classroom. Jared has had Type 1 diabetes “since … sometime before he started school.” As a young child, Jared learned how to develop self-care from his parents (Craig and Lydia) who had
him assume the responsibility to practice “a very strict nutrition cycle.” Each school day, Jared eats an assortment of “fruits and vegetables, all the breads and rice, and dairy—yogurts, milk, cheeses, and what not” for “first snack, lunch, and afternoon snack.”

In late August, Paul and his full-time educational assistant, Celine, met Jared and his parents at school, so Paul could get “an idea of what Jared was like and how his day currently is like” and figure out “what diabetes was all about and whether there was other related health issues of some sort.” Jared appeared “quite reserved,” while his parents were “well-intentioned” and “cordial” about the school’s need to “share the knowledge about the care and sort out who is supposed to do what.” Craig and Lynda were “given the opportunity to delegate the responsibilities—who should do what, how, and when.” Celine was “quite aware of what Jared needed to do and how the care was to take shape,” having already developed “a great relationship with Lynda and Craig,” “knowing them for some time now outside of the school in the community.” The meeting was “nothing new” to everyone except for Paul.

Paul “didn’t really know much” about Jared as “a person or student,” either. Paul approached Jared with “little idea about his lifestyle and health behaviours.” Not only did Paul have to keep his “eyes peeled here because diabetes is quite the serious illness,” he further needed to construct an understanding of the “health needs of Jared as he faced them at school.” To that end, Paul needed to “find out what was good in terms of the numbers; how the parents approached the care; what Jared was like socially; how stable his appetite was, given that he is a growing boy.”

Celine accepted the task to “arrive into the portable for 10:35 am to check in on Jared” once a day every day to “make sure that Jared checked his blood, that he wrote
down the numbers into the black book, that the information was ready to be signed, and that he ate his snack.” Celine has also had to “relay the health information” to Paul, so he could “inform the parents about the display of any worrisome behaviour,” such as when Jared is “being a bit lackadaisical in adhering to the plan.” Having Celine is “much like having another teacher in the class—she’s professional, sensitive, and supportive.”

As diabetes has been “a big part” of Jared’s life, he is expected to “come in, operate the insulin pump, put away bandages, discard the used items in the bin, do the testing, record his levels and amounts, act openly about his health needs.” However, Jared is not yet “responsible for his own nutritional regimen,” in that “when to eat and when not to, or how much of something he should have and for what purpose—is still very much a challenge.” Paul is generally “so consumed with the needs of the classroom,” being “wrapped up in the academics,” that he doesn’t always “check in with Jared during the course of the day.” Paul wonders what “the rest of the day is like for Jared.” “I’m assuming that he’s okay. I think he is good.”

Jared has an Individual Education Plan (IEP), “established for purposes of his diabetes.” Paul believes that the IEP should be about Jared’s academic needs as well as his health needs, especially as those academic needs can be affected by Jared’s health needs. “Teaching instruction should be differentiated, because, for Jared, a little bit more onus needs to be put on the academic part in tailoring education to suit his health needs.”

This year, Paul has treated his pedagogy as “a regime,” having “tailored … a sense of ownership to the business of learning.” Jared and his classmates hold ownership over making sure that the classroom is “tidy, neat, and up to speed,” but they also are expected to understand “why … we take ownership over these things.” As a result of this
philosophy, Paul manages certain aspects of Jared’s health support needs but expects Jared to take ownership in a number of ways. “Are you having enough sleep at night? Are you having breakfast?”

**Communication**

Paul found out about Jared’s health support needs initially from some of his teacher colleagues. “Just near at the end of the year, some of the teachers let me know that I would be getting Jared in my class next year.” Paul was told that his “best bet is talking with the EAs.” Celine in particular was helpful for Paul, because “she has known [Jared] the most since the primary school years.” Celine understands about “how Jared is and how he has changed” over the course of his time at school.

The School Health Support Services (SHSS) meeting in August produced “documentation about Jared’s health needs,” so that “the school could then take care of the rest of that.” Paul’s school regularly makes use of SHSS documentation. “Jared’s name and a few other students with health conditions, such as allergies, asthma, or epilepsy, are posted on several different locations where teachers frequent.” The postings “list information about insulin shots, emergency procedures, contact information, and other routines.” At staff meetings, “the principal reminds us about who has diabetes and what to look for; this child has an allergic reaction to this, and other similar cases.” “All staff members are on board and made aware.”

In the first week of September, Paul’s school welcomed staff from Public Health to “address who in the board has health conditions going on.” The visiting nurses shared “a lot of information all at once,” thus making it difficult for Paul to comprehend the meaning of his role in caring for Jared. “I didn’t have a whole list of questions right
away, because the training was more generic. … These are some of the signs; if you see these, here is what you do.” No documents were distributed in the presentation, so the nurses “didn’t leave any of that behind.” Paul would rather have participated in “a workshop that features a simulation of what it is like to observe a low blood sugar and how to spot these among different age groups of students,” because “it would give me an idea of how to see the health behaviours of Jared in a more critical light.”

According to Paul, “the communication line with the parents and the medical staff is disconnected.” Better communication “would be useful in telling [Paul] what new things [he] should be worried about.” In return, classroom observations of Jared “for like half-an-hour or a period and maybe do that throughout the year” could be beneficial for “Mom and Dad or doctors.”

The most important aspect of addressing Jared’s health support needs is having “an open communication system with Craig and Lynda.” “Sharing questions, talking about practical things, even finding relations between eating and sugar levels, carb counts and those types of things—there’s lots to digest.” Through ongoing conversations with Jared’s parents, Paul has realized “how important Celine is to caring for Jared’s health and wellbeing.” “I’m totally dependent on her, perhaps relying too much.” As a result, Paul often meets with his EAs to debrief about “the extremes in Jared’s blood sugars,” citing Jared’s overall lack of communication and recognition of his low blood sugars.

Each school day, Jared “opens up his logbook and records his numbers.” In addition to penning his blood glucose results, Jared is expected to “jot down how he was feeling.” In practice, however, the logbook “has not really been taken care of. … Some days the book was being signed by Mom or Dad. Some days it wasn’t. Sometimes Jared
would forget to record his numbers.” In reviewing the logbook, Paul has observed that Jared “would never fib his numbers. However, sometimes Jared would forget to jot down his experiences, how he felt at the time of his readings.”

In the event of a diabetic emergency, Jared is typically forthcoming with Paul: “Mr. G, I am really low.” In these contexts, Jared “will get out his emergency paper that we laminated.” Jared “will then call home. Sometimes I even told him, don’t even ask. You just need to go. We have a phone right here. Go and call home. Afterwards, I’d talk to Mom and explain what happened.” However, Paul and Jared “really never talk about the struggles to care for the diabetes.” Instead, “we’ll call home and that is that.”

Jared’s classmates have known for quite some time about Jared’s diabetes and his health support needs. They haven’t “shown the need to know about Jared’s diabetes or anything like that.” Paul usually “read[s] to the class during snack time,” while “Celine or another EA comes in to work with Jared’s health, prompting some whisper talk.” For the most part, these caring interactions “go undetected by Jared’s peers.” Jared “takes care of his health. He has his snacks.”

**Inclusionary Practices**

At Paul’s school, the health support needs of students with diabetes are addressed through two modes of care. One mode—diabetes management—involves “other people giving support to the child, through prompts, reminders, and check-ins.” School caregivers involved in that support include “the EAs, social peers, the teacher, and the parents.” Their support is designed to “aid in the child’s development of one day being able to take care of himself on his own and being able to live on his own.”
Diabetes management is not entirely “couched in a social relationship of caregivers.” It extends to “the order of operations that have been put into place by the SHSS plan.” The SHSS plan essentially “incentivizes the student with a ticket to explore how to care in a safe and supporting environment” and “ensures that students with diabetes need never feel alone,” even if “members of the team are not all present at once.” The end goal of diabetes management is for students like Jared to seek “a balance between academics and health at school,” because “Jared is on that different spectrum—having to share responsibilities unique to his disability to ensure his health and wellbeing.” Paul doesn’t think that Jared “understands deeply the significance of the position that he is in. And nor should he. He is a kid. He’s safe to not get it all right away. Kids need a helping hand.”

The other mode of care—diabetes self-care—is about “becoming that self-advocate,” specifically “what diabetes impresses upon the self: the need to seek out specific actions, because the body doesn’t work on its own any longer. The body needs to bring about health by taking action.” Unlike diabetes management, self-care “springs from the disease itself and stays with the person, everywhere he goes.” Having self-care means “showing the initiative to realize healthy goals and moving from being a ‘spectator’ to a ‘participant’ in making positive change.”

Self-care is “not at odds” with diabetes management, although it “works apart from what others do in the practice to manage diabetes.” It reflects a developmental stage of living with diabetes, in that, “Eventually … self-care will work hand-in-hand with the management, as Jared becomes older.” At the present moment, “there are two distinct areas of practice, because at this point I do not think he can cope with his care completely
on his own, without some of those prompts, reminders, and check-ins.” Currently, Jared’s “battling against all the noise that’s happening in the body: he’s passing from being a kid to becoming a young adult,” so “self-care can be really tough to exercise.” “Accepting greater powers of responsibility to manage a health disability as you age is tough, especially when you’re at a stage where you desperately want to fit in.” Paul and his EAs are “keen to find out what works best. We’re dedicated to being the best educators for them; getting them to move in directions that will help out their health and academics.”

Paul has related to his classroom overall through an “academic standpoint,” charged with the ambition to “spur some self-awareness of becoming a better student.” “We’re doing a Homework Club—Mondays and Thursdays—to motivate Jared and a few others into becoming more responsible students. That’s when I can find out how the diabetes is being managed, too.” Whereas Paul desires to see in Jared “the initiative to take the lead and speak up without relying on others to pick up the tab,” Jared’s parents have urged their son to “focus on enjoying school, without being overly concerned with having a dip in the sugars, here or there. Shrug it off and move on!” Jared “wishes to be independent and away from all the health attention,” so he “seeks out opportunities to play with Legos—he loves that stuff!—and getting his hands into action with building ideas.” Jared has the potential to be “exercising a bit more on the health fundamentals,” specifically, “communicating, setting attainable health and academic goals, working in small steps to improve his overall management.” In the process of exercising these fundamentals, Jared might help “show others in the class how to put a positive spin on being a self-advocate.”
Coping with Care

Since the beginning of September for this school year, Jared has “come to school and you’d think he just rolled out of bed,” appearing “dishevelled, somewhat droopy, and disinterested” and having only “two hours of sleep.” These observations make Paul “very uncomfortable,” triggering him to “question everything about what’s important in setting up routines,” such as “Am I being unreasonable?” “How does having diabetes impact school performance?” and “How should a teacher deal with these issues?”

In response to Jared’s “reluctance” to take his health “proactively,” Paul shared his “anxiousness with the EAs,” asking them “several questions” and requesting the school to ensure that “some EA is present in the class.” “You are always worrying and you don’t want to put that on him [Jared],” so Paul has used the social support of his EA team. “The EAs have lots on their plate—day-in, day-out; but Celine shares the bits and pieces that add to my awareness of what’s going on.” Paul has focused primarily on “developing Jared’s learning skills,” specifically, “showing responsibility, initiative, and collaboration” in all facets of Jared’s school performance, from “academics to self-care—these are about taking on behaviours that would drastically improve the health and can bump up the academic results.”

Paul has started to “figure out a little more about what works and how best to implement the ideas and procedures from the SHSS plan.” Paul’s orientation to Jared’s health support needs “operate[s] with an awareness of knowing the kid now,” through the “position of knowing him more than a name on paper; but as a student, living and breathing, in my classroom.” Paul has started to explore the use of his class website as a tool to “develop Jared’s self-advocacy for diabetes.” “Jared is quite comfortable with
communicating with other students on the main page. ... But I’d like Jared to forward me messages about his health management, so that we’re both more aware.”

Paul has “found out from the EAs that Jared was 2.0,” even though “judging from what you see at the front of the classroom—Jared there being quiet and doing his own thing—you wouldn’t have suspected that at all.” “That freaks me out! It’s scary to imagine. Having a low is like a silent, invisible force that seems to creep over Jared without him being able to know that.” At other times, Jared “comfortably follows through on the emergency plans,” using the “laminated paper with the contact numbers on it,” and he calls “Mom or Dad to reassure them that he’s getting back to square one.” These observations have made Paul “confused and lost for meaning. ... Why is Jared aware sometimes and other times he behaves like nothing is happening to him?”

Despite having “feelings of unease about the inconsistency of Jared’s health management,” Paul attributes the success of the SHSS plan to the “social structure around Jared at school.” “The EAs are the biggest resource, because, without them, Jared’s ability to work through his health needs would not go as well.” Furthermore, “the secretary is great, you know, if we say, ‘can you call Jared’s mom?’ She’s right on it.” Finally, Craig and Lynda are “available too,” having participated in “several meetings and each time we’ve tinkered with getting Jared to take better care of his health.” Jointly, these individuals contribute to the successful management of Jared’s diabetes.

**Tim**

Knowing how the medical and social sides of the equation operate definitely would help to work out the solutions to health problems in a more inclusive way and as they arise in the student’s life. A way to do that is making good connections with the parents, and, if lucky, with the medical staff. But that’s hard to predict and it’s asking a lot on the teacher. However, the teacher’s never alone—that’s for sure.
Tim is currently a Grade 2 Catholic teacher, with 7 years of teaching experience. In addition to having a Bachelor of Arts (Economics and Geography) and a Bachelor of Education (Primary/Junior Divisions) degree, Tim has an additional teaching qualification in Religious Education (Part I). Tim has certification in Body Management Systems (BMS), a training program that “focuses on holds and restraints so that children do not engage in self-harm.” Tim’s school had “a visiting nurse give a talk to the whole primary division at our school about diabetes management.” The content of that talk addressed “insulin action and administration, blood glucose (BG) testing, exercise, guidance and lifestyle counselling, and interacting with peers and/or adults.”

**Roles and Responsibilities**

Tim has so far had only one student with diabetes in his teaching career. Jenny, 7, has had Type 1 diabetes since late in her Senior Kindergarten school year. She is “very smart, very independent, and very well-liked by other students in the class.” Jenny is a “goal-oriented student,” who “advocate[s] for herself as a student with diabetes.” Outside of school, Jenny “loves to dance and participate in gymnastics.” Overall, Jenny is “a pleasure to teach.”

Jenny’s parents, Kate and Adam, are “very well-off,” going on “vacations down South” and having “respectable jobs.” Both have “flexible hours in their employment,” so they are “able to come to the school and pursue having active roles in supporting their daughter.” Instead of “taking the school bus like most volunteers on field trips,” Kate and Adam have typically “driven their vehicle,” taking Jenny and several of her classmates, “whether it is to the zoo, the rink, or the sugar-bush.”
Two years ago, Tim first became aware of Jenny’s diabetes through Jenny’s older sister, Megan, who was a student in his class. At that time, Megan “carried the flag for the family at the school,” helping out “Jenny when she became diagnosed in her Senior Kindergarten school year.” Tim didn’t perceive Jenny’s diabetes as “being a big deal in the school then.”

During Jenny’s Grade 1 school year, Tim and the Grade 1 teacher took their students to the Toronto Metro Zoo. While there, Jenny “bottomed out,” sparking fear that “she was going into a coma.” As a “first aid-responder in the school,” Tim is “one of two teachers in the school who addresses any injury that pops up.” On that day, Tim felt “very unprepared,” having “not … the knowledge to carry out my role effectively” and “stupidly not having a cell phone on hand.” Tim started to question “what I knew about the family, diabetes, and of the responsibilities to support students with the disease.”

Tim’s prior knowledge of diabetes had come primarily from his family. “My grandpa had diabetes.” Tim’s grandfather “developed diabetes later in his life,” having to take “insulin to control the diet.” Additionally, Tim has “a nephew (aged 2) and a niece (aged 6) that regulates their diabetes through the insulin pump system.” In “having the two children with diabetes, my aunt is more responsible over her health, having to lose weight and learn how to manage diabetes as part of a new, healthier lifestyle.”

Tim also gathered perspective about the nature of care for diabetes from the experiences of a former Grade 8 student with diabetes, Michael. During the previous school year, Michael was “very proactive at advocating for Jenny,” looking after Jenny’s health needs after she was diagnosed. “Michael ended up being Jenny’s guide,” supporting Jenny in her development of self-care. Specifically, Michael assisted Jenny
with “getting that routine set up and established—going for tests, teaching her that what she was going through was okay and that the procedures … become a matter of habit.”

A week before this school year, Tim became preoccupied with “setting up the classroom, going over the class lists, and examining the students who were red flagged, IEP’d.” Jenny was one of four students who had “a red flag.” Jenny’s parents set up a School Health Support Services (SHSS) meeting in August, so that “the school was on board with getting their daughter’s diabetes recognized for another year.”

For the SHSS meeting, in addition to Tim, Jenny, and Jenny’s parents, “the previous teacher, the Special Education Resource Teacher (SERT), the principal, and one of my EAs that I knew was going to be in my class were all present.” At that meeting (“about an hour long”), “Kate and Adam took control,” while everyone else “sat back and learned about what had changed since over the summer.” Kate and Adam “updated the books,” specifically addressing “responsibilities about who is in charge of doing what, how the care operates, Jenny’s health management goals, the time at which Jenny needed to go to the centre, and how to make for an overall easy day.” Tim and the rest of the school attendees “went through the book with a fine tooth comb,” updating Jenny’s care regimen to fit with Jenny’s current health management expectations and her emergency care procedures. Overall, Jenny’s parents “expected the school to cover a lot of the situations,” leaving “very little margin of error in terms of Jenny’s day and in terms of what happens in it.”

Kate and Adam envisioned Tim and Jenny’s care relationship to be similar to that occurring in the drama between “a lighthouse (teacher) and … a ship (student),” where the ship is “attempting to navigate safely under direction of the lighthouse in the bay.”
Whereas Tim’s “job became oriented towards making the school environment ‘tack-able’ for Jenny,” Jenny’s parents took responsibility to “restock the school with fruits and snacks, review Jenny’s progress in the logbooks, and give consent for the nurse to do the medical management part of the health routines.”

The school secretary, Lynn, whose husband has diabetes, “has served as Jenny’s advocate behind the scenes.” While Lynn has “no formal, assigned responsibility for Jenny,” she nonetheless “offers Jenny care in her office space.” Lynn “draws on her experience in knowing what it is like to deal with diabetes … to support Jenny’s day-to-day interactions at school.” Lynn’s office space “holds extra stockpiles of juice and snacks, a testing machine, and has Jenny’s parents’ contact numbers,” so Lynn has “access to these supplies and makes sure that they are well looked after.”

Located at Tim’s school is the Life Skills and Development Centre (LSDC), “a specialized room” that offers “developmental health services for students with health conditions.” The room features “fully accessible spaces,” including “electronic doors; customized lighting, its own set of bathrooms, shower, medical beds, fully-equipped kitchen, bubble-tube room, TV room, bean-bags, and more.” Each school day, Jenny is expected to leave class for three 20-minute blocks. During these blocks, Jenny travels with a nurse to the LSDC, with the nurse subsequently having to perform “the testing, insulin injections, disposal, and recording the results into the logbooks.”

**Communication**

Before Jenny entered into Tim’s class, Megan “would write a lot about Jenny in her journal.” In that journal, Tim would find “reflections of the impact Jenny’s diabetes has had on the family” and experiences about “how Megan felt about helping her sister
out.” Megan felt that “diabetes was a big thing; it shouldn’t be ignored.” Tim drew further insight on the nature of diabetes and its impact on Jenny’s family through his “close friendship with the Grade 1 teacher.” While on the trip to the Toronto Metro Zoo last school year, the Grade 1 teacher and Tim “talked about what happened after the incident [Jenny experiencing severe hypoglycemia].” Tim knew what he was “getting into” in preparation for Jenny’s Grade 2 school year.

For the August meeting, Kate and Adam asked Tim several questions, with the intent of being “flexible with the schedule.” At that time, Jenny “didn’t know how to tell time,” so Tim assured Jenny’s parents that, at approximately 9:50 am, Jenny would be cued that she “could stay at her desk, eat her snack, and then come to the carpet.” Today, with Tim’s “daily schedule being posted on the wall,” Jenny appears to interpret that as “a notice board” to “make informed decisions about her health and what she needs to do for her diabetes.”

Soon after the August meeting, Kate and Jenny visited the school with a nurse to talk about diabetes with over 100 students in the gym. Some of the presented information was “hard to swallow,” leaving Tim with not knowing “a lot about diabetes.” Kate and the nurse answered some audience questions, while others they deferred to Jenny.

The two EAs in Tim’s class support him with Jenny. For example, while Tim is preoccupied with teaching his students, they “circulate around the room,” being “empowered to act like a caregiver,” addressing students with autism and Jenny’s health needs as they arise. The EAs have assisted Jenny with “getting into her routine,” making the transition from care at home to school life. Otherwise, Jenny would “have missed a
lot of snacks, probably in the first month.” Every day at the end of the day, the EAs have “a quick pow-wow” with Tim, so the three can share insights.

Last school year, “the principal had to phone twice … for an ambulance to come and bring Jenny to the hospital.” This school year, Tim’s classroom has “been lucky enough to recognize when Jenny is close to the edge,” such that “all the incidents so far seem to have happened in the LSDC or at the office.” Tim has “never been present when these things have severely happened.” Whenever Jenny has come up to Tim and said, “I’m getting low,” Tim has immediately told an available EA “to take her out to the office,” because he “cannot leave the whole class.” Emergency situations such as these tend to “trickle back” to Tim. Whereas the LSDC nurses inform Tim about “Jenny’s number and what happened at the time … before the conclusion of their shifts,” the afternoon EA, Jessica, has told Tim “to take it easy on her,” echoing the suggestion of the secretary who has “told the EA to bring back Jenny to the classroom.”

Jenny’s experience of education in Tim’s class “doesn’t differ much” compared to her classmates. While Jenny is away from the classroom, attending to “the care arrangements made for her health needs,” she “doesn’t miss a lot,” perhaps only some of Tim’s “bloated tangents or off-topic talks” and very rarely being excluded from “key points in the lesson.” These “gaps to her schooling” are time periods when the class is typically “very engaged with each other” rather than “independently completing an assignment” or “starting fresh on something.” However, the missed time is problematic when the class is doing a group assignment, and Jenny has been out of the classroom.

As the first-aid responder, Tim is not far removed from the scene of any emergency at school. Should Jenny ever go into diabetic distress in the presence of some
supervising school representative, Tim is notified immediately. Tim follows through by offering some first-aid assistance either remotely or in person, so “Jenny’s health can be managed.” “Luckily,” in Tim’s own words, “I haven’t seen any of that this school year.”

**Inclusionary Practices**

Addressing Jenny’s health supports at Tim’s school is accomplished through two pathways of care. One pathway—diabetes management—involves “the school offering a hand in the affairs of setting up the health routines and in what Jenny needs from us to accomplish them.” Diabetes management is about “working towards the long-term goals,” whereby school members are “directed towards the planning procedures,” “following through on their responsibilities and on the codes of conduct set out in the rulebook.” Those school members who care for Jenny through diabetes management have a vested interest in helping Jenny out, making “the care work” on her behalf. Although diabetes management “falls to the parents, the EAs, the nurse, the secretary, and on down the chain of command,” “it varies on whom Jenny is with and where she is based in the school.” Every person has “gone to lengths,” insofar as their “capacities allow them,” to provide for Jenny “a safe, supportive, and helpful experience in her diabetes care.”

Outside of his first-aid responder duties, Tim has “never had an inkling” to get “too much involved” in Jenny’s diabetes management. He leaves diabetes management to the EAs, the nurse, and the secretary. The EAs keep “a watchful eye towards the physical manifestations of the disease,” seeking to detect “signs and symptoms” along with “addressing a misstep with the sugars whenever it has happened.” Although Tim doesn’t exactly know what the nurse is “doing on a day-to-day basis,” he is aware that the nurse is hired to “regulate the sugars day-in and day-out,” for as long as “Jenny needs for that
to happen.” The secretary provides emotional support to Jenny, as she has “always wanted Jenny to feel acknowledged,” specifically through “the sharing of stories of how her husband has dealt with his ordeals.”

Self-care for Tim allows a person to “live with diabetes day-to-day and in a way that does not jeopardize the health status worse than it already is.” Self-care is about “making life still liveable,” wanting to be “independent and not reliant on others to look after you” but in such a way “not to be centred out in front of everybody.” “Self-care is very intentional. It has Jenny acting up out of the individual, herself doing it. It’s a deliberative process.” Self-care “starts to really take shape” when the person with diabetes is “ready to accept the onus of taking on the practices,” such as “setting up the machines” and “keeping with it,” having the foresight to “make sense of all the numbers,” and forging ahead through “all the differing opinions on health—you know, like, what’s good for you.” In Jenny’s specific case, she “gradually enters into having more ownership over the care tasks associated with managing her diabetes.”

In the first few months of this school year, Jenny was “very timid.” “She wasn’t sure of the routine and didn’t want to be left behind.” She was “focused on developing friendships,” “learning about the classroom culture,” and “attempting to fit in with everybody,” so that “diabetes was a secondary concern.” As a result, the adult caregivers had to work “very hard at making the health routines clear and easy to follow,” in that Jenny “was more dependent at that time.”

Although Jenny continues to “feel strongly about wanting to focus on her learning with peers,” she seems less inclined to “keep the diabetes under the carpet.” No longer does Jenny appear to believe that “diabetes is a problem itself” as if her health condition
is “a roadblock to success at school.” Today, Jenny looks like she believes “the self can accomplish many positive things,” despite her experiencing “some tough luck that doesn’t appear to go away.”

**Coping with Care**

Tim has felt “very afraid” in addressing Jenny’s health needs, specifically setting up the health routines,” making sure that such procedures had been “done right.”

I was very troubled. I didn’t know what was going on. Jenny kept coming to the bench, being all covered in sweat, head drooped slightly, and even sometimes gasping for some air. It didn’t take long before Jenny was just bottoming out. The class was in a bit of a panic. These really scary lows were happening more often than we could count. Then we finally made the connection, that having gym before lunch was doing it, that it was contributing to her lows.

For Tim, health routines are “those movements in the classroom that work to safeguard Jenny’s diabetes management,” which include social supports like “communication practices, sharing the workload, and access to supplies.” As a teacher, Tim has “never been alone in the classroom,” having the EAs address not only the “special needs students,” but most of the “health needs that accompany 20 kids, let alone Jenny.” “It’s a team effort. In one way or another, we’re pulling the strings even though the symphony may not sound enchanting at times.”

The nurse’s daily classroom interactions with Jenny have, furthermore, “greatly impacted” Tim’s concentration. “The nurse comes in, at a time you can’t exactly pinpoint, and stops me full track in my teaching. I’ve tried to tell her to quietly tap on Jenny’s shoulder, but to no avail.” As well, Jenny’s nurse is “quite forgetful,” having “great difficulty in learning the class schedule,” especially that Jenny is in the library, rather than the classroom, at the scheduled pick-up time on Tuesdays and Thursdays.
For Tim, “it would be beneficial to have some better training” for working with students who have diabetes. “There’s lots to think about and work through.” “Addressing health supports is more than waiting and seeing if the fish bites the lure; it’s about teaching someone how to fish—to become fit to address life’s challenges.”

Lacy

It’s very difficult and at times nerve wracking. With the little guy I had, he didn’t articulate very well for the longest time and still sometimes not at all. Like others around his age, they don’t have the descriptors for the experience of diabetes completely yet. They don’t know what’s normal or not and are transitioning into learning how to cope with the illness. Overall, it’s my duty to make sure the classroom is kept safe and the kids in it are able to do their work as best they can.

Lacy is currently a Grade 1 teacher with 14 years of teaching experience. With a Bachelor of Applied Science (Child Studies) and a Bachelor of Education (Primary and Junior Divisions), Lacy has two professional qualifications. She has additional qualifications in Special Education (Specialist) and Reading (Part I), as well as holding certifications in First Aid (Wilderness Survival) and aquatics (National Lifeguard Service). With respect to diabetes management, Lacy has received a “very basic level” of training, relating to “blood glucose (BG) testing, nutrition therapy, exercise, prevention, detection, and treatment of hypoglycemia/hyperglycemia, and medical safety.”

Roles and Responsibilities

As part of an exchange of students between the Grade 1 classes, Lawson, 6, transferred into Lacy’s class during the second week of September, along with “two ESL students” and “two behavioural students.” Lacy “didn’t know anything about Lawson,” except for the previous teacher’s perception that the incoming students were all, in one way or another, “in need of special care.” Lacy was expected to provide “extra support” to these students to increase their likelihood for success.
In the first few weeks in Lacy’s class, Lawson was “shy,” following “the rules and routines” and “what everyone else was doing.” Academically, Lawson appeared “average orally” and less than average in reading and writing, compared to his peers. Lawson was “extremely, extremely pale,” along with having “black circles under his eyes.” Lacy didn’t see “any of the classic symptoms” of diabetes, since Lawson “didn’t make frequent trips to the washroom, or have more water, or experience sudden loss of weight.”

In early October, Lawson’s parents, who already have “diabetes in their family,” took Lawson to the hospital because he was “peeing too much.” “Lawson was diagnosed with Type 1 diabetes.” He was “off school for about 2-3 weeks” while in the hospital. During that time, “the family had some diabetes education from the pediatrician, just so the need for support and adjusting to a new form of life could take place.”

At the time of Lawson’s diagnosis, Lacy had “very little” knowledge of diabetes. Lacy’s Bachelor of Arts program emphasized how to “take special care for special needs,” but it “didn’t do anything that stands out for diabetes.” Lacy’s grandmother lived with diabetes, but Lacy doesn’t “remember much” about “the disorder,” other than that “the body doesn’t produce insulin” and “certain complications can arise,” such as “loss of sight” and “amputations to feet and fingers.”

However, some school personnel and two other students (besides Lawson) have had “very personal” experiences with diabetes. For example, Lacy’s “girlfriend that teaches upstairs—her daughter is diabetic,” so she knew “what it was like to care for diabetes … from the parent’s perspective.” A Grade 5 student, formerly in Lacy’s Grade 1 class, became diagnosed with Type 1 diabetes a few years ago, while Lacy was on
maternity leave. Furthermore, last school year, while Lacy was on another maternity leave, a Grade 3 student became diagnosed with Type 1 diabetes. This student’s mother divides her time in the school as “the Milk program coordinator,” visiting classrooms to “make the necessary deliveries on a daily basis,” and as a “substitute teacher,” qualified to teach Kindergarten to Grade 6.

When he came back to school, Lawson appeared “really, really reluctant to come back in.” “He hid behind his mother … looking scared, unsure, and nervous.” Lacy’s classroom was “just crazy.” Several of Lacy’s students had “significant behavioural issues,” including some with “unstable, aggressive tendencies towards their classmates,” which resulted in “biting, suffocating, and getting into fights.” Another student, dubbed “the walker,” had “major urges to simply leave the classroom.” Having “immediate concerns” over Lawson’s newfound “health needs,” but with so much else going on in the classroom, Lacy had Ken, the EA in charge of the other students with diabetes’ health support needs, become “a fundamental part” of Lawson’s school experience too.

The school organized a School Health Support Services (SHSS) meeting. Besides Lacy, “an administrator, Ken, another EA, nurse, and Lawson’s mother” met to “understand diabetes, set up the caring practices, assign responsibilities for the school year, and draft the plan.” Whereas the nurse “took charge of the medical aspects of the disease,” Lawson’s mother and the administrator “brought perspective on the school’s position of whom would do what, when, and where.” Lawson’s mother “very much wanted” to have a nurse administer insulin injections during school hours, so that “someone with expertise” had oversight on “regulating the sugars.” Despite such a plan, the administration of insulin injections to date “does not happen at school.” For Lacy and
the EAs, they each “agreed to the health supports as laid out,” but Lacy didn’t leave the meeting with the feeling that she had acquired an “adequate understanding” of her assigned role. “It was a bit too fast, too furious, to digest.”

After the SHSS meeting, Lacy realized that she had to “fundamentally help manage the highs and lows for a young child.” She needed to “find out more about Type 1 diabetes,” with a focus on “what causes the highs, what causes the lows, and how to prevent both.” This knowledge helped Lacy in “protecting Lawson’s overall health and wellbeing,” but not the means to “perform the testing, the insulin shots, or any invasive treatments.” Lacy’s role was confined to “noticing all of the bodily changes, checking in with Lawson, making sure the diet is followed according to plan, and facilitating communication of health needs.”

Ken’s “circuit in the school encompasses the care for five students,” but he “primarily rotates around the three students with diabetes—Ivy (Grade 5), Dustin (Grade 3), and Lawson.” Ken performs “the testing, the recording, and making sure the children have someone on their side.” In Lacy’s classroom, Ken “just addresses Lawson’s medical health needs.” Ken “has to be very accommodating in his job, because sometimes the testing occurs outside the routine times, like, happening on the spot, unexpectedly.”

Lawson’s health needs are also supported through members of the school’s “safety team.” In cases of “medical emergencies,” such as “severe highs and lows,” “allergic reactions,” and “asthmatic attacks,” the safety team is called upon to “administer first-aid procedures,” so that “whoever is in dire straits can be properly cared for.” If Lawson is found to be “severely hypoglycemic,” the supervising teacher is expected to “transfer caring responsibilities over to Ken; if Ken is not available, then to Eunice
(another EA); if Eunice is not available, then to Lori (acting VP).” All three have “the full authority to address even the worst-case scenarios, before passing the reins over to the emergency first-aid responders.”

Lawson’s classmates “all work together to keep everyone safe and healthy,” but, with respect to Lawson’s diabetes, some students have “the special responsibility to lend their eyes over to his health status, checking and making sure that he doesn’t dip too far, as well as to make Lawson feel comfortable about responding to his health in the classroom.” These students are identified as a cohort of “secret spies.”

At Lacy’s school, addressing Lawson’s health support needs requires school members to operate as a team. Although these school members have different duties of care, each of them contributes in “mapping the learning journey of health supports” for Lawson. Essentially, “it’s more than, you know, what to do, how to do it; caring for Lawson involves working to avoid worst-case scenarios.”

**Communication**

Each school year in September, Lacy gathers “critical information” about her students, by perusing “report cards, artifacts of student work, and anecdotal comments from the parents and former teachers that are passed along to the administration team.” While Lacy recognizes that these documents provide her with “a biased and distorted understanding of things,” they nonetheless allow her “just to get a picture of what someone else was thinking.” Next, Lacy “initiate[s] dialogue with those who have been mainly involved in the care of the student’s life,” as a way to “fill in the gaps and resituate my understanding to get a more accurate portrayal of things.” While “there was nothing in the OSR or from past work that was useful,” Lawson’s Kindergarten teacher
described him as “the kid that flies under the radar,” someone whom “you wouldn’t flag” and who “didn’t come to your attention as a source of off-task behavioural problems.”

When Lawson became diagnosed with Type 1 diabetes, Lacy did “a lot of research on the disease.” Lacy needed to understand “how the body works in having diabetes, the feelings, the language to manage the disease, and the real symptoms, as opposed to just having off-task behaviours.” To find out more about diabetes, Lacy has “picked the brains” of several school members. The mother of another student in the school with diabetes has in particular responded to Lacy’s “ongoing questions,” because “she visits the classroom regularly and has information on the whole process.” As well, one of the Educational Assistants (who is a trained nurse) has shared “great insight on the cause-and-effect happenings, like, when to do the testing and how many times.” “The learning is all very self-directed, but teachers are professionals and, as a professional, the communication and all that goes with it should involve self-directed learning.”

The nurse and Lawson’s mother “mainly contributed to the drafting of the administration, medication, and medical procedures” for Lawson, while the school administrator, along with Ken and another EA, “put together Lawson’s emergency plan.” Lawson’s “medical profile” was posted in the staff room and Lacy’s classroom, represented by “a picture, notes about symptoms, getting juice, and contact numbers.”

Every morning, Lacy checks her students’ agendas. Upon reading Lawson’s agenda, “if Mom has a note, either Ken or I will usually respond.” However, “sometimes the agenda has questions in it that refer to episodes in which more than one of us has been involved. So it is only fair that the question has received our full attention before it is answered.” As well, Lawson’s agenda is used to note Lawson’s testing numbers and
provide “a snapshot of the overall pattern of how Lawson has been doing with his
diabetes.” Upon reading Lawson’s health data entries, Lawson’s mother may “respond to
them with a note saying, ‘The insulin level has been adjusted. Log all testing; write what
he was at 20 minutes after having the low yesterday.’”

With Lawson having to adopt “special health routines,” Lawson’s classmates began
to ask several questions. Lacy organized a “team meeting” to address their questions and
to “facilitate inclusivity around the disability.” Lacy “had to explain to the class in a
really, really, basic level of understanding” about Lawson. To “help learn how to care for
Lawson’s health,” Lacy’s students “have practiced the [emergency] drill many times.”
“First, tell the teacher that Lawson needs help. Second, get the teacher to page for Ken. If
unconscious, call 9-1-1.” This response occurs when Lawson indicates he needs help by
moving a toy dinosaur into a picture of a nest. “His mom wanted a way to show me that
Lawson feels funny, without him telling everyone so. Because he’s pretty shy.”

“Lawson has had his share of episodes over the year” when Lacy has seen
Lawson “becoming docile.” In these instances, Lacy checks in on Lawson’s health status:
“Thumbs up or thumbs down? Are you okay? Not okay?” Regardless of his response,
Lawson’s blood sugar is tested. While Lawson’s health is attended to, Lawson’s
classmates are challenged to perform a self-regulating activity. “They’ll be occupied with
that activity, as I’m testing him. ... I always ask myself: What can I get the class to do and
manage on their own, while I address Logan’s health needs?”

**Inclusionary Practices**

At Lacy’s school, addressing Lawson’s health supports is based on two models of
care: diabetes management and diabetes self-care. Diabetes management refers to “the
immediate actions taken to regulate the blood sugars levels,” so that “the body is kept from falling into a low or climbing into a high.” It works through having “organized teamwork,” which involves designated school members (primarily Ken, Lacy, and another EA) assisting Lawson with “the medical aspects,” such as “testing, writing the levels down, and recommending the diet intakes,” as well as, more broadly, school members encouraging Lawson to be “more open and transparent about things,” so that everyone at the school has “a better idea of what’s going on inside him.”

Unlike diabetes management, self-care is “an individual wanting and being able to care for the diabetes … so that he or she is at maximum production—you can rank and process everything, speak well, and feel good.” Having maximum production implies that the individual with diabetes is “self-regulating,” which is about “taking actions to stay at his or her best—experiencing peak performance.” Self-care is “never over,” since it develops through “the individual having exposure to the diabetes management routines,” a point of contact that is “very critical” in allowing for “the desire to try the management out, take a step, and go on with it.”

Self-care is “a lifelong process,” consistent with “Piaget’s theory of conservation.” It is “most evident according to the maturity level and for how long you’ve had it.” As an “almost 7–year-old,” Lawson is relatively “not that far along the way.” Lawson is recently “starting to advocate for his health needs.” “I’m hungry’ is a big accomplishment for him.” After March Break, Lacy was “really pushing on the class to be independent, striving for independence, to make positive, healthy choices,” because “the Grade 1s will be in Grade 2.” For Lawson, it looks like he’s ready to “build up for
his own successes with the diabetes,” with showing “more independence and comfort.”

“He’s showing signs of wanting to manage more.”

**Coping with Care**

After first coming to Lacy’s class, Lawson “didn’t really talk,” being “very reluctant to engage with others” with “extremely passive behaviours.” Lacy thought Lawson had “very low self-esteem,” needing, “extra attention to cope with the expectations outlined for Grade 1 students.” In his return to school, the “very slight progress” Lawson achieved in Lacy’s classroom prior to his diagnosis “simply vanished,” as Lawson “didn’t show any signs of being confident or comfortable with the situation.”

Ken immediately “took Lawson and said to him, ‘Come on buddy bud. You’re not alone.’” Ken’s approach to Lawson made Lacy feel “very relieved.” Lacy knew Lawson needed another “male figure” possessed with “a sensitive touch.” Furthermore, Ken had “some background working experience with the disease” and could offer “the necessary one-on-one time.” On that day, Ken was “especially chummy” with Lawson, which “really helped” Lawson to “climb out of his shell.” Overall, “Ken has taken on the challenge very well to work with Lawson’s health needs. He’s very good that way.”

While away from school, Lawson “did miss some of the group building dynamics, developing the classroom rules, and building the culture of the learning experiences.” However, given that Lacy’s classroom already had “very difficult safety issues” in “large measure” due to the “very aggressive behaviours of several students,” Lacy took Lawson’s return to school as “another chance to reiterate the building blocks of our classroom: safety, teamwork, and positive learning experiences.” “Building safety and cohesion was already challenging; now with Lawson’s health concerns—it was too much,
very overwhelming.” Although Lacy sat with Lawson “every so often...trying hard to make him feel more comfortable,” “he didn’t say much to” her. “He would only nod to Ken. So I kind of let Ken manage that and deal with that from then on.”

Lacy has “struggled quite a bit” with the SHSS plan through “not having a deep understanding of the relation between the academic and health issues.” Lacy doesn’t feel “at all informed” about how to “deeply engage with Lawson on a day-to-day basis,” including through “diabetes-health instruction, classroom practice, and communication strategies.” Lacy’s experience has been met with “a lot of unforeseen parts” and “additional obstacles.” As a result, Lacy’s approach has been “quite experimental.” “I’d prefer as the caring, competent teacher to have the knowledge outright, especially when you’re dealing with such a serious health condition; not find out after the fact.”

While Ken has been “the mainstay in addressing Lawson’s medical care,” thus far facilitating “many of the blood sugar tests,” Lacy has, “on occasion,” “stepped into that foray.” “It’s very challenging to do the testing in the classroom. I’ve had to balance the demands of an unruly class with a bunch of wild cards flying in every direction, while addressing the immediate health needs of Lawson.” “If Ken can’t come here in 5 minutes or if he’s tied up with other things, who, then, can help out Lawson? I guess it’s me.”

Overall, Lacy has felt her experience to be “very much” like “going on a rollercoaster blindfolded.” In October, Lacy felt “very anxious” about helping Lawson with his diabetes. “Since then, moving towards solutions—sometimes feeling extremely unsure, irritable and moody; other times, okay, I’ve seen this before, tired but more relaxed.” For other teachers who might face a similar situation, Lacy feels, “the most important thing a teacher can take away from my experience is that, as a teacher, you
have the power to build a powerful alliance—with the student, with your students, and with the EAs.” “These people are the keys to unlocking most of the uncertainties you can expect to face in situations dealing with Grade 1s with the diabetes.”
CHAPTER 7: DISCUSSION

This chapter explores meanings of eight teachers from the perspective of the empirical literature and in relation to Wagner’s (1998) Chronic Care Model (CCM). Similar to previous chapters, the organization of the research data is based on the study’s four themes: roles and responsibilities, communication, inclusionary practices, and coping with care. Within each of these themes, the research data have been interpreted from the perspective of the research literature, with the production of a more textured account of the New Brunswick and Ontario teachers’ experiences. Following the interpretations of the research data, this chapter concludes with a critical conversation on the limitations of this study and implications for future research.

Roles and Responsibilities

The care for diabetes at school for all participants was formally organized through the assemblage of care agents, ranging in levels of knowledge of and experience with diabetes. In New Brunswick (NB), the central team of caregivers typically involved the classroom teacher, the parents, and the educational assistant (EA), in addition to the child with diabetes. For Ontario (ON), the partnership of care was typically distributed among the classroom teacher, the parents, the EA, a health professional (e.g., rotary school nurse), and the child with diabetes.

These cohorts of caring practitioners in each province reflect the adoption of an educational-health system, equipped with a combination of specialist and general care agents and designed to operate as a systemic and sustained practice of long-term management within the school setting (Richard & Shea, 2011). It also suggests the prevalence of mobilizing a team of health and educational stakeholders in response to
explicitly recognized health needs (Craig et al., 2007), while furnishing the team with the
collective duty to address the health, safety, and educational expectations that accompany
the experience of schooling for children with diabetes (Gelfand et al., 2004).

Teachers’ responsibilities for the care of children with diabetes vary by province. In NB, teachers had more of a central role. For example, Kathleen, as the Education Support Staff specialist at her school, set up training workshops on diabetes to facilitate awareness about which corresponding students at school required specialized care and extra attention from the school personnel. Rachelle addressed her two students’ health needs—Robert and Lydia—through the administration of medically-invasive procedures, including glucose testing, insulin dosage and injections, and safe disposal of used biohazardous materials. While Kathleen and Rachelle seemed to focus largely on medical care for the students with diabetes, both Susan and Casandra exhibited more concern about social dimensions. Susan was sensitive to using language like “Kevin” not “Kevin with diabetes,” while addressing any and all perceptible “barriers to full participation.” In Casandra’s experience, she had to make sure that her Grade 5 student, Darryl, never felt “alienated in the class.”

In contrast, Ontario teachers’ roles tended to be more peripheral. For instance, Greg basically needed to develop sensitivity for any perceptible “health issue” emerging in the everyday school behaviour of his Grade 1 student, Ashley. Likewise, Lacy had the responsibility to detect any “bodily changes” in her Grade 1 student, Lawson, while she also had to make sure that Lawson’s “diet is followed.” In addition to keeping a lookout for diabetic distress symptoms, both Paul and Tim assumed responsibility in making sure the classroom was designed in such way as to make academic learning accessible for
each student. However, only Tim among all four Ontario teachers had an additional official duty of care, serving as one of two first-aid responders at his school.

Parents were reported as having an essential educational role in relation with school personnel. NB parents, other than Kevin’s parents, co-facilitated diabetes training workshops along with a health professional. In Ontario, the parents were typically characterized as assuming a more central and decisive role in the education of school personnel. With the exception of Lacy’s experience, parents were not joined by a health professional in educating school personnel. Greg, Paul, and Tim all had experience with at least one parent acting like a “manager,” a care agent who typically “took control” of all things related to diabetes health care, helping to “delegate responsibilities” to the corresponding classroom teacher and educational assistant.

In addition to having an educational role, parents had a logistical function with respect to the school. Parents typically restocked the school with food rations and equipment on an ongoing basis; furthermore, parents played a pivotal role in the organization, selection, and timing of food choices for their children while at school, especially for the children (Darryl and Lawson) who became diagnosed during the school year. In Rachelle’s experience, both Robert and Lydia had to receive insulin at school, so Rachelle had to daily ask for parental input on insulin dosage and for parental permission to inject a loaded syringe into Robert’s and Lydia’s bodies, all according to a rotating injection site plan. Like the parents in Amillategui, Mora, Ramón Calle, and Giralt’s (2009) study, Robert’s and Lydia’s parents had to make adjustments in their daily schedule to support Rachelle’s school in matters relating to insulin dosage and administration.
In New Brunswick, educational assistants (EAs) did not play a prominent role in the care for students with diabetes. Unlike New Brunswick, the Ontario EAs occupied a central role in the care for students with diabetes compared to the classroom teachers, with the exception of Tim’s experience. For Tim, two EAs circulated in his room mainly to address the academic needs of the classroom as they arose, but in the process they assisted Tim’s student, Jenny, in “getting her into routine,” thus enabling her to make the perceived successful transition from care at home to school life. In Greg’s experience, Robyn was characterized as “the go-to staff member,” while, in Paul’s care, Celine was “much like having another teacher in the class,” exhibiting that she was “professional, sensitive, and supportive.” Both of these EAs assumed primary care responsibilities (glucose testing, recording of health data, supervising insulin dosage and injections) in relation to the students with diabetes. Likewise, Lacy’s relationship with Lawson depended in large measure on the caregiving support of Ken. In addition to caring for two other students with diabetes at Lacy’s school, Ken’s relationship with Lawson was based on “the testing, the recording, and making sure the children have someone on their side.”

The roles of health professionals varied by province as well. In New Brunswick, only one health professional was involved in the training of school personnel on medical procedures related to diabetes care. Rachelle and her EA learned how to use diabetes care instrumentations like Glucagon, the glucometer, and syringes through the modelling behaviours of the “diabetic nurse.” Health professionals either made visitations to schools as part of board-mandated health promotions programs (e.g., Kathleen’s experience), or offered their contacts in case the teachers perceived the need for further assistance in setting up the diabetes care plan at school (e.g., Casandra’s experience). Health
professionals’ conspicuous absence in daily care routines may point to the influence of a provincial mandate that expresses the need in having unlicensed assistance personnel (UAP), such as teachers and EAs, act in substitution of licensed health professionals (National Association of School Nurses, 2014), delivering health services at a lower cost than would be had through the hiring of school nurses (Tetuan & Akagi, 2004).

In Ontario, the available health professionals (N = 2) visited the school on a rotary basis and according to the health needs of students in their care. As in Kirchofer et al.’s (2007) and Lear’s (2007) research, they typically assumed routine and emergency nursing services for students with diabetes. Both Greg and Tim saw the school nurse every day either make visitations to the classroom (Greg) or escort the student to a designated safe space (Tim) to perform the full medical procedures regimen. Additionally, when the student exhibited out-of-range blood sugars, the attending school nurse in both Greg’s and Tim’s experience spent further time with the impaired student until he or she was safe to depart. However, in Tim’s case, the school nurses offered themselves as primary care providers for children with medically-dependent health needs across the school board, so that these children, including ones with diabetes, had the means to access pediatric health care while participating in the school setting. Regardless of the exact composition of the team, all students with diabetes had a team caring for them.

**Communication**

Communication within the everyday school life of all the participants involved an organized schema of social support designed to facilitate the mobilization of health information (Moore et al., 2009). In both New Brunswick and Ontario, health information moved through the exchanges of caregiver dyads; namely, parent-teacher/EA, student-
teacher/EA, teacher-EA, and health professional-student. As a result, formal and informal sources of information circulated in context (Cunningham & Wodrich, 2006; Eyong, Anah, Asindi, & Ubi, 2012) and built on process-context knowledge about the perceived strengths and limitations of the students with diabetes (Logan, Coakley, & Scharff, 2007).

Health information was additionally communicated by being made available online and posted through the distributions of school health support services (SHSS) documentation. In New Brunswick, provincial and school websites featured an assortment of digital sources relating to the SHSS program, including “medical forms,” “the medical alert bracelet application,” and “tips about how to practice care routines for students with health support needs.” Moreover, both provinces used a template of health profile documentation to represent critical health information about students with health support needs, which were subsequently posted in key locations within the school setting.

Social communication networks and levels of health literacy emerged as critical components of a communication strategy for children and adolescents with diabetes at school (e.g., Hardin & Banaji, 1993; Nguyen, Mason, Sanders, Yazdani, & Heptulla, 2008; Schultz & Kopec, 2003).

Parents and School Personnel

The social communication network constructed among New Brunswick and Ontario parents and school personnel was forged through episodic and ongoing dialogue. Episodically, the School Health Support Services (SHSS) meeting, typically scheduled in advance of the school year, established the means for parents and school personnel to acquaint or reacquaint. The New Brunswick teachers reported that setting up the SHSS program predominantly emanated from parents. In the case of Kathleen and Susan in
particular, parents were reported as making a single visitation to the classroom to supplement the SHSS meeting, conducting a book talk or staging a classroom presentation about health information related to diabetes care. Similarly, the Ontario teachers all indicated that SHSS documentation was primarily parent-driven. Like Kathleen and Susan, Tim experienced having a parent visit the school as a special guest presenter. With over 100 primary-school students (K – 3) in the gymnasium, Kate co-presented health information about diabetes and its care, which left Tim with the impression that he did not know “a lot about diabetes.”

Despite some variance in the practice of communications, SHSS programs, regardless of province, joined parents and school personnel in the experience of an interactive dynamic (Nutbeam, 2008), where both parties speak and listen effectively to each another and communicate productively about corresponding diabetes-related information. In contrast, communication through parental classroom visits relied not only on mutual interactivity but also upon a critical mindset primarily carried by the parent (Al Sayah et al., 2012).

Past the initial encounters, communication within the context of the parent-school personnel dyad readily occurred on an ongoing basis for the remainder of the school year. Two of the New Brunswick teachers practiced contact with parents over the telephone to address perceived diabetes care challenges, such as in the case of Casandra checking in with Darryl’s parents about planning classroom parties featuring high carbohydrate content. Similarly, Rachelle or Noreen (EA) daily telephoned Lydia’s mother sharing with her the specifics of Lydia’s dietary choices as a means to determine the proper course of medical treatment in response. In contrast, Paul was the only Ontario teacher
who had intermittent telephone conversations with the parents; these occurred either because his student, Jared, recently experienced a distressful event (e.g., “Mr. G., I am really low”), or because either Paul or Jared had perceived some challenges with respect to regimen adherence at school. According to Howells, Wilson, and Skinner (2002), these health measures collectively appear to point to the increase of self-efficacy levels within the embodiment of the school caregivers from an initial position, but may not significantly impact children’s HbA\textsubscript{1c} levels.

The other New Brunswick and Ontario teachers facilitated back-and-forth communications between the home and school through use of the student’s agenda or diabetes logbook. In Paul’s experience, however, the use of a diabetes logbook relayed the data tracking procedures of his student, Jared, from school to home. Despite such intentions, “some days the book was being signed by Mom or Dad,” indicating that the parent-teacher communication dyad was interrupted, because Jared “would forget to record his numbers” as well as “forget to jot down his experiences; how he felt at the time of his readings.”

**Students with Diabetes and Others in the School Setting**

Students with diabetes in both provinces needed to communicate (i) with their classmates their health needs in general, thereby increasing the classmates’ health literacy; and (ii) with their teachers/EAs when they were experiencing distress. New Brunswick teachers tended to be more proactive in encouraging the student to classmates communication. For example, Susan facilitated a “proactive dialogue … that helped to build a supportive classroom community.” Susan linked her conversation about Kevin’s special health needs to the perceived need to make adjustments to the existing classroom
and school rules, pointing out that, if she strictly enforced “the rule that ‘all students mustn’t rest their head and take a break,’ or that ‘no one could have an extra juice box at recess or outside of snack time,’ I, as a teacher, would be inflicting harm.” Susan’s orientation to her students appeared to involve not only an interactive capability to discuss sensitive health issues (Nutbeam, 2008), but also a critical interpretation of the school environment (Al Sayah et al., 2012) through viewing the school as placing unnecessary systemic barriers to Kevin’s “learning as well as his medical safety.”

In contrast, Rachelle and Casandra left the health literacy communication primarily to the student. Rachelle offered Lydia the chance to make a special presentation in response to the girl’s request. Approximately four weeks into the school year, Lydia and Rachelle organized a “class meeting,” so that Lydia could explain the meaning of her diabetic equipment, as well as introduce to her classmates a familiar face to an otherwise unfamiliar process of medical care. Likewise, Casandra enabled Darryl to pursue a “self-chosen” research project on Type 2 diabetes, which was meant to cultivate some autonomy over his care, as well as to allow him to project the face of an “expert” in the company of his peers. Both Rachelle’s and Casandra’s approaches to communication with their students appeared to further the expression of health literacy as a construct shaped in the exchange of health information between students and teachers (Parker, 2009) through interpersonal contact (Harrington & Vallerio, 2014).

Two Ontario teachers had their student’s health literacy needs communicated. Lacy, like Susan, organized a “team meeting” to address questions that emerged in the wake of Lawson’s diagnosis, as well as to “facilitate inclusivity around the disability.” Tim and his students attended a gymnasium presentation in which Jenny, joined by a
visiting school nurse and her mother, presented information about diabetes and answered questions from an estimated audience of 100 students. The other two Ontario teachers didn’t make such efforts. Paul cited his students’ prolonged exposure to the health care needs of Jared as the underlying reason why Jared’s peers haven’t “shown the need to know about Jared’s diabetes or anything like that.” Greg also didn’t feel the necessity for such communication, given that Ashley had been in his class for two years.

With respect to student-to-teacher/EA communications, teachers reported that they and some of their EAs participated in ongoing, individualized conversations with the students with diabetes. With respect to daily routine health care, teachers typically responded to their student’s expressed health needs, such as, needing to “get juices and snacks,” or to “go to the washroom,” as well as reviewing the daily and culminative patterns of glycemic behaviour and/or perceived quality of life recorded in logbooks at school in moments of transition or at regularly scheduled intervals.

In New Brunswick, without the presence of an attending school nurse, two of the teachers had to pay special attention to their student’s glucose levels. In Rachelle’s case, the daily use of a “standard fixed chart” helped her understand a range of blood glucose levels and corresponding insulin dosage rates. Casandra had to be extra-attentive to Darryl, who exhibited difficulty in adopting a consistent health routine post-diagnosis. Without such efforts, Casandra was convinced that Darryl would have “totally just forgotten about his own health.” Rachelle and Casandra exhibited the need for having *numerical* and *functional* health literacy skills (Berkman et al., 2010), in addition to being competent in the daily practice of interacting with their students (Nutbeam, 2008).
In Ontario, communications in the context of routine and emergency health procedures were typically carried forth through the efforts of the EAs. For example, Greg felt like “a newbie” in comparison to Janice, who had familiarity with the use of the glucometer and what all the digital information displayed on its screen meant. Furthermore, Paul, Tim, and Lacy relied to a large degree on their EAs to daily consult with their students. According to Paul, “I’m totally dependent on her, perhaps relying too much.” For Tim, the EAs in his classroom were “empowered to act like a caregiver,” further addressing any emergent health or academic needs as they arose in his students with special needs, including diabetes. Lastly, Lacy’s EA, Ken, performed much of the communications with Lawson.

**Classroom Teacher and Other School Personnel**

For both New Brunswick and Ontario teachers, data gathering, debriefing, and planning for substitution days were the three main events that involved them constructing health literacy skills for diabetes care in collaboration with other school personnel. With respect to data gathering, the teachers conducted some background investigation on the nature of diabetes and its relation to the health needs of the particular student in their care. In most cases, teachers sought out members within their own immediate social network: teachers who formerly taught the child; EAs who previously addressed the health needs of the student; and, even in Rachelle’s case, the school principal. Such data gathering helped to tie teachers and other school personnel together on the mission to construct a more supportive social communication network (Cammarata et al., 2009).

All seven classroom teachers participated in some form of debriefing on the subject of diabetes care with at least one other member from their school staff. Rachelle,
for example, debriefed with her EA, Noreen, on the subject of care for administering medically-invasive procedures. Similarly, Paul often met with at least one of his classroom EAs to reflectively explore “the extremes in Jared’s blood sugars,” and to find ways to further support his EAs in their practice of “whisper-talk” with Jared.

Teachers often prepared a folder for substitute teachers consisting of health information detailing routines and emergency health routines, contact information, and diabetes care practice. In transitioning their authority for the care of the classroom over to the substitute, classroom teachers in general took efforts to ensure that supportive, social communication networks within the school were ready and actively oriented to support that transition. Having greater satisfaction with communication networks in elementary schools is associated with better metabolic levels in children with Type 1 diabetes (Lehmkuhl & Nabors, 2008).

Health Personnel and Students

The social communication network forged between health personnel and students with diabetes took place primarily in Ontario. School nurses either visited the classroom or another room in the school, usually once a day, to escort students with diabetes to a designated safe space. These visits lasted anywhere from 10 to 40 minutes per school day. During these times, the school nurses administered medically invasive health care procedures. School nurses documented the results of testing and recorded health data into a diabetes logbook, which subsequently was used to communicate the health data tracking procedures from the school to home. Students who experienced partial withdrawal to address special health needs were reported as having some limited academic and social difficulties due to corresponding missed class time. Assigning
children with diabetes to the care of someone who can decode nutritional and glycemic information with at least 50% proficiency is more likely to result in better glycemic control than placing them in the care of someone who cannot (Hassan & Heptulla, 2010).

**Inclusionary Practices**

The teachers’ orientation to the care for students with diabetes in the inclusive setting was embedded within two primary concepts: self-care and diabetes management. These frameworks encompassed notions of disability according to the biopsychosocial model and worked to construct a form of life that simultaneously gave expression to an example of inclusive education. While self-care and diabetes management featured the fingerprint of different care agents involved in their expression within the school environment, both constructs were ultimately bound up in the more fundamental quest to realize a form of schooling and learning in the image of health and wellness, safety, and accessibility.

**Self-care**

All the teachers believed that the individual with diabetes had the obligation to address his or her own biological, emotional, and social health needs as best he or she could. Self-care was conceived as a complex, evolving construction (Glass & McAtee, 2006), because students with diabetes had to adapt themselves to perceived bodily and environmental stressors. As well, they needed to respond to the behaviours, actions, and strategies of other individuals in their environment, including teachers, educational assistants, classmates, and health professionals. Students were thus required to motivate themselves to pursue self-care development in the complex context of interactions between the self and the school environment (Lounsbury & Mitchell, 2009).
Diabetes self-care as it manifested in the student’s experience was significantly shaped through the student’s age, length of diagnosis, and perceived developmental abilities. Students in Kindergarten, Grades 1, and 2 generally demonstrated the ability to perform some self-care functions like assemble and set up the glucometer ready for its administration, inform others in their proximity about any emergent health needs, and practice daily healthy dietary choices. Students in Grades 5 and 6, however, generally were held accountable to further and more involving self-care behaviours like insulin dosage and administration, health data recording procedures, and safe disposal of used diabetes equipment. However, some students, like Robert and Lawson, exhibited signs of self-care challenges with respect to their “special needs” or “at-risk” behaviours, thus indicating developmental abilities having a role in the formation of his self-care. In addition, both Darryl and Lawson had demonstrated limitations in their progression of self-care in association with their diagnosis occurring within the same school year. These associations of health behaviour with respect to self-care at age, length of diagnosis, and perceived developmental abilities indicate that teachers tended to assess children’s relation to their diabetes mainly through a medical model of disability (Falvo, 2014), since these constructions tended to focus on some physiological impairment that resides within the individual (Llewellyn & Hogan, 2000).

Self-care was further shaped according to caregiver expectations and family dynamics. For the most part, classroom teachers held the view that children with diabetes wanted to construct increasing independence from others through a series of developmentally appropriate “steps” or stages in life, as well as to problem-solve moment-to-moment situations productively as best they could. Health professionals
believed that elementary students with diabetes required less assistance with self-care functions as they got older, especially with those involving medically-invasive procedures. The family was represented as a major source of self-care development, charged with educating their children to become proactive, critically minded, and conscientious with respect to their own unique health needs. These combined caregiver expectations and family dynamics suggest an explicit desire to see students with diabetes using their own talents to participate in schooling as much as possible (Ashman & Elkins, 2009), thus placing less onus on others to assist them (Thomas & Vaughn, 2004).

**Diabetes Management**

All teachers perceived diabetes management as a socially constructed practice of care that emerges from the inputs of care agents and is derived from corresponding educational and health policy systems. Diabetes management was conceived both as a complicated construction or limited health measure (Bennett, Dworet, & Weber, 2013) and as a social schema designed to achieve equilibrium in the child’s school experience (Anastasiou & Kauffman, 2013). As such, diabetes management encompassed advanced planning (Falvo, 2014), responsiveness to the perceived social and systemic barriers within the school (Mohebi, Azadbazht, Feizi, Sharifirad, & Kargar, 2013), sensitivity to the emergent health needs of the children (Jackson, 2013), and caregivers’ limitations (Thomas & Vaughan, 2004).

The formation of diabetes management at school was significantly shaped according to the educational-health policy systems. School and health personnel were governed by their provinces’ SHSS program and, in Ontario, by the Board of Education SHSS policy. In New Brunswick, elementary classroom teachers took responsibility for
all primary health care duties for the children, while other care agents were more peripheral. In contrast, Ontario classroom teachers took some diabetes management duties, primarily in addressing health needs during school activities, while health professionals assumed medically invasive care procedures. Ontario educational assistants assumed a more prominent role in the construction of diabetes management compared to their New Brunswick counterparts. This division of diabetes management was consistent with each province’s policy guidelines on inclusive education (New Brunswick Department of Education, 2012; Ontario Ministry of Education, 2009).

Policy implementation protocols additionally had a tangible influence in the construction of diabetes management at school. All teachers participated in an SHSS meeting for their student with diabetes. Goal-setting for self-care, assignment of caregiver responsibilities for non-invasive diabetes management, emergency procedures, and key contacts were common topics of conversation at these meetings. These conversations had an influence on teachers’ everyday care duties, including specific roles as first-aid responder, yard duty supervisor, and physical education teacher. SHSS meetings served to link school children with diabetes to forms of inclusive schooling (DeLuca, 2013), as all care agents were positioned to co-construct a culture of social health and wellbeing (Hutchinson, Freeman, & Berg, 2004).

Coping with Care

The SHSS program in each province was customized to the unique health needs of the child with diabetes and encompassed a school re-entry approach (Prevatt, Heffer, & Lowe, 2000), to give the children the chance to reintegrate into the school community and to participate in the everyday educational activities within the classroom (Canter &
Roberts, 2012). Care was facilitated through a series of progressive steps (Alderfer & Rourke, 2014). Pedagogical strategies were planned in advance of re-entry but required flexibility to address the children’s emergent and unexpected health needs.

The orientation to diabetes care differed by province. In New Brunswick, the SHSS programs incorporated an ecological health delivery service model (Lounsbury & Mitchell, 2009), because the child, family, and school and health care communities interacted to build the competence of the teacher in taking care of the health issues associated with diabetes (Bobo, Kaup, McCarty, Parker, & Carlson, 2011; Wagner, 2001). In Ontario, teachers and health professionals operated as separate agents with the health professionals primarily responsible for health needs and educational professionals for academic needs, with limited cross-domain dialogue (Middlehurst & Morrison, 2008).

Consistent with previous research (e.g., Nabor, Little, Akin-Little, & Iobst, 2008), most participants had little to no previous knowledge about diabetes care prior to the child’s entry into their classroom (and re-entry in two cases), which left them with feelings of very low confidence to meet the child’s perceived health needs (see Robinson & Summers, 2012). During the SHSS meeting, classroom teachers with no prior experience in the care for diabetes felt unsure of what to expect from the parents and child; still the SHSS contributed towards building rapport with the family and student with diabetes. Greg participated in follow-up training. He mentioned having difficulty transitioning his learning from outside the classroom to his everyday diabetes care practice, because of cognitive overload and the abstract nature of the teaching. Similar to Pinelli et al. (2011), these findings exhibit tensions teachers were likely to carry in their initial encounters with children having diabetes.
The teachers contributed to mobilizing health information in the school. In her administrative role, Kathleen constructed the medical health profiles of all students with health support needs, including those with diabetes, and posted them in key locations for school staff to use in their care for such students. The classroom teachers introduced the meaning of diabetes care to their students, mainly because the parents and/or the child with diabetes expressed interest in building a caring, inclusive community in the classroom. Students with diabetes showed initial discomfort in making public their health needs for diabetes, coupled with shock and levels of separation anxiety from parents for those students diagnosed during the school year (see Cammarata et al., 2009; Shiffrin, 2001). Teachers felt that sharing the experience of diabetes care according to the child’s perspective was professionally and personally rewarding. They generally felt more hopeful about the current situation and about the future prospects of the child’s self-care than they had been at first. They would be willing to work with another child with diabetes, with Susan, Greg, and Tim explicitly interested in having more practical education on the subject.

**Strategies**

In response to the presence of diabetes health support needs, classroom teachers used health-infused teaching strategies (Daneman, Frank, & Perlman, 1999), some of which were exclusively geared to the collection of health information, while others were supportive to the overall aims of developing self-care in children according to their developmental age. As a result, teachers played a pivotal role in supporting the transition of diabetes care from the home to the school environment and, in so doing, demonstrated an interpretation of the SHSS policy through their caregiver functions.
After the SHSS meeting, Susan, Rachelle, Casandra, and Greg additionally sought to make use of the child’s goals for self-care by allowing the child to present information about diabetes, similar in structure to motivational interviewing (Kucera & Sullivan, 2011). However, Kathleen, Rachelle, and Lacy, largely because of the child (or another child) being unwilling or unable to present, employed health measures similar to behaviour contracting (Halvorson et al., 2005). For example, in her relation with Grade 3 students with special education and health needs, Kathleen employed self-regulation strategies involving coloured “zones” to assist students in their difficulties to navigate their learning processes and their agency in the school environment. With Robert, Rachelle made up goals for his self-care and taught him to become more aware of his diabetic distress symptoms, despite his developmental challenges. Similarly, Lacy took efforts to transition Lawson from his erratic glycemic behaviour post-diagnosis to more regulated glycemic behaviour by teaching him to be more open about how he felt with others at key moments during the day.

Apart from having to make use of heavily teacher-dependent strategies, classroom teachers used strategies that required them to undertake less active participation in the child’s daily self-care development. An interpretation of direct supervision was commonly used among all classroom teachers (Nyugen et al., 2008), to determine if and when signs of diabetic distress emerged in the child and required their immediate intervention. However, teachers generally reported difficulty with identifying and differentiating the symptoms of hypoglycemia and hyperglycemia as they manifested in the body of the particular child.
Another strategy that was used in conjunction with the parents’ participation was telephone case-management (Howe et al., 2005). In these cases, classroom teachers coordinated the care with the family mainly to support the everyday health routines and to inspire compliance behaviours at school relative to the child’s health plan. Unlike the conclusions reported in Nordfeldt et al. (2013), Rachelle, Casandra, and Greg explicitly indicated that their contact with the parents led to perceived tangible improvements in the process of diabetes care at school. Lastly, teachers included the child’s classmates and school peers in the process of self-care development through peer support and mentorship models (Dennis, 2003; Embuldeniya et al., 2013), with Kathleen and Lacy facilitating the construction of inclusive learning communities through students joining together to learn about developmental health activities and to partake in buddy systems, while Casandra and Tim offered the chance for their students to spend time with other students at school with diabetes for extended periods of time to learn how these students have managed. Similar to Newman, Steed, and Mulligan (2009), teachers who offered their student peer support and mentorship generally felt these strategies proved useful in complementing their caregiving functions and increasing the child’s self-confidence.

**Study Limitations and Implications for Future Research**

Phenomenology as an iteration of the qualitative research tradition is predisposed to a number of study limitations (Patton, 2002). Accordingly, there were four main limitations that impacted the performance of educational research conducted in this study: (i) generalizability, (ii) researcher bias, (iii) data collected solely from a singular perspective, and (iv) the obstacles to conducting phenomenological research.
First, phenomenology assumes that what is most important to know about the world is through what people experience and how they interpret the world (Costello, 2012). However, the teacher perspectives of diabetes self-care represent only their understanding of their experiences. Such understanding in and of itself does not permit for subsequent generalizations beyond the context of inquiry (Moustakas, 1994). Therefore, this study is limited to showcasing my effort to construct a rigorous understanding of the experiences of four New Brunswick and four Ontario teachers of children with diabetes at school. As such, future research on the subject of diabetes self-care at school would more substantially contribute to the research literature by extending the domain of participant perspectives to include members from the educational, health, and family systems. Specifically, investigating the perspectives of educational assistants, school secretaries, and administrators would enlarge the current picture of the educational system involved in diabetes self-care. Similarly, school nurses, appointed health specialists, and health personnel facilitating School Health Support Services (SHSS) workshops would add additional insight from the perspective of the health system. Finally, parents, siblings, and the student with diabetes could link the educational and health systems involved in the development of self-care.

Second, phenomenology constructs knowledge about the world through direct encounter with the phenomenon of interest, thus introducing the researcher as an instrument of data collection (Moustakas, 1994). The researcher’s background biases and focused perceptions in relation to participant behaviour (Costello, 2012) may influence the selection of word choice, intonation, and other forms of behaviour by participants at the time of the interview (Moustakas, 1994). In addition, my analysis of the participants’
words during my analysis is predicated on my personal experiences and subjectivities with respect to diabetes. In this respect, my ongoing peer debriefing with my supervisor assisted in reducing my researcher bias. However, future research might consider a wider network of peer debriefers and data analysts with less personal connection to the topic.

Third, in conducting a phenomenological inquiry to address the perceived interdisciplinary nature of the research context, I appropriated the ontological assumption that each teacher’s perspective must refer to some fixed, essential reality (e.g., New Brunswick and Ontario teacher perspectives of self-care) in the face of other possible research designs and their implicit corresponding ontological assumptions (Costello, 2012). Upon that methodological platform, I activated the idea that beyond the encounter of each participant’s subjectivity made known through their self-report data and my own field note transcriptions, the school environment and all its activities occupied the status of an unrelenting and enduring presence in the background. As a result, the participant experiences disclosed through their self-reports and further portrayed through researcher notations were taken for granted as evidence pointing to the real-life behaviours of the school environment and of its intersecting contexts involving other care agents and the student with diabetes described therein and about.

Finally, although I set out to conduct this study in the Husserlian phenomenological research design, my data collection, analysis, and representation gradually shifted to more of a case study methodology (Stake, 2010). Had the 10-minute follow-up interviews with each participant taken place, my systematic investigation into the experience of self-care promotion according to the perceptions of teachers would have likely featured deeper and more sustained observation in line with
phenomenological research. Accordingly, my two-phased, in-depth interview approach to the collection, analysis, and representation of participant-inspired data was designed to be congruent with the applications of phenomenology in research practice (Moustakas, 1994). With only one phase of interviews completed, my data collection, analysis, and representation became set up to project evidence at best horizontally (Stake, 2010), with description functioning to broadly contextualize the qualitative features of the family, educational, and health systems operating in relation to diabetes self-care according to the New Brunswick and Ontario teachers’ self-reports.

While conducting in-depth interviewing illuminated an insightful understanding of the experiences of eight teachers, it did not elicit data from the standpoint of fieldwork observations and focus group interviews. Nevertheless, adapting the participant questions from the in-depth interview to suit the focus group environment and the fieldwork setting should provide the means to consider future directions of research, offering the chance to construct a wider and more textured picture of self-care at school.

Additionally, the qualitative nature of the research data suggests the complementarity of quantitative research on the development of diabetes self-care at school. Based on a review of the literature, several instruments have been designed to measure perceived access to participation, Quality of Life, and other measurable scales (e.g., Bourke-Taylor, Howie, & Law, 2010; Bourke-Taylor & Pallant, 2013). Methodologists may wish to consider the qualitative knowledge obtained in this study to further the interests of instrument design and/or adaptation to quantitatively measure the perceived dimensions of caregiving involved in relation to a young child with diabetes.
This study adds layers of insight to the research on diabetes care. In consideration of educational policy, educational policymakers may wish to consider how the School Health Support Services (SHSS) program in Ontario and New Brunswick might be presented to educational care agents in the future to promote further clarity of caregiver expectations and how to implement protocols of care expeditiously but inclusively.

Theoretically, educational and health care theorists may find the interpretation of Wagner’s (1998) Chronic Care Model (CCM) according to the teacher’s embodiment of roles and responsibilities, communication, inclusionary practices, and coping with care a useful picture to understand chronic care practice in education and to further explore how delivery system design, clinical information system, self-management support, and decision support might emerge in the context of diabetes care in particular. For educational practitioners, the eight teacher perspectives of diabetes self-care in this study provide a voice of concern about the need for teachers to network with other care agents to support the safety, health, and wellness of a small but significant population of students who attend school and require enhanced levels of teachers’ care.
EPILOGUE

My greatest challenge as a researcher throughout the research process has been the need to exercise trust. Throughout my research journey, my researcher standpoint emerged and shifted according to unsettled boundaries taking place through ongoing interactions between the self and the research environment. Yet such shifting contexts experienced along the way were ultimately navigable, because of the effort at addressing the enduring personal need to cultivate trust in others— with colleagues, with participants, and with the research team. With such an embedded perspective and relationally humanistic encounter, my orientation challenged me to engage in modes of “rigorous self-scrutiny” (McMillan & Schumacher, 2010, p. 332) throughout the duration of inquiry to keep implicit biases in check (Peshkin, 1988). However, my subjectivity was also a source of great strength, enabling me to carefully fashion a qualitative research orientation tailored to the needs of the research project, which was to describe the multiple, intersecting threads of meaning that culminated in eight teacher perspectives of school-based diabetes care from two provinces.
REFERENCES


### APPENDIX A: ELEMENTS OF FUNDAMENTAL CARE UNIT

<table>
<thead>
<tr>
<th>Elements of Wagner’s (1998) Chronic Care Model</th>
<th>Definition</th>
<th>Examples</th>
</tr>
</thead>
<tbody>
<tr>
<td>Community Resources and Policies</td>
<td>Refers to practices of care that serve to link patients with community programs and services (e.g., SHSS program) to mobilize these resources to meet patient needs.</td>
<td>Specialist staff (e.g., appointed school staff and school health personnel) coordinate referral to community resources, to peer group support groups, offering incentives for self-management activities, and making students aware of advocacy efforts like promotion and participation in diabetes walks.</td>
</tr>
<tr>
<td>Organization of Health Care</td>
<td>Addresses the culture and policies of the system in which care takes place. The mission, business plan, and goals of the organization are carried into practice by care-providers (e.g., school staff and school health personnel).</td>
<td>In-service professional learning programs, endorsement of effective improvement strategies aimed at improvements of care practices, provide incentives based on quality of care, and development of agreements that facilitate care coordination within and across organizations (e.g., Ministry of Education, Ministry of Health, and Ministry of Community and Social Services).</td>
</tr>
<tr>
<td>Self-Management Support</td>
<td>Activities that empower and prepare students with diabetes to understand their health behaviours and to develop strategies to live life as a student as fully as possible.</td>
<td>Health and wellness coaching, use of goal sheets, developmentally appropriate literacy materials, and teaching of diabetes self-care behaviours in line with contemporary evidence-based standards.</td>
</tr>
<tr>
<td>Delivery System Design</td>
<td>Refers to the organization and scheduling of planned proactive care (e.g., helping with dietary and physical exercise planning, carbohydrate counting, insulin administration, blood glucose monitoring, regulation of hydration usage) to assure compliance with effective, efficient clinical care and self-management support.</td>
<td>Customized practice team (care provider) roles with scripted activities, group visits/planned visits, and care practices that are based on and attuned to the students’ understanding and that fit with their cultural background.</td>
</tr>
<tr>
<td>Decision Support</td>
<td>Promotes School Health Support Services (SHSS) care that is consistent with evidence-based practices (e.g., proven care provider education methods, such as academic detailing and motivational interviewing that inspire behaviour change leading to self-care practices) and student preferences through several mechanisms (e.g., protocols, reminders, and standing orders that facilitate the coordination of care delivery for diabetes self-care management).</td>
<td>Documentation of flow sheets, progress note templates, referral guidelines design and use, pocket cards, and registry data, all teachings that involve the use of communication devices (such as the above texts) that aim to promote adherence to customized care guidelines prescribed by physician or clinical practice guidelines.</td>
</tr>
<tr>
<td>Clinical Information Systems</td>
<td>Refers to a computerized disease registry that includes critical information about each patient and the performance and results of important aspects of care.</td>
<td>Registry of the School Health Support Services (SHSS) program and electronic health record use, performance feedback, preaddressed reminders of care provider roles and responsibilities, and documentation of clinical care prescriptions and medication data to registry.</td>
</tr>
</tbody>
</table>
APPENDIX B: ETHICAL CLEARANCE FROM QUEEN’S UNIVERSITY

GREB Ref #: GEDUC-690-13; Romeo # 6010665 Title: "GEDUC-690-13 Teacher Perspectives of Diabetes Self-Care at School"

Dear Mr. Cousins:

The General Research Ethics Board (GREB), by means of a delegated board review, has cleared your proposal entitled "GEDUC-690-13 Teacher Perspectives of Diabetes Self-Care at School" for ethical compliance with the Tri-Council Guidelines (TCPS) and Queen's ethics policies. In accordance with the Tri-Council Guidelines (article D.1.6) and Senate Terms of Reference (article G), your project has been cleared for one year. At the end of each year, the GREB will ask if your project has been completed and if not, what changes have occurred or will occur in the next year.

You are reminded of your obligation to advise the GREB, with a copy to your unit REB, of any adverse event(s) that occur during this one year period (access this form at https://eservices.queensu.ca/romeo_researcher/ and click Events - GREB Adverse Event Report). An adverse event includes, but is not limited to, a complaint, a change or unexpected event that alters the level of risk for the researcher or participants or situation that requires a substantial change in approach to a participant(s). You are also advised that all adverse events must be reported to the GREB within 48 hours.

You are also reminded that all changes that might affect human participants must be cleared by the GREB. For example you must report changes to the level of risk, applicant characteristics, and implementation of new procedures. To make an amendment, access the application at https://eservices.queensu.ca/romeo_researcher/ and click Events - GREB Amendment to Approved Study Form. These changes will automatically be sent to the Ethics Coordinator, Gail Irving, at the Office of Research Services or irvingg@queensu.ca for further review and clearance by the GREB or GREB Chair.

On behalf of the General Research Ethics Board, I wish you continued success in your research.

Yours sincerely,

Joan Stevenson, Ph.D.
Chair
General Research Ethics Board

C: Dr. John Freeman, Faculty Supervisor
   Dr. Don Klinger, Chair, Unit REB
   Erin Wicklam, c/o Graduate Studies and Bureau of Research
APPENDIX C: RECRUITMENT EMAIL

Teacher Perspectives of Diabetes Self-Care at School

Hello,

My name is Sean Cousins. I am a Master’s Student in the Faculty of Education at Queen’s University. For my master’s thesis, I am studying what it is like to be an elementary school teacher working with a student with diabetes. If you teach elementary school (Kindergarten to Grade 8) and have taught or are currently teaching a student with diabetes mellitus, I would really like for you to consider taking part in a 90-minute interview about your experiences working as part of a School Health Support Services (SHSS) team to help this student. If you are interested, please contact me at 0spcl@queensu.ca, or 613-583-6562 for more information. Persons who are interviewed will receive a $25 gift card as a token of appreciation. Thank you for considering this request.

Sean
APPENDIX D: LETTER OF INFORMATION

Teacher Perspectives of Diabetes Self-Care at School

**Principal Investigator:**
Sean Cousins  
Faculty of Education  
Queen’s University  
Kingston, Ontario, Canada  
*(613) 583-6562*  
0spc1@queensu.ca

**Faculty Supervisor:**
Dr. John Freeman  
Faculty of Education  
Queen’s University  
Kingston, Ontario, Canada  
(613) 533-6000 x.77298  
freemanj@queensu.ca

**What am I trying to discover?**
I am doing this research for my master’s thesis in Education. The purpose of this study is to explore how elementary teachers work with students with diabetes. I am hoping to learn how elementary teachers understand their role in addressing the health support needs of students with diabetes and how such teachers interact with students with diabetes in their development of diabetes self-care.

My research is guided by the question: What might the experience and insight of elementary school teachers working in collaboration with other educational stakeholders (e.g., children with diabetes, their parents, peers, and health care professionals) have to offer to the challenge of constructing a model of diabetes self-care in education?

**What will happen during the study?**

*Interviews*
I will be conducting interviews with elementary teachers who have experience in caring for a student with diabetes.

*Initial Interview*
I will provide you with a demographic information sheet that will take approximately 10 minutes to complete and then interview you (the primary caregiver of the student with diabetes at school) for 80 minutes on one occasion during the day at your home school. With your permission, the interview will be audio recorded and field notes will be documented on site by the primary investigator. Alternatively, if you would prefer, I could interview you at the local public library in a private study room or at your home. I will ask you questions designed to understand your experience in working with a student with diabetes, such as “how has having a child with diabetes in your care shaped your experience of teaching?”

*Follow-up Interview*
I may interview you in a follow-up session via telephone for 10 minutes after school hours within three months of my initial interview with you to answer any questions that arisen from the first interview. The telephone interview will be audio-recorded, with your permission. Alternatively, if you would prefer, I could interview you via Skype.
Are there any risks to doing study?
There are no known risks associated with participating in this study.

Are there any benefits to doing this study?
The research will not benefit you directly. I hope to learn more about some of the ways elementary teachers interact with children with diabetes, to address their diabetes care needs, to interact positively with others, and to develop self-care behaviour. This information could help educators and families of children with diabetes better support the development of teaching children with diabetes to self-manage their chronic illness.

Reimbursement
Persons who are interviewed will receive a $25 gift card as a token of appreciation.

Who will know what I said or did in the study?
Every effort will be made to protect your confidentiality. No one but the principal investigator will know whether or not you participated. I will not use your name or any information that would allow you to be identified directly. However, we are often identifiable through the stories we tell. Your name will be replaced with a pseudonym in all presentations and publications resulting from this research. The data will be used for my master’s thesis and may also be published in professional journals or presented at conferences, but any such publications and/or presentations will be of general findings and will never breach individual confidentiality.

The audio recordings of the interview sessions will be saved in password protected folders until they are coded for content. The coded information and the transcribed interviews will be stripped of any identifying data. They will be stored in a locked cabinet. According to the regulations of Queen’s collective agreement, all data have to be maintained for 5 years. At that time, the data will be destroyed.

Participation and Withdrawal
Your participation in this study is voluntary. You do not need to answer questions that you do not wish to answer or that make you feel uncomfortable. If you decide to be part of the study, you can decide to withdraw, at any time, even after signing the consent form or part-way through the study, by contacting Sean Cousins at ospc1@queensu.ca or (613) 583-6562. If you decide to withdraw, there will be no consequences to you. In cases of withdrawal, any data you have provided will be destroyed unless you indicate otherwise.

How do I find out what was learned in this study?
I expect to have this study completed by approximately July, 2014. If you would like a brief summary of the results, please let me know how you would like it sent to you.

Questions about the Study
Any questions about study participation may be directed to Sean Cousins at 613-583-6562 or his supervisor, Dr. John Freeman, at freemanj@queensu.ca or 613-533-6000, ext. 77298. Any ethical concerns about the study may be directed to the Chair of the General Research Ethics Board at chair.GREB@queensu.ca or 613-533-6081.

This study has been granted clearance according to the recommended principles of Canadian ethics guidelines, and Queen's policies.
APPENDIX E: CONSENT FORM

Teacher Perspectives of Diabetes Self-Care at School

Name (please print clearly): ________________________________________

1. I have read and retained a copy of the Letter of Information and the Consent form. I have had any questions answered to my satisfaction.

2. I understand that I will be participating in the study called Teacher Perspectives of Diabetes Self-Care at School. I am aware that the purpose of the study is to explore how elementary teachers work with students with diabetes. I understand that I will be completing a demographic information sheet that will take about 10 minutes and an interview that will take about 80 minutes of my time. I have been informed that the interview will be recorded by audiotape and field notes will be scribed by the principal researcher. I am aware that the principal researcher may contact me to schedule a follow-up interview of approximately 10 minutes, via telephone or Skype, if something I said needs to be clarified.

3. I understand that my participation in this study is voluntary and I may withdraw at any point during the study. I may request the removal of all or part of my data by contacting Sean Cousins without any consequences to myself, including my future employment at the District School Board I teach in.

4. I understand that every effort will be made to maintain confidentiality of the data now and in the future. Only the principal researcher Sean Cousins and his supervisor Dr. John Freeman will have access to these data. The data will be used for Sean’s master’s thesis and may also be published in professional journals or presented at conferences, but any such publications and/or presentations will be of general findings and will never breach individual confidentiality. I understand that, upon request, I may have a full description of the results of the study after its completion.

5. I am aware that if I have any questions about my study participation, I may contact Sean Cousins at 613-583-6562 or by email at ospc1@queensu.ca or his project supervisor, Dr. John Freeman at 613-533-6000 x77298 or by email at freemanj@queensu.ca. Any ethical concerns about the study may be directed to the Chair of the General Research Ethics Board (613-533-6081) at Queen’s University or chair.GREB@queensu.ca.

6. If you would like to receive a summary of the study’s findings, please complete the contact information listed below:

   Tel: ( )_____--_______ Email:_______________________ Other: __________________

I have read the above statements and freely consent to participate in this research.

Please sign one copy of this Consent Form and return to Sean Cousins. Retain the second copy for your records.

Signature: _______________________________ Date:__________________________
APPENDIX F: DEMOGRAPHIC FORM

Please complete the following questions. Leave any questions blank that you are uncomfortable answering.

1) What grade level(s) are you currently teaching?
   K, 1, 2, 3, 4, 5, 6, 7, 8

2) How many years have you been teaching?
   a) less than 5 years
   b) 5-14 years
   c) 15-24 years
   d) 25 years or more

3) What professional (teaching, first-aid, medical) qualifications do you currently have (please list)?
   __________________________  __________________________
   __________________________  __________________________
   __________________________  __________________________

4) What in-service training have you had on diabetes?
   o professional workshops
   o book clubs
   o online courses
   o colloquia
   o conventions
   o Other (Please describe _____________________________.
   o None
5) What aspects of diabetes did the training address (check off any that apply)?

- Insulin action and administration
- Dosage adjustment
- Blood glucose (BG) testing
- Ketone testing
- Nutrition therapy
- Exercise
- Sick-day management
- Guidance and lifestyle counselling
- Interacting with peers and/or adults
- Prevention, detection, and treatment of hypoglycemia/hyperglycemia
- Other (please describe) ________________________________
- N/A
APPENDIX G: INTERVIEW GUIDE

Foci 1: Knowledge (approx. 25 min. times are approximate)

Tell me a bit about the student(s) with diabetes whom you taught (teach).

What did you know about diabetes before you became his/her (or their) teacher? What did you previously know about the child?

What did you need to find out about diabetes? How did you find out this information?

What did you need to find out about the child? How did you find out this information?

How dependent is/was the child on your care to manage his or her diabetes?

Prompting strategies: Tell me more about… What did you mean by…? Give me an example of…

Foci 2: Beliefs (approx. 20 min.)

What do you believe is most important about the management of diabetes?

What responsibilities do you feel you have for diabetes management?

How much do you think instruction needs to be differentiated for students with diabetes?

In the research about diabetes, people talk about “diabetes self-care.” What does diabetes self-care mean to you?

What do you see as the difference between diabetes management and diabetes self-care?

Prompting strategies: Tell me more about… What did you mean by…? Give me an example of…
Foci 3: Practice (approx. 25 min.)

How has having a child with diabetes in your care shaped your teaching?

How do you think the educational experience for the student with diabetes in your class differs from other students in your class?

What challenges have arisen in your care for the child with diabetes? How have you responded to these challenges?

What supports do you have in working with the child with diabetes?

What supports do you feel are missing in working with the child with diabetes?

If you had a chance to sum up your understanding and experience of being the student’s teacher, what message would you give to other teachers?

Prompting strategies: Tell me more about… What did you mean by…? Give me an example of…

Is there anything else you wish to share before we conclude this interview?