

“A Place Where I Belong”: Exploring the Meaning of Social Support Among Manitoban Youth  
Living with Type 2 Diabetes through a Grounded Theory Study

by

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A Thesis Submitted to the Faculty of Graduate Studies of  
The University of Manitoba  
in partial fulfillment of the requirements of the degree of

Master of Arts

Faculty of Kinesiology and Recreation Management  
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## **ABSTRACT**

Manitoba has the highest rate of type 2 diabetes in Canada, exceeding other provinces 12-fold. Youth with diabetes suffer from high rates of physiological and psychosocial complications. Youth with type 2 diabetes report living with increased disease burden. Current literature has suggested that peer and social support are critical to the promotion and adoption of healthy living in young people living with type 2 diabetes. As such, high quality social support has been perceived as positive and can enhance children and youths' resilience against life stressors. Despite this suggestion, there is little evidence on how best to support this population. Thus, the purpose of this Masters thesis was to explore the meaning of social support among Manitoban youth living with type 2 diabetes. Guided by a constructivist grounded theory approach, semi-structured interviews were employed to unravel this question. Youth identified the following avenues of social support: family, friends, health care professionals, school and programming. In this thesis, I have worked with youth to fill gaps in the literature and have advanced knowledge on how youth would like to be socially supported. Based on my findings, future intervention development in the field of type 2 diabetes should focus on addressing unmet social support needs so as to better the health and wellbeing of this marginalized population. Future interventionists should also be aware of the vast incongruence in patients' and physician's perceptions of health in type 2 diabetes and design interventions accordingly.

## **ACKNOWLEDGEMENTS**

I would like to thank my thesis advisor, Dr. Fiona Moola. You exposed me to my first opportunity in the research field and, since then, continued to provide me with ongoing opportunities to learn. Thank you for supporting and mentoring me through this process, as well as supporting me in my growth as an academic and as a person. I would like to thank my committee members, Dr. Shaelyn Strachan and Dr. Brandy Wicklow, for their assistance, time and feedback throughout this thesis. I would also like to thank Dr. Heather McRae for your mentorship and advice through my graduate degree.

Thank you to the Faculty of Kinesiology and Recreation Management for their support and information, in particular to Dr. Todd Duhamel and Tobi Hawkins. As well, thank you to the University of Manitoba Graduate Research Assistantship.

I would like to acknowledge and thank my partner, Vanda Pov for your endless and unconditional support not only in this endeavour, but also in my life. You continue to provide me with stability and comfort. I appreciate your patience and for you enabling my sushi and Starbucks addictions.

Lastly, I would like to acknowledge my participants and their families, for without them, none of this would be possible. I am fortunate enough to have you entrust your experiences with me to share with the rest of the world.

## **DEDICATION**

It is without a doubt that I would like to dedicate this thesis to my parents. Words cannot explain my gratitude for the endless sacrifices you have made to make this possible. Thank you for always supporting my academic pursuits. Not one day goes by where I am not completely grateful and appreciative for all you both do to provide me with opportunities to flourish. I am forever indebted to your time and efforts. I hope I have made you both proud. Thank you again for giving me all I could ask for, and then some. I love you mom and dad

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## CHAPTER ONE – INTRODUCTION

Diabetes mellitus is a chronic illness that negatively affects health and wellbeing. In particular, there is a growing prevalence of type 2 diabetes among children and youth worldwide (Zimmet, Alberti, & Shaw, 2001). The burden of disease is particularly exacerbated in the province of Manitoba, Canada where factors such as poverty, colonialism<sup>1</sup>, and a shift from traditional to modern diets have contributed toward what some might call an epidemic. Current literature has suggested that peer and social support are critical in the promotion and adoption of healthy living in youth with type 2 diabetes. In this thesis, I sought to understand and explore the meaning of social support for youth with type 2 diabetes. I explored how these youth want to be socially supported. This chapter provides the rationale for the chosen research topic.

### **Background and History**

Diabetes mellitus is a chronic illness that affects approximately 2.7 million Canadians (Canadian Diabetes Association [CDA], 2014). In the 21<sup>st</sup> century, it has been considered to be one of the main afflictions that affect human health (Zimmet, Alberti & Shaw, 2001). Diabetes is characterized by the deficiency of insulin or a decreased response to insulin resulting in high levels of blood glucose. With diabetes, cells are not able to take up adequate amounts of glucose to meet metabolic needs, and as a result, blood glucose levels rise. Instead of cells, fat becomes the primary substrate for cellular respiration – the process of converting nutrients into energy (Campbell, 2008). Due to the high levels of glucose in the blood, the kidneys capacity to reabsorb this nutrient is compromised. This results in the presence of glucose in the urine, and as the concentration of glucose in urine increases, more water is excreted along with it and frequent urination occurs.

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<sup>1</sup> Colonialism is defined as the policy or practice of acquiring full or partial political control over another country, occupying it with settlers, and exploiting it economically.

There are mainly three types of diabetes: type 1 diabetes, type 2 diabetes and gestational diabetes. Type 1 diabetes (T1D) — formerly known as insulin-dependent diabetes or juvenile diabetes (IDDM) — is an autoimmune disorder in which the immune system destroys the beta cells of the pancreas. Treatment consists of daily insulin injections (World Health Organization [WHO], 2012). Type 2 diabetes (T2D), formerly noninsulin-dependent diabetes mellitus (NIDDM) – and the focus of this thesis – is characterized by the failure of glucose uptake by target cells, despite the production of insulin. Gestational diabetes is a temporary condition where the expecting mother experiences high levels of blood glucose during pregnancy (WHO, 2012).

**Table 1. Diagnosis of Diabetes** (CDA, 2014).

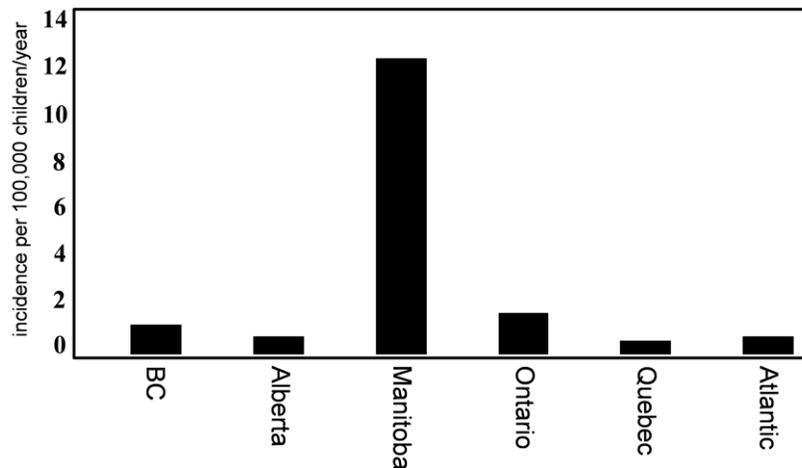
<b>Test</b>	<b>Plasma Glucose Level</b>
Fasting Plasma Glucose	$\geq 7.0$ mmol/L
HbA1C (Glycated Hemoglobin)	$\geq 6.5\%$
2-Hour Plasma Glucose in a 75g OGTT	$\geq 11.1$ mmol/L
Random Plasma Glucose	$\geq 11.1$ mmol/L

Fasting = no caloric intake for at least 8 hours, OGTT = Oral glucose tolerance test

T2D is one of the fastest growing chronic illnesses worldwide (Zimmet et al., 2001), accounting for approximately 5 billion dollars in annual health care expenditures in Canada (Dawson, Gomes, Gerstein, Blachard & Kahler, 2002). While it was once considered to be a disease restricted to older adults (Zimmet et al., 2001), it has now become a novel condition that pediatric endocrinologists must deal with. In Canada, T2D accounts for 96% of new cases of diabetes (Government of Manitoba, 2009). Specifically, Manitoba has the highest rates of T2D in youth, exceeding other provinces 12 fold (Figure 1) (Dean, 2001). The Canadian Diabetes

Association (CDA) identifies numerous risk factors related to T2D. Some examples include: excessive weight, physical inactivity, a family history with diabetes, belonging to a particular ethnic group (Aboriginal, Hispanic, South Asian, Asian, or African descent), and previous diagnosis of a psychiatric disorder, such as schizophrenia, depression, and bipolar disorder.

**Figure 1. Incident Rate for Type 2 Diabetes in Canadian Children** (Amed et al., 2010)



### **A Brief History of Type 2 Diabetes**

*Pre-1985: Type 2 diabetes is a disease of adults* (Dean & Sellers, 2015). T2D was a disease of adults and was thought to be non-existent in children. Children who could not be classified as suffering from T1D were thought to be “rare autosomal dominant transcription factors diabetes or maturity-onset diabetes of the young (MODY)” (Dean & Sellers, 2015, p. 2). In 1965, there was an increase in rates of T2D in the Pima Indians of Arizona. These increases led to a longitudinal screening study of Pima Indian’s 1600 community members, lasting until 2007. During this time, the “thrifty gene” hypothesis was the most common theory used to explain the higher rates of T2D in Indigenous populations across the world (Hales & Barker, 1992). This gene was thought to provide a survival advantage during periods of feast and famine (Neel, 1962).

*1985-1995: The decade of scepticism* (Dean & Sellers, 2015). This decade was the first

time clinicians around the world began to witness children with T2D. There were case reports stating that NIDDM was not as uncommon as was originally believed in African and Mexican American teenagers (Gauder, 1984), Pima Indian children (Savage, Bennett, Senter, & Miller, 1979), and Oji-Cree First Nation children (Young, McIntyre, Dooley, & Rodriguez, 1985). Efforts were made to disprove that children were suffering from T1D. In 1993, the International Conference on Diabetes in Indigenous peoples in Hawaii included its first ever session on T2D in children (Dean & Sellers, 2015).

*1995-2005: The decade of growing international interest* (Dean & Sellers, 2015). In 1996, an international meeting on T2D in children of minority groups was held in Tuscon, Arizona. This was a pivotal moment in the global recognition of this novel children's disease. In 1998, the Diabetes Division of the Centre for Disease Control held a meeting among epidemiologists and pediatric endocrinologists to develop a "gold standard" criterion to classify T2D in children (Dean & Sellers, 2015). Commonalities were found between children living with obesity, of Mexican American, African American, or Indigenous heritage, having one or both parents with T2D, and from underprivileged life situations (Dean & Sellers, 2015). At this time, there were no validated measures to differentiate between T1D and T2D. During this decade, the focus on treatment grew. However, this was restricted to "national and international consensus statements because of the lack of safety and efficacy data on lifestyle interventions, insulin regimes, and oral diabetes medication in children" (Dean & Sellers, 2015, p. 3).

*2005-2015: The decade of intensive international research* (Dean & Sellers, 2015). In the past decade, the uniqueness of T2D in children has grown in global awareness. Data has emerged revealing the aggressiveness of this disease and the negative impact that it has on health. A study by Dart et al. (2014) reported renal and neurologic complications such as dialysis, blindness,

and/or amputation by 5 and 10 years post diagnosis, respectively. Dean and Sellers (2015) forecast that the next decade will consist of numerous substantial challenges and endeavours for this population and researchers.

### **Statement of the Problem**

Children and youth diagnosed with T2D report living with increased disease burden (Sellers, Moore & Dean, 2009), and are at higher risk of physiological complications such as heart attack, kidney failure, blindness, and limb amputation (CDA, 2014). By the age of 18, almost 1/3 of diabetic patients in Manitoba exhibit some degree of renal injury (Dart et al., 2012). In addition, there is a higher risk of psychosocial complications including decreased quality of life, decreased productivity (Sellers et al., 2009), and increased depression rates (CDA, 2014). Psychiatric illness encompassing suicidal ideation has been reported as the most common cause of hospitalization in youth with T2D in Manitoba (Coish & Dean, 2008). Depression and depressive moods are associated with decreased physical and mental functioning, therefore making it challenging to manage diabetes (CDA, 2014). These influence both the risk of complications, and the probability of adhering to effective disease management strategies (Sellers et al., 2009). In turn, this may lead to poor blood glucose management, diabetes-related health problems, increased family problems, and increased health-care costs (CDA, 2014). The cost of diabetes in Canada is projected to rise to \$16 billion by 2020 with complications of diabetes accounting for 80% of costs (CDA, 2014). Collectively, these complications will threaten life expectancy (Sellers et al., 2009). However, due to the nature of T2D treatment being more multifactorial relative to T1D treatment, this situation lends itself to more challenges as the attention for treatment is focused on lifestyle modification and behaviour change (Sellers et al., 2009). This is important to recognize as when T2D is managed effectively, patients with this

chronic illness can live long and healthy lives (CDA, 2014).

### **Purpose of the Study**

Previous studies have investigated the facilitators and barriers to self-management of T2D in youth (Protudjer, Dumontet, & McGavock, 2014; Mulvaney et al., 2008). These findings discussed social support as a key determinant in successful self-management. Researchers are uncertain as to how best support youth with diabetes in Manitoba. Due to the increase in the prevalence of youth living with T2D, and the consequences of the illness, knowledge of how youth would like to be supported socially may prove invaluable in the development of appropriate interventions aimed to reduce future complications. Given that social support increases health outcomes and reduces morbidity (Ozbay et al., 2007), interventions that increase social support among youth with T2D are important to develop in the future. However, before broader scale research initiatives can be developed to increase social support for these youth, it is critical to discover the form and function of this concept in their lives. Thus, by drawing attention to this gap in the literature, I conducted a qualitative investigation to explore what strategies, ideas, and methods are most sensitive to youths' social needs. This information provides the necessary foundational work needed to plan an effective behavioural intervention in the future. More specifically, the following research objectives and questions guided this Master's thesis:

- 1) What is the meaning of social support to youth living with T2D?
- 2) How do youth with T2D want to be supported socially?
- 3) What roles do friends, parents and clinicians play in the management of T2D and the provision of social support?

- 4) What is the perceived feasibility and acceptability of a behavioural intervention aimed to improve social support?

**Definition of Terms**

Particular terms were referenced commonly throughout this Master’s thesis. The following definitions were used:

*Social support:* In order to discuss the role of social support in the self-management of T2D, the term must be defined. Albrecht and Adelman (1987) defined social support as “verbal and nonverbal communication between recipients and providers that reduces uncertainty about the situation, the self, the other, the relationship, and functions to enhance a perception of personal control in one’s life experience” (p.19). Social support has been recognized as essential for maintaining physical and psychological health (Ozbay et al., 2007). However, the quality of social support is of equal importance as its presence. High quality social support that is perceived as positive can enhance one’s resilience to life stressors (Ozbay et al., 2007). Four common types of social support have been identified (Table 2).

**Table 2. Types of Social Support** (Wills, 1991).

<b>Construct</b>	<b>Definition</b>
Emotional Support	Expressions of empathy, love, trust and caring
Instrumental Support	Tangible aid and service
Informational Support	Advice, suggestions and information
Appraisal Support	Information that is useful for self-evaluation

*Quality of life (QOL):* Quality of life is the standard of health, comfort, and happiness experienced by an individual. Schalock (2010) has developed a quality of life framework that

includes eight domains that affect an individual's quality of life. The eight domains include:

1. Emotional well-being – contentment, self-concept, lack of stress
2. Interpersonal relations – interactions, relationships, supports
3. Material well-being – financial status, employment, housing
4. Personal development – education, personal competence, performance
5. Physical well-being – health and health care, activities of daily living, leisure
6. Self-determination – autonomy/personal control, personal goals, choices
7. Social inclusion – community integration and participation, roles, supports
8. Rights – legal, human (respect, dignity, equality)

These domains are interconnected and apply to all people, regardless of sex, age, race and ability.

*First Nations versus Indigenous:* The term First Nation was used in this thesis to describe Aboriginal people from Canada. People who are considered to be First Nations are those who identify with a recognized reserve community. On the other hand, the term Indigenous was used to describe Aboriginal people in an international context. The University of British Columbia, Department of Indigenous Foundations, has provided the definitions of these terms.

*Marginalization:* Marginalized individuals are those who exhibit social disadvantage. The term marginalization was defined as “the laws, policies, decisions, institutional behaviours and structures that serve to systemically exclude entire communities of people from rights, opportunities, and resources that are available to most other people in society,” (Adler University, 2015, para. 2).

*Physical activity:* Physical activity was defined in accordance to the World Health Organization's (WHO) definition. This definition identifies physical activity as “any bodily

movement produced by skeletal muscles that require energy expenditure,” (WHO, 2015, para. 1). Though terms such as sport and exercise are planned and structured, they fall under the physical activity umbrella. Additionally, this definition encompasses daily activities such as walking, running, dancing, swimming, yoga, and gardening.

### **Self-Reflexivity**

The reflexive process consists of examining both oneself as a researcher and his/her relationship to the research (Hsiung, 2010). When one is self-reflexive, he/she is better able to address values, assumptions, and experiences. Further, a self-reflexive stance facilitates awareness of how these value judgments may influence the research process (Probst & Berenson, 2013). Thus, my perspectives on the research topic influenced how I collected and interpreted the data. To remain reflexive, I acknowledged that I effect and was changed by the research. My own experiences influenced my desire to undertake this research.

As a child whose parents are refugees of the Vietnam War, I have always considered privilege as an earned concept. Growing up, my parents instilled the idea that you get what you work for in life. In this sense, they adopt an individualist, neoliberal approach toward life. Up until the last two years, I have thought this way. However, now I recognize that the idea of privilege as a socially constructed one, and that some groups of people are born with more privilege and societal advantages than others. Crotty (1998) defines social constructionism as “the view that all knowledge, and therefore all meaningful reality as such, is contingent upon human practices, being constructed in and out of interaction between human beings and their world, and developed and transmitted within an essentially social context” (p. 48). I witnessed firsthand the difficulty my parents faced trying to provide for my sister and I financially. There were often times where it felt as if it were “us against the world” – if there were problems

occurring with the family, such as loss of a job or repairing the car, those problems were to be solved solely by my parents. For myself, I have had the opportunity to develop a wide, meaningful social network, one that I cannot say my parents possess. But, I recognize that I only had this privilege because my parents made sacrifices in an attempt to give me the same opportunities as my peers. With the sacrifices made by my parents, I have had opportunities to engage in social events and to develop meaningful relationships. In turn, these experiences have supported my growth intellectually and emotionally. To think and acknowledge that I come from a family that I would considered marginalized is disheartening. However, this has coloured my passion to advocate for marginalized and oppressed populations.

My dedication to this population, youth with T2D, truly flourished when I completed a fieldwork placement in the Faculty of Kinesiology and Recreation Management with the Children's Hospital Research Institute of Manitoba. Here, I served as a student research assistant. My job was to co-coordinate a project called Beating Diabetes Together (BDT). This program was originally designed to reduce sugars and complications associated with T2D using physical activity. BDT sessions included education about physical activity, healthy snacks and diabetes awareness. When I started with BDT in January 2014, the youth had already attended the program for more than a year. The youth were quite aware of the importance of physical activity and nutrition relating to T2D. The diabetes educational piece developed into open discussions over time. Here, youth shared the hardships they faced with diabetes and life. The youth discussed the stigma and isolation they felt identifying as a youth with T2D. The aim of the program for me, then shifted to providing this population with a safe, inclusive environment for physical activity and more importantly, social support. It was evident that the youth formed new and lasting friendships as a result of BDT.

Concurrently, I was working with Dr. Moola as a physical activity counsellor for children with cystic fibrosis (CF) in the project “CF Chatters.” These counselling sessions were well received and I began to wonder how youth with T2D would respond to physical activity counselling. This came to mind during challenges faced with BDT. Youth would often not attend, and, if they did, were reluctant to participate—revealing the complexity of physical activity relevance. This originally prompted me to pursue a Masters of Arts in Kinesiology to explore if the findings from CF Chatters were transferable to the T2D population.

However, after surveying the literature, I began to notice that there was a vast amount of literature; quantitative and qualitative, suggesting that youth with T2D require social support to be successful in their self-management. There remained mixed findings on the best way in which to provide youth with support. My passion for working with this population remained strong – however, I started to wonder if youth really wanted or needed a behaviour change intervention. In my search of the evidence, it was very clear that current behavioural interventions are not guided by or based on youths’ perceived needs and recommendations. Thus, after reflecting on my research goals and the relationships I made with this population, I felt driven to conduct a qualitative investigation that is relevant and can have immediate impact. This research also provides foundational work for future interventions.

One particular concern during the reflexive process was how to manage the power relationships that are inherent in research. There was a power imbalance between myself and the participants. In an attempt to shift this power imbalance, I acknowledged that the participants are the experts of their diabetes and disease-management strategies and that as a researcher, one of my tasks was to develop research questions that were meaningful to youths’ social and psychological worlds.

## **Summary**

The progression of T2D in children remains alarming worldwide. Despite the recognition that youth with T2D require social support in the self-management of their illness (Protudjer, Dumontet & McGavock, 2014), the form and content of this support remains unclear. In this chapter, I introduced the research topic that I investigated, provided a brief history of T2D in children and youth, and defined the terms in which this thesis referenced. I also explained my self-reflexive stance in an effort to show how the self is always embedded in the work that we do. The following chapter reviews the qualitative literature relating to youth with T2D. Specifically, their experiences, facilitators and barriers to the self-management of their illness are studied.

## CHAPTER TWO – REVIEW OF LITERATURE

As the rates of T2D continue to increase among children and youth, a review of literature regarding the psychosocial aspects relating to this illness was warranted. Riediger, Lukianchuk, and Bruce (2015) reported a high burden of risk for young adults in Manitoba. This is of significance and relevance as increased risk of diabetes complications and mortality is often accompanied by younger age of onset (Riediger et al., 2015). Thus, strategies to reduce this burden in young adults are warranted. Social support has been documented as beneficial in enhancing resiliency (Ozbay et al., 2007) and is a critical resource for disease management (Protudjer et al., 2014). Therefore, the focus of this thesis was to understand the meaning of social support among youth living with T2D in Manitoba, Canada. In this chapter, I systemically reviewed the literature on psychosocial considerations concerning youth living with T2D. Following this, research limitations are identified and the rationale for this Masters thesis is provided. This review includes a board range of psychosocial outcomes involving this population, while recognizing and critiquing both the available quantitative and qualitative evidence. Thus, this review was essential to conduct, as it drew upon previous and current literature related to this topic, while acknowledging gaps in the literature. The term T2D and diabetes are used interchangeably from this point on.

### **Search Strategy**

A comprehensive review of literature was conducted using five databases accessed through the University of Manitoba library system. Since T2D in youth is a relatively novel condition, the literature pertaining to this population and their needs remains scant. Thus, no date limit was set and articles published up until September 2016 was examined. Databases that were utilized in this search included *PUBMED*, *PsychInfo*, *Psychiatry Online*, *Child Development and*

*Adolescent Studies, and Sociological Abstracts*. Keywords were divided into three groups (Group 1 AND Group 2 AND Group 3). Group 1: Youth OR Adolescents; Group 2: Type 2 diabetes; Group 3: Psychosocial OR Quality of Life. The inclusion criteria were: (1) participants under the age of 18, (2) diagnosis of T2D, (3) the presentation of original, rather than secondary data, and (4) written in English. Articles were excluded when: (1) participants were identified as adults, (2) a diagnosis of T1D or “at risk” of T2D was deemed, or (3) access was not available online. This initial search strategy resulted in 31 articles selected from 249 potentially relevant articles. Of these 31, eight articles were duplicates. The reference lists of articles were also reviewed to identify articles that may have been missed in the electronic search. After screening the selected articles against the inclusion/exclusion criteria, 16 studies were included in this systematic review.

Three longitudinal studies (Walders-Abramson et al., 2016; Hood et al., 2014; Richards et al., 2013), five cross-sectional studies (Yi-Frazier et al., 2016; Walders-Abramson et al., 2014; Rhodes et al., 2012; Wilfley et al., 2011; Allan, Flett & Dean, 2008), two pre-post studies (Chambers et al., 2015; Larkin et al., 2015), one randomized clinical trial (Sylvetsky et al., 2015), and five qualitative studies (Protudjer, et al., 2014; Salamon et al., 2012; Brouwer et al., 2012; Auslander et al., 2010; Mulvaney et al., 2008) were included (See Appendix One for a complete breakdown of these studies). The study date ranged between 2008 and 2016. All studies were conducted in the North American countries of Canada and the United States. This might reflect the greater attention that American and Canadian scholars have recently devoted toward the topic and/or a high prevalence of T2D. The participant sample included African American, Hispanic, White, American Indian, and First Nations people. The total sample size for the quantitative studies was 2682. The total sample size for qualitative studies was 58. The mean

range of the included studies was 13-18 years of age. However, it is noteworthy to mention that multiple studies (Walders-Abramson et al., 2014; Richards et al., 2013; Wilfley et al., 2011) included in this review drew upon data collected from the Treatment Options for Type 2 Diabetes in Adolescents and Youth (TODAY) study. Therefore, the number of participants who completed data in more than one study is unknown. As such, the reported total sample size for quantitative studies may be overestimated. The socioeconomic status of families with T2D in this review could not be determined. However, other demographics such as educational level and family dynamics were reported. Parental educational levels varied among each study. Reports ranged from 32-37% obtaining some college education (Hood et al. 2014; Rhodes et al., 2012; Mulvaney et al., 2008), to greater than half of participants' parents achieving a high school education or less (Wilfley et al., 2011). It has been reported that 50.7% of participants live in one-parent households (Hood et al., 2011). In the study conducted by Auslander et al. (2010), 70% of mothers reported not being married and 40% reported unemployment. Specific to Manitoba, the study conducted by Allan et al. (2008) reported that 56% of First Nation youth living with T2D reside in isolated/Northern reserves.

## **Findings from the Review**

### *Quantitative Findings*

The self-management of T2D has posed challenges for both adult and adolescent populations alike. There is a general consensus that there is a broad range of psychosocial issues associated with T2D. Previous quantitative inquiries have utilized questionnaires to evaluate psychosocial burden and functioning (Hood et al., 2014; Walders-Abramson et al., 2014), learning needs (Richards et al., 2013), binge eating and mood (Wilfley et al., 2011), and quality of life (Yi-Frazier et al., 2016; Larkin et al., 2015; Rhodes et al., 2012; Wilfley et al., 2011; Allan

et al., 2008) relating to type 2 diabetes in youth. The common psychometric instrument used to assess QOL in the quantitative literature is the well-validated PedsQL. The PedsQL is a multidimensional self-report questionnaire for children and parent proxy. There are four scales the PedsQL measures, including physical, emotional, social and school functioning (Varni, Seid & Kurtis, 2001).

*Stress:* Specifically, Walders-Abramson et al. (2014) investigated the relationships between stressful life events and physiological measures, such as glycemic control, depressive symptoms, and quality of life. Depressive symptoms were assessed using the Children's Depression Inventory for participants under the age of 16, and the Beck Depression Inventory II for participants over the age of 16. Youth reported – on average – five stressful events happening within the previous year, with more female reports than males. The primary association found within this study was that treatment adherence and psychosocial functioning declined with the accumulation of stressful life events. From this finding, health providers were encouraged to measure stressful events, in their frequency and severity, as it may help uncover barriers to diabetes management and factors impairing QOL. Similarly, Hood et al. (2014) examined psychosocial burden, and its trajectory and relationship with glycemic control. It was found that as diabetes-specific QOL declined, youth suffered from higher levels of A1c – the primary measure of plasma glucose concentration, at 60-month follow up. The authors suggest that the stress of stigma and discrimination might contribute toward glycemic outcomes. Though stigma and discrimination were not measured in this study, Hood et al. (2014) suggest future screening of QOL in this population, as it has an important influence on psychosocial burden. Larkin et al. (2015) as well emphasized the need to evaluate depressive symptoms in this population.

*Binge Eating:* As successful adoptions of a healthy lifestyle are crucial to optimal self-

management of T2D, such as achieving healthy eating habits, Wilfley et al. (2011) investigated the prevalence of binge eating and its association with psychosocial functioning. These authors found that 26% of youth living with T2D reported the act of binge eating. Unsurprisingly, youth who reported overeating also reported higher psychosocial distress and poorer QOL. This finding was troubling as binge eating not only accelerates weight gain, but also contributes to increased risk of cardiovascular complications. Additionally, binge eating has been identified as a predictor for failure in weight loss treatments (Hood et al., 2014). This poses further challenges for youth with T2D whose treatment prescription for disease management is to improve dietary habits and physical activity.

*Parent by Proxy:* Despite the belief that the management of diabetes is an individual act, studies have recognized parental proxy as a contributor to self-management. Such studies compared adolescents' self-reports of QOL to parental proxy (Yi-Frazier et al. 2016; Richards et al., 2013; Rhodes et al., 2012; Allan et al., 2008). As a result, studies found that parental perceptions of the impact of illness on their child were more negative than their child's perceptions. Specifically, Rhodes et al. (2012) found that parents' perception of physical functioning of their child was more impaired than the child themselves, again suggesting that parents' perception of the child's illness was more severe than the child's own judgement. Similarly, Yi-Frazier et al. (2016) found that youth reported higher QOL scores when compared to their parents. However, Allan et al. (2008) found this to be consistent among all domains of the PedsQL (generic and diabetes specific) – physical, emotional, social and school functioning. When compared to adolescents' reports, parents' reports overestimated the burden, discomfort and difficulties associated with diabetes management and treatment (Allan et al., 2008). The greater level of pessimism reported by parents may be explained by the added parental

responsibility to protect the child from future diabetes complications (Allan et al., 2008). Thus, it appears that parents overestimate the burden of illness and underestimate youth's reported QOL (Yi-Frazier et al., 2016). Additionally, both parents and children discussed feelings of difficulty when sharing emotions and questions relating to their illness with doctors and nurses (Allan et al., 2008). First Nation youth with diabetes residing in remote communities reported lower QOL scores on both scales. The assessment of health-related QOL using the Health Utilities Index, family conflict, and diabetes burden were also conducted. There has been a significant inverse correlation between youth reports of family conflict and health-related QOL and PedsQL (Rhodes et al., 2012).

*Learning Needs:* There has been little research available relating to the learning needs of youth and their families on diabetes education. Richards et al. (2013) investigated this need using the Participant Needs Assessment questionnaire. Participants with diabetes and their family support person completed this questionnaire every two months for one year. The intent was to determine behaviours that are associated with successful self-management. These included medication, nutrition, blood glucose monitoring, exercise, and self-esteem. There were no differences in learning needs between genders. Overall, youth reported greater needs in Focus and Teen Issues, with girls reporting higher needs on the latter. There were also no differences between youth and their family support person on the scales of Ordinary Day, Nutrition, and Living with Diabetes.

*Interventions:* There have been several studies conducted which have attempted to investigate the feasibility of interventions aimed at improving glycemic control (Walders-Abramson et al. 2016; Chambers et al., 2016; Sylvetsky et al., 2015). The evaluation of attitudes and beliefs about sustained participation was conducted in the TODAY study (Walders-

Abramson et al., 2016). It was found youth continued to participate in study for the following reasons: 1) strong relationships with medical staff, 2) receiving diabetes care, 3) access to free medicine and supplies for their diabetes, and 4) learning about better care practices. As well, the following challenges were reported: 1) scheduling conflicts, 2) disappointing the study team, family and/or friends, 3) transportation issues, and 4) occurrence of other medical issues (Walders-Abramson et al., 2016). Chambers et al. (2016) conducted an investigation on the feasibility of a family-based diabetes prevention and management intervention for American Indian youth with type 2 diabetes. The program consisted of four components: youth home-based lifestyle education, psychosocial support person home-based education, facilitated referrals to clinics, and community-based healthy-living activities. Lastly, Sylvetsky et al. (2015) conducted a randomized clinical trial to investigate whether pairing a “buddy” with youth with type 2 diabetes improves glycemic control. “Buddies” were volunteers that identified as young, healthy, and motivated. At 6 months, no change in A1C or QOL was found.

*Reduced Quality of Life:* Quantitative studies have indicated that youth and parents/family members dealing with T2D are likely to experience impaired psychosocial wellbeing and QOL. Though quantitative studies have provided very important objective measures of psychosocial function in this population, they do not provide an avenue to understand the lived experience of illness as qualitative approaches might facilitate. Studies utilizing qualitative inquiry provide a medium for the explanation of a phenomenon, and the lived experience of diabetes. In this regard, further review of literature pertaining to qualitative studies is warranted.

### *Qualitative Findings*

Qualitative literature illustrates the complexity of diabetes management through the

perceptions and lived experiences of youth with T2D. Feelings associated with the diagnosis of T2D were explained. Common to youth and caregivers, feelings of devastation, shock, and fear immersed (Protudjer et al., 2014; Auslander et al., 2010). Youth developed a *sense of acceptance* over time. However, despite achieving better self-management with time, the diagnosis still remained difficult for youth (Auslander et al., 2010). Youth's beliefs about the cause of diabetes included family history, a lack of physical activity, and poor eating habits (Salamon et al., 2012). *Adjustments* were discussed by youth as having to make a change in their life. This included having to monitor blood glucose, manage time and diet, taking injections and medication, and increasing physical activity levels (Auslander et al. 2010). However, the failure to manage diabetes due to noncompliance or forgetfulness conflicted with youth's perception of control over their illness (Protudjer et al., 2014). Indeed, youth recognized the *seriousness of diabetes*. Auslander et al. (2010) found that parents utilized family stories about diabetic relatives in attempts to motivate their children to improve their diabetes management. These mothers described wanting a complication-free future for their children. Youth interviewed by Salamon et al. (2012) described being motivated both by immediate consequences, as well as long-term consequences. Consequences such as hospitalization, extra needles and fainting were provided. While it carries gendered assumptions regarding caregiving, it was found that the *mother's role* of primary support was a psychosocial resource when managing this illness for youth (Auslander et al., 2010). Youth often found their mother's reminders helpful (Auslander et al., 2010) and encouragement to be positive (Mulvaney et al., 2008). However, these youth also described negative emotions such as annoyance when mothers "nag" or do not understand food cravings (Auslander et al., 2010; Mulvaney et al., 2008). Some youth disliked having parents impose diabetes goals on them. Despite these reservations, youth described home as the easiest place to

manage their illness (Mulvaney et al., 2008).

Several barriers have been specified relating to the self-management of youth living with T2D. Specific to the youth interviewed by Auslander et al. (2010), *comorbidities* were a common barrier. Youth discussed the difficulties comorbidities imposed on self-management. Such comorbidities included obesity, asthma and learning disabilities. These comorbidities posed challenges to participating in physical activities. Other barriers found in the qualitative literature included: dietary challenges (Auslander et al., 2010; Mulvaney et al., 2008), educational needs (Salamon et al., 2012), financial concerns (Protudjer et al., 2014; Auslander et al., 2010), and the concept of disclosure (Salamon et al., 2012; Brouwer et al., 2012; Auslander et al., 2010).

Youth discussed the *struggles of adopting healthy behaviours* such as avoiding high-sugar foods and fast foods (Auslander et al., 2010), and a lack of food choices available at their school (Mulvaney et al., 2008). Additionally, attempts to continue healthy behaviours at home presented challenges. This was discussed in the context of other family members who were reluctant to adopt new food choices (Auslander et al., 2012). In regards to *educational needs*, there were mixed feelings among youth on whether sessions aimed at diabetes and management education should be offered in one versus multiple sessions (Salamon et al., 2012). This suggests that diabetes educators should offer various types of educational sessions to accommodate the different needs of this population.

Families discussed *financial concerns* as a barrier to helping their child's diabetes management (Protudjer et al., 2014; Auslander et al., 2010). There was additional stress associated with disease management when financial resources were limited. The difficulty of making healthy food choices was discussed as a result of having minimal household incomes. Additionally, mothers expressed their concerns about health care coverage for their child's

medication (Auslander et al., 2010). This barrier may be specific to the United States and not observed to the same extent in Canada where there is universal health care.

Lastly, the *concept of disclosure* is an evident theme among multiple qualitative studies. Youth often expressed that they did not feel comfortable disclosing their illness to peers (Brouwer et al., 2012; Auslander et al., 2010), as they believed that peers are unlikely to understand what it means to live with T2D (Salamon et al., 2012). Alternatively, they did not want to concern their peers (Brouwer et al., 2012). Other youth feared the possibility of social exclusion after disclosure (Protudjer et al., 2014). Youth described disclosing their illness on a “need to know” basis, for example, to teachers (Brouwer et al., 2012). However, some youth preferred not to disclose this information to teachers as they felt a lack of understanding on the part of educators (Mulvaney et al., 2008). Specifically, these youth depicted teachers as often unknowledgeable of issues pertaining to diabetes.

To complicate disclosure dilemmas, youth commonly lacked a sense of *normalcy*. Youth often felt embarrassed to check their blood sugar levels at school, as there were very few others who needed to do so (Brouwer et al., 2012). As such, a sense of isolation was commonly noted (Mulvaney et al., 2008). Struggling to avoid embarrassment and feelings of difference from peers came forth (Salamon et al., 2012; Auslander et al., 2010; Mulvaney et al., 2008). The fear of questions, judgment, or false beliefs about diabetes – such that the false notion that the illness is contagious – furthered damaged a sense of normalcy (Mulvaney et al., 2008). Youth described feeling like an “outsider” due to their illness (Brouwer et al., 2012).

In spite of issues concerning disclosure and fear of appearing not “normal”, those who did disclose their illness to friends found it to be a positive experience. Youth discussed the complexity of the decision of diabetes disclosure. As the “need to know” basis idea was

previously presented, some youth felt that it was important to disclose their illness to those they considered close friends (Mulvaney et al., 2008). Youth explained that careful consideration occurred prior to disclosure (Protudjer et al., 2014). *Disclosure to peers* was a positive experience because it provided youth with a safe place to be themselves (Mulvaney et al., 2008). Further, youth felt that supportive peers facilitated exercise together, provided helpful reminders about treatment, and encouraged them to avoid eating certain foods (Auslander et al., 2010). Youth also discussed the support provided by peers for non-diabetes behaviours. They described the importance of simply spending time together and participating in non-diabetes related activities. Having friends available to engage in “normal” activities with was meaningful to youth (Brouwer et al., 2012).

Parallel to having supportive peer relationships, youth felt a *sense of belonging* and connectedness to others living with T2D, particularly family members (Brouwer et al., 2012; Mulvaney et al., 2008). It was evident that caregivers played an important role in providing guidance in the management of T2D for youth. To have support from a family member also living with diabetes provided youth with comfort to express diabetes-related concerns (Brouwer et al., 2012). Also, youth described a positive aspect to having a family member with the same illness. Indeed, family members with diabetes provided a forum for learning, and the feeling that one was not going through diabetes alone (Mulvaney et al., 2008). Overall, youth who shared their illness with others found it to be helpful to have family and friends in their self-management. Family and friends acted as supportive reminders for disease management, and provided assistance in educating others about diabetes (Brouwer et al., 2012). Protudjer et al. (2014) found that youth who were successful in achieving target glycemic control identified supportive relationships as a key determinant in their success. Youth, caregivers, and health care

professionals commonly suggested this as a main contributor for successful diabetes management. Youth who were unsuccessful in managing their blood glucose attributed the lack of familial and social support as the primary barrier. Thus, this reaffirms the importance of supportive relationships for this population.

As diabetes management is often regarded as an individual effort, youth presented *strategies for coping* with and navigating the illness. As previously discussed, youth often felt a lack of normalcy when managing their illness. Some youth described handling this difficulty by pouring water into a regular soda. This allowed them to deceive peers by leading them to think that they were drinking regular soda while at the same time, avoiding excess sugars (Mulvaney et al., 2008). Other strategies youth adopted for coping included: finding distractions to avoid thinking about diabetes, remaining optimistic about a cure, praying, and realizing that their illness does not change their identities (Mulvaney et al., 2008). Additionally, some youth developed psychological and behavioural techniques for coping and adjustment (eg. “When I get mad, I try and calm myself down ‘cause I don’t want my blood sugar going way up”) (Salamon et al., 2012, p. 550).

Based on the systematic review of available literature, then, there is consensus in both quantitative and qualitative inquires that youth with T2D live with impaired quality of life and poor psychosocial health. Quantitative literatures provide insight for various psychosocial measures to be considered. Specifically, it was reported that youth with T2D who suffered from stressful life events have poor treatment adherence (Walders-Abramson et al., 2014; Hood et al., 2014), are at an increased risk for binge eating (Wilfley et al., 2011), and require attention to particular learning needs (Richards et al., 2013). However, youth’s perception of their illness was less severe than their caregivers, suggesting a degree of optimism and resiliency (Richards et al.,

2013; Rhodes et al., 2012; Allan et al., 2008). Qualitative inquiries capture the complexity and struggles youth face in their pursuit to diabetes management. Such concepts as normalcy, disclosure, acceptance, and belonging were illustrated. Particularly, youth have shared their experience both with and without social support. These findings continue to provide evidence for the invaluable role social support has for youth with chronic illnesses. It is well accepted that social support is essential for establishing and maintaining physical and psychosocial health. It has been suggested that high-quality social support can enhance resilience to stress (Ozbay et al., 2007).

## **Discussion**

There has often been a focus on the treatment of physiological factors affecting youth with T2D. However, it has been argued that psychosocial factors may be more important to successful disease management for individuals living with chronic illnesses (Bernstein et al., 2013). It has been reported that youth living with T2D are at an increased risk of depression compared to the general population (Hood et al., 2012). The lack of success for diabetes management may be explained by the reported poor mental health and low quality of life. People living with T2D are perceived to have the sole responsibility to manage their illness. Specifically, they are responsible for managing their diet, physical activity, and blood glucose regularly (Heinrich, Schaper & de Vries, 2010). It remains evident that there are difficulties and challenges to maintaining sufficient self-management. The positive news is that with proper management of T2D, people suffering from this illness can live long and healthy lives (CDA, 2014). Due to these considerations, future research relating to strategies for successful self-management was imperative.

## **Gaps in Literature**

This review gathered critical insights to consider when exploring the meaning of social support and strategies to increase this key determinant for successful diabetes management. Despite the hardships and barriers previously discussed, qualitative literatures have brought forth positive aspects of the illness, such as a sense of connectedness. While poor quality of life has been reported (Allan et al., 2008), youth have remained more optimistic about their health compared to their parents. Although there is an agreement on the importance of social support for youth with T2D, high-quality supports remain difficult to achieve. This review illustrated the complexity of social support ranging from reasons for non-disclosure to the benefits of doing so. This review also illustrated the need for further studies on the meaning of social support for youth.

Conversely, this review also shed light on the significant knowledge gaps in relation to how we understand social support for youth with T2D. Although there is unity on the importance of social support in this context, youth remain reluctant to pursue social support as an aid to self-management. Quantitative inquiries have recommended screening for predictors of poor psychosocial health, and have suggested the exploration of the benefits of social support. However, there remains a lack of quantitative literature that strongly supports successful strategies for self-management. This limitation warranted qualitative investigations to explore the strategies appropriate for youth, from youth's own perceptions. Despite the potential qualitative research has in filling this gap, the qualitative literature on suitable ways to achieve high-quality social support is lacking, particularly in the context of Manitoba where there are harsh weather conditions and greater socioeconomic disparities. When considering the abnormally high rates of diabetes in Manitoba, it warrants a specific investigation on how youth

perceive social support and what strategies are necessary for youth to acquire and maintain meaningful social support that will better aid in disease management.

It is evident that there are significant knowledge gaps in the existing literature on the meaning of social support in youth with T2D. As such, this provided the foundation to employ further qualitative investigations to address this gap. In this Masters thesis, I addressed this gap within the literature by using the richness that qualitative inquiry has to offer. Further, in this thesis, I developed a grounded theory of social support in youth with T2D to guide this population and future research on strategies to achieve meaningful social support in the management of T2D. Further, this thesis aligns with the Government of Manitoba's (2009) guiding principles to address diabetes – specifically, the principle of promotion of mental health and wellbeing. This principle called for “initiatives to be designed to help individuals achieve a sense of control over their lives, feel capable of making decisions, cope with life’s challenges and participate in meaningful ways” (p. 3).

### **Summary**

By evaluating the existing literature, this systematic review documented the psychosocial considerations for youth living with T2D. Moreover, it illustrated the complexity to achieving optimal psychosocial health in this population. This review assessed quantitative and qualitative literature that has documented the significance of social support in facilitating successful disease management and improving quality of life. By including both quantitative and qualitative inquiries, I have managed to identify a range of factors that health care professionals and caregivers should consider when dealing with people with T2D under the age of 21. Lastly, the knowledge gaps in the literature have been acknowledged. Thus, this allowed me to contextualize my thesis within the existing literature. It is evident that social support has great

potential in its effectiveness for diabetes management, both for physical and psychosocial health. This review has appraised the multifaceted psychosocial considerations for this population, described the influence it may have in their lives, recognized knowledge gaps in the literature, and provided the rationale for exploring the meaning of social support to this population.

## CHAPTER THREE – METHODOLOGY AND METHODS

Based on the systematic review of the literature, there remained limited research that examined the meaning of social support for youth living with type 2 diabetes. Examining the meaning of social support in this population was essential, as positive social support of high quality may enhance resilience against stress (Ozbay et al., 2007). In this chapter, I describe the research design and participant characteristics. I also outline the methodological considerations that influenced my rationale for particular methods. I then outline specific qualitative methods that have been conducted to collect and analyze data in order to explore this research question. Lastly, I discuss the underpinnings of trustworthiness within the grounded theory methodology.

### **Research Design**

To reiterate, this Masters thesis explored the meaning of social support for youth with T2D and strategies to achieve meaningful social engagement for the self-management of T2D. The following research objectives and questions guided this Master's thesis:

- 1) What is the meaning of social support to youth living with T2D?
- 2) How do youth with T2D want to be supported socially?
- 3) What roles do friends, parents, and clinicians play in the management of T2D and the provision of social support?
- 4) What is the perceived feasibility and acceptability of a behavioural intervention aimed to improve social support?

*Setting, Recruitment and Participants:* This study occurred at the Children's Hospital Research Institute of Manitoba. Participants were recruited from existing studies within the Children's Hospital Research Institute of Manitoba. Youth with T2D who were between the ages of 12-17 were recruited to participate over the phone. Eight participants were recruited from existing

studies at the Children’s Hospital Research Institute of Manitoba with the assistance of Dr. Brandy Wicklow. With her assistance, potential participants were identified that met the inclusion criteria. Only parents who agreed to be contacted for future studies were contacted. Interested parents/guardians were sent consent forms outlining the study and were encouraged to ask questions. All youth resided in Winnipeg to minimize inconvenience with travel to the hospital. No exclusion was made on the basis of gender, socio-economic status, race or ethnicity. Approval from the University of Manitoba Research Ethics Board was obtained prior to recruitment, as well as informed consent from participants.

## **Methodology**

This thesis was guided by the grounded theory qualitative research tradition. Grounded theory is an approach from which theories are created from collected data (Glaser & Strauss, 1967). This is opposed to other approaches, where theories are outlined prior to data collection, and influence the methodology and methods that are selected for the study. At its core, grounded theory is a systematic methodology that discovers theory using the data collected (Martin & Turner, 1986). The purpose of grounded theory is to generate “concepts and their relationships that explain, account for and interpret the variation in behaviour in the substantive area under study” (Glaser, 1992, p. 19). Grounded theory was useful in this research as it “aims to understand what is going on in a given instance, particularly in common social settings that are not well understood and have not been exhaustively researched” (Hunter et al., 2011, p.4).

### *History of Grounded Theory*

In the 1960s, sociologists Barney Glaser and Anselm Strauss developed the methodology of grounded theory. The basic position of grounded theory proposed by Glaser and Strauss (1967) was that it “was a way of arriving at theory suited to its supposed uses” (p. 3).

Additionally, grounded theory was thought to provide a systematic analysis of qualitative inquiry, with the “intent to construct abstract theoretical explanations of social processes” (Charmaz, 2006, p. 5). Charmaz (2006) summarizes the defining components of grounded theory to include:

- (1) Simultaneous involvement in data collection and analysis, (2) Constructing analytic codes and categories from data and not from preconceived logically deduced hypotheses, (3) Using the constant comparative method, which involves making comparisons between interviews during each stage of analysis, (4) Advancing theory development during each step of data collection and analysis, (5) Memo-writing to elaborate categories, specify their properties, define relationships between categories, and identify gaps, (6) Sampling aimed toward theory construction, and not for population representativeness, and (7) Conducting the literature review after developing an independent analysis (p. 5).

The 7<sup>th</sup> criterion is greatly debated in the literature. Although my review was conducted prior to data collection, I was prepared to theorize novel and unexpected findings that resulted from the study.

Glaser and Strauss (1967) provided foundational work that legitimized qualitative research as trustworthy by challenging the view that qualitative research is impressionistic and unsystematic. Other ideas that were challenged include: “(1) the separation of data collection and analysis phases of research, (2) prevailing views of qualitative research as a precursors to more ‘rigorous’ quantitative methods, (3) the arbitrary division between theory and research, and (4) the assumption that qualitative research could not generate theory” (Charmaz, 2006, p. 6). The discovery of grounded theory made analytic guidelines for verbal data accessible. Since Glaser

and Strauss's discovery, there have been three adaptations of Grounded theory – Glaser's and Strauss's original version (Classic Grounded Theory), Strauss and Corbin's version (Straussian Grounded Theory) and Charmaz's version (Constructivist Grounded Theory).

### *Types of Grounded Theory*

Epistemological differences exist within the three versions of grounded theory mentioned above. Crotty (1998) defines epistemology as “a way of understanding and explaining how I know what I know” (p. 3). According to Denzin and Lincoln (2005), epistemological inquires examine the relationship between the knower and knowledge. For the purposes of this thesis, three epistemological stances are discussed – objectivism, subjectivism and constructionism. Further, I discuss the version of grounded theory that aligns within each stance and paradigm. Before I outline the constructivist version of grounded theory that I used in this thesis, it is necessary for the reader to understand the different epistemological visions of grounded theory.

Crotty (1998) defined *objectivism* as “the epistemological view that things exist as meaningful entities independently of consciousness and experience, that they have truth and meaning residing in them as objects (‘objective’ truth and meaning, therefore), and that careful scientific research can attain that objective truth and meaning” (p. 5). Post-positivism has emerged under the objectivist epistemology. This research paradigm challenges the notion of complete objectivity and has been suggested as the “less arrogant form of positivism” (Crotty, 1998, p. 29). Post-positivism suggests probability rather than certainty and attempts to estimate the truth rather than aspiring to grasp it whole (Crotty, 1998). Specifically, post positivism proposes that the nature of reality is knowable and predictable. Further, according to post positivism, human beings are thought to respond rationally to external forces. The goal of research under a post-positivist perspective is to understand and predict human behaviour by

developing general theories (Crotty, 1998). Following this thought, the *Classic Grounded Theory* fits within the post-positivist perspective. Within this perspective, Levers (2013) explains that “the researcher approaches grounded theory with the understanding that reality exists external to oneself and the research participants” (p. 4). Evans (2013) states that in order “to be true to theory development, an effective use of literature it should not occur at the beginning of the study” (p. 41).

The interpretivist perspective is in opposition to the post-positivist stance. This research paradigm is conceptualized as having a subjectivist epistemology. Crotty (1998) describes how “in subjectivism, meaning does not come out of an interplay between subject and object but is imposed on the object by the subject” (p. 9). Interpretivist research accepts multiple meanings and realities by acknowledging that “objective reality can never been captured,” (Denzin & Lincoln, 2005, p.5). Epistemological assumptions made by the *Straussian Grounded Theory* fall within the interpretivist perspective. This version of grounded theory claims that “is it not possible to separate who I am as a person from the research and the analysis that I do” (Corbin & Strauss, 2008, p. 11). As such, meaning is suggested to come entirely from the subject/participant.

Lastly, the epistemological roots of constructivism conceptualize the third version of grounded theory, known as *Constructivist Grounded Theory*. Crotty (1998) explains that in this epistemology,

Truth, or meaning, comes into existence in and out of our engagement with the realities in our world. There is no meaning without a mind. Meaning is not discovered, but constructed. In this understanding of knowledge, it is clear that different people may construct meaning in different ways, even in relation to the same phenomenon (p. 8).

According to Charmaz (2006), this approach to grounded theory acknowledges mutual creation of knowledge, both by the viewed and the viewer. She further explains “the form of constructionism I advocate includes examining (1) the relativity of the researcher’s perspectives, positions, practices, and research situation, (2) the researcher’s reflexivity; and (3) depictions of social constructions in the studied world” (p. 398). Levers (2013) elaborates that the researcher is “external to the data yet internal to the emergence because there is a relationship between the data and the emergence through the researcher” (p. 5). The constructionist epistemology is conceptualized as having aspects of both post-positivism and interpretivism (Levers, 2013). This approach prioritizes the phenomena of the study and recognizes that data and analysis creation is a shared experience between the researcher and participant (Charmaz, 2006).

The constructivist grounded theory proposed by Chamaz (2006) and its philosophical underpinnings guided this Masters thesis to generate a theory about the meaning of social support for youth with T2D in Winnipeg. I selected constructivist grounded theory in particular because it represents my own epistemological values and beliefs. Further, since I acknowledge that “truth” is always subject to context and its historical influences, the theory that I generated will only ever be socially situated, historically specific and subjected to change with time.

## **Methods**

Guided by the constructivist grounded theory methodology described above, in this thesis, I conducted qualitative semi-structured interviews with open-ended questions. Qualitative methods are beneficial in this research question as it is designed to study a small number of cases in detail, explain complex phenomena, and determine how participants understand constructs such as social support (Johnson & Christensen, 2007). According to Bernard (1988), semi-structured interviews are most advantageous in instances where participant-researcher interaction

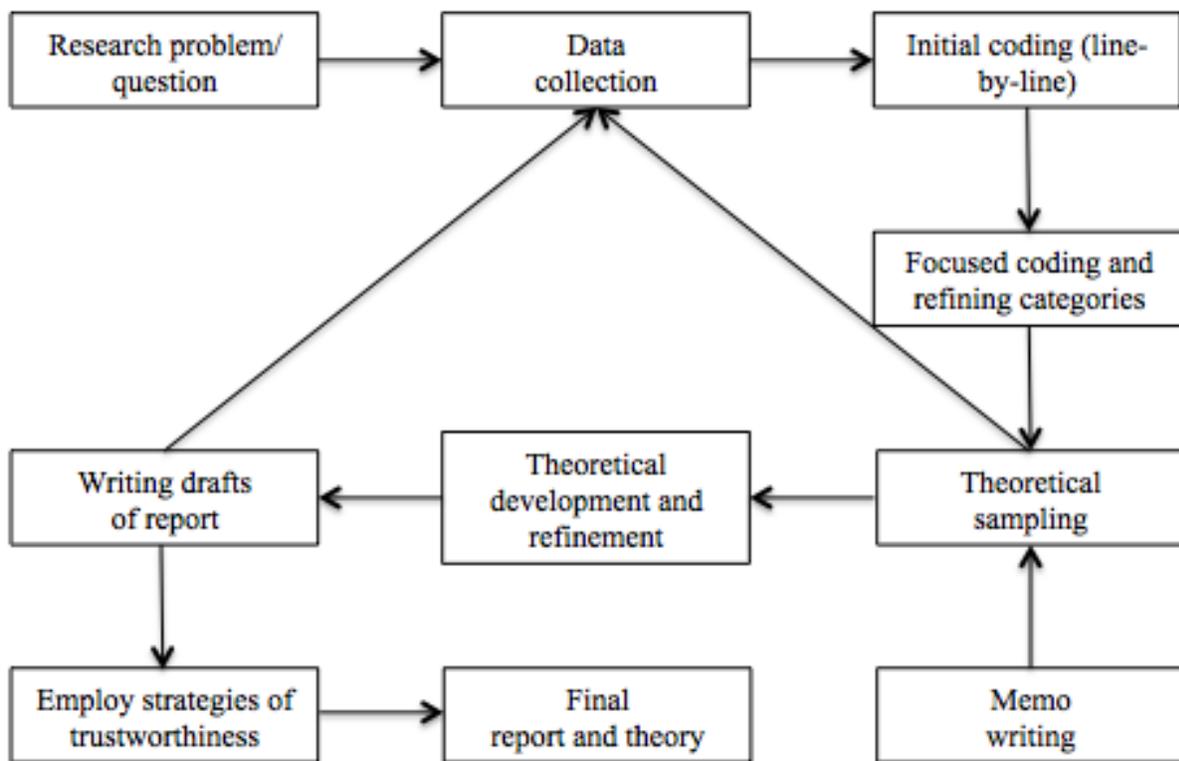
is limited to one. Another advantage to semi-structured interviews is that it allows the researcher to have prepared questions, while allowing flexibility for the participant. Participants engaged in 30-60 minute interviews to discuss the research objectives previously described. The interview questions were flexible in nature and unobtrusive, and were guided by participants' responses. To facilitate discussion and to promote child and youth friendliness, participants were provided a piece of paper (Appendix Two) with the words 'diabetes' and 'support' labelled. Participants were allowed to draw or write any thoughts relating to those topics. The purpose of this activity was solely to facilitate discussion. The drawings were not used as data. Additionally, to increase the likelihood of participation and to accommodate the needs and comforts of participants, youth were given the option to participate in interviews via face-to-face (in person or Skype) or phone. In person interviews were conducted in a private room within the Neil John Maclean Health Sciences Library. Interviews were audiotaped and transcribed verbatim. See Appendix Three for the interview guide that was used during the collection of data.

### **Data Analysis**

The nature of grounded theory proposes a cyclical process of data collection, coding, analysis, writing, design and theoretical categorization. Thus, a constant comparative analysis of cases with each other occurred and data analysis commenced immediately following the first interview of data collection. The process of grounded theory followed the cycle illustrated in Figure 1. Firstly, *initial coding* took place. Charmaz (2006) explains "coding means categorizing segments of data with a short name that simultaneously summarizes and accounts for each piece of data. Your codes show how you select, separate, and sort data to begin an analytic accounting of them" (p. 43). Specifically, initial coding consisted of line-by-line coding, where naming of each line of the written data took place. Coding the data early allowed me to gain perspective on

what participants have shared, as well as what they struggle with (Charmaz, 2006). The second phase of coding includes *focused coding*. Focused coding is defined as “using the most significant and/or frequent earlier codes to sift through large amounts of data. Focused coding requires decisions about which initial codes make the most analytic sense to categorize your data incisively and completely” (Charmaz, 2006, p. 57). During this phase of coding, I cross-examined multiple interviews and observations to compare participants’ actions, interpretations and experiences. Codes were compared back to the data, to refine each code and to develop categories.

**Figure 2. Constructivist Grounded Theory** (modified from Charmaz, 2006).



Memo-writing occurred following the coding phases. Memo-writing allowed me to remain involved in the analysis and to “construct analytic notes to explicate and fill out categories” (Charmaz, 2006, p. 72). Theoretical sampling was then implemented to saturate

categories. The foundation of theoretical sampling was to elaborate and refine categories comprising the theory. Once theoretical sampling was achieved in all interviews, a theory was constructed and refined through the process of peer debriefing. Thus, through this analytical approach, I generated a theory of social support among youth living with T2D.

### **Trustworthiness**

Lincoln and Guba (1985) used the term trustworthiness to describe the overall quality of the results from a qualitative study. Lincoln and Guba (1985) described four concepts for establishing quality in qualitative research: credibility, transferability, dependability and confirmability. Glaser and Strauss (1967) have proposed techniques to ensure credibility and trustworthiness in grounded theory research. *Credibility*, defined as the confidence in the ‘truth’ of the findings, was conveyed through the presentation of direct quotes from the interviews with participants. Each theme presented was supported through the use of these quotes. Also, credibility was upheld by following the detailed analysis described previously. This ensured credibility by demonstrating in depth how the rigorous standard required for proper grounded theory analysis was followed. *Transferability*, defined as the ability to show that the findings have applicability in other contexts, was conveyed through an audit trail of the research process to provide clarity in the research, methodology, and interpretations of results. To increase transferability, I will also try to establish contact with another pediatric diabetes group to ask about the relevance of my findings to their clinical practice at a later date. Thus, this process potentially provides the opportunity for future researchers to transfer these processes to another context. *Dependability* and *confirmability*, defined as the ability to show that the findings are consistent and could be repeated — and as the ability to address whether another can place ‘faith’ in the results — respectively, was established through peer debriefing and reflexivity. As

provided in Chapter 1, I stated how my experiences shaped the research question at hand. I continued to remain reflexive throughout this thesis through a reflexive journal.

### **Summary**

Informed by the previous systematic review of literature, I formulated a research design equipped to undertake research on the meaning of social support for youth living with type 2 diabetes. This chapter provided the various versions of grounded theory, and philosophical underpinnings associated with each. Thus, through a reflexive process of my personal beliefs and worldviews, I provided the rationale for the chosen constructivist grounded theory methodology. As well, the justification for particular qualitative methods was illustrated. Lastly, this chapter elucidated the process of data analysis and strategies to establish trustworthiness for the research and resulting theory.

## CHAPTER FOUR – FINDINGS

Youth discussed various life and health experiences that resulted from a type 2 diabetes diagnosis. For the purposes of this chapter, the term ‘type 2 diabetes’ and ‘diabetes’ are used interchangeably to provide cohesion in the terminology used by youth. Eight participants between the ages of 16 and 17 shared their experiences and thoughts for this study. The average age of participants was 16.38. Table one provides a description of each participant. Each participant was assigned an alias for the purposes of confidentiality and presenting the findings. One participant, due to special needs, participated in an interview with the company of her mother.

**Table 3. Participant Description**

<b>Alias</b>	<b>Age</b>	<b>Sex</b>	<b>Ethnicity</b>
Karen	16	Female	First Nation
Elaine	17	Female	First Nation
Joyce	17	Female	First Nation
Michael	16	Male	Filipino
Mary	16	Female	Caucasian
Avery	16	Female	First Nation
Stacy	17	Female	Filipino
Rebecca	16	Female	First Nations

Based on the experiences shared — and the grounded theory which I created through my coding process — I created a diabetes management paradox to conceptualize the experiences of youth with type 2 diabetes. In this chapter, I discuss this concept in the form of a *mountain metaphor* (Figure 2). As well, the complexities of social support are illustrated in Figures 4-4.5 in this chapter. Youth explained the social support they currently possess, as well as avenues for improving support. All youth explained that they had access to at least one source of social

support who supported their diabetes management endeavours. Additionally, interviews with youth provided a forum for them to discuss other concepts such as what living with diabetes is like, feelings associated with diabetes, and things youth wanted others to know about diabetes.

Table 2 has been created to outline themes and subthemes that I discuss in this chapter.

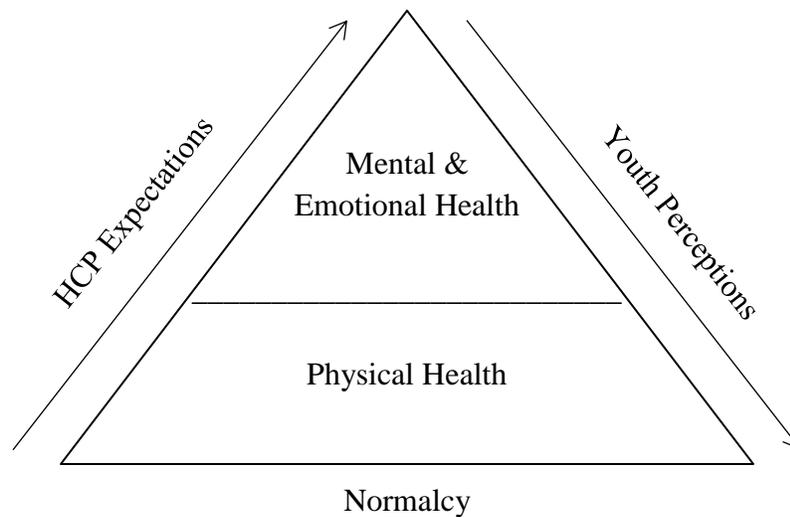
**Table 4. Themes and Subthemes**

<b>Themes</b>	<b>Subthemes</b>
Diabetes Management Paradox	
The Complexities of Social Support	Family Friends Health Care Professionals (HCP) School Programming
Living with Type 2 Diabetes	Identity Barriers Burden of Care
Negative Emotions	
Things We Want You to Know	

### **Diabetes Management Paradox**

The discussion of the complex nature of diabetes management revealed a paradox between the perceptions of youth and youth’s perception of health care professionals’ (HCP) expectations. This “mountain metaphor” has been derived from my grounded theory of the data and forms the overall conceptual framework used to discuss the findings.

**Figure 3. Mountain of Health**



### *HCP Expectations*

In regards to diabetes management, youth described the expectations that they feel from health care professionals. In this situation, the expectation for successful diabetes management was that behaviours that improve physical health must take priority over mental and emotional health. Youth explained physical health and its behaviours included participating in exercise, maintaining a healthy diet, and regularly taking their medication – all in efforts to improve A1C levels. Here, youth are expected to conquer this “mountain of health”, first by attaining optimal physical health, followed by establishing mental and emotional wellbeing. In this regard, youth perceived their health providers as wanting them to conquer their physical health, while emotional and psychological health was often overlooked. Karen described how the type of support she receives from HCPs solely encompasses information about her physical health. Specifically, Karen states that physicians focus heavily on giving her information about her A1C levels during clinic and ensuring that she has no physical or functional problems:

*They tell me what my average, average blood sugar is. And they check everything – make sure I'm ok. And ask me questions about if I'm having any pain and/or problems*

*recently or something like that. That helps when like, cause I can't tell by myself sometimes like if I lost feeling in foot or whatever. And they would know and tell me and I would be like "oh I didn't know".*

Youth discussed receiving disproportionately higher amounts of advice and support for their physical health. As such, youth explained that they receive less support for their mental and emotional health. This is demonstrated in Avery's explanation:

*I think for me, I really need a doctor that will talk to me on a more personal level because living with type 2 diabetes isn't really all that great for emotional state too. So I would like to see more help with my emotions, not just like my physical, my physical health. Because like that they have it covered.*

Thus, in this paradigm, youth are perceived to begin their journey at the bottom of the mountain, where 'normalcy' exists. As youth are diagnosed with diabetes, they are expected to participate in healthful activities above and beyond the 'normal' expectation of youth without diabetes – to ultimately conquer the mountain of health.

### *Youth Perceptions*

In contrast to the previous paradigm, in this scenario, youth perceive themselves first at the top of the mountain. Many youth described their mental and emotional health to take precedent over their physical health. Michael explained:

*Well I think like mental health to me is more important because if you're mentally healthy then you're more happy with yourself. It can like help you to motivate you to be physically healthy too, to balance it out.*

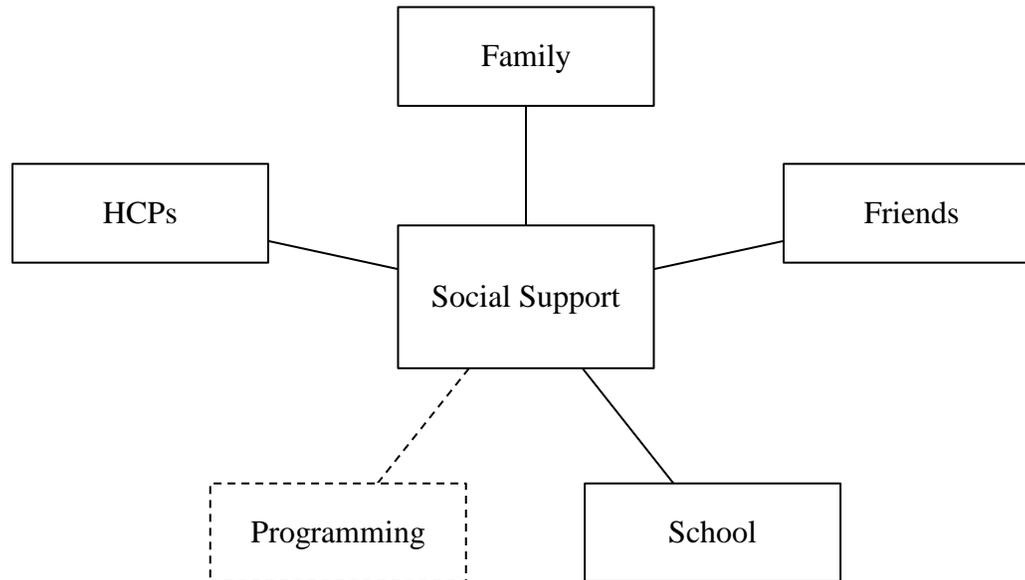
As such, in this paradigm – where youth begin at the top of the mountain - they feel that they must first establish mental and emotional wellbeing, which in turn facilitate opportunities to

attain physical health and wellbeing. Once youth are able to achieve wellness in both domains, then are they able to partake in ‘normal’ activities such as travelling. In this scenario, youth felt that managing diabetes hinders the participation of activities deemed normal. Difficulties in diabetes management emerge when youth attempt to exist in both paradigms. Youth are tasked with the decision on whether they should follow expectations or whether they should participate in resources they consider more important. Thus, youth and health providers perceive diabetes in very different ways with each group placing a different degree of emphasis on physical versus mental health. Next, I explore the complexities of social support through the lens of participating youth and illustrate avenues and connections of social support for both physical and mental/emotional wellbeing in relation to diabetes and overall health.

### **The Complexities of Social Support**

Youth discussed five potential sources of social support: family, friends, health care professionals, school and programming. To discuss the complexities of social support, each of the identified five sources are examined (Figure 4).

**Figure 4. Network of Social Support**



In this figure, and subsequent figures, ***solid line connections*** (eg. Social support – school) represent ***established*** sources of support, whereas ***broken line connections*** (eg. Social support -- programming) represent ***desired*** sources of support.

#### *Family*

Youth described the various supports they receive from their families (Figure 4.1). Family members included mothers, fathers, grandparents, siblings, aunts, and daughters. All youth possessed at least one family member also living with type 2 diabetes. Avery described this *history of diabetes* with a sense of optimism and belonging, where type 2 diabetes is a commonality between generations. Thus, her family's strength to handle this illness is comforting.

*Well it makes me feel like I'm not alone like my family has been through this before because hmm ... It's run down my family since, from my dad's side too. I guess generation over generation, I'm here and unfortunately have type 2 diabetes but just*

*knowing that if my family could go through that too, I can get through it.*

As a result of having family members with diabetes, Rebecca similarly does not feel alone. As well, Stacy further discussed:

*It helps knowing that there's people in my life that know how it's like so I don't feel alone and I can ask for help from those who have had it for quite a while longer than me.*

Family members with diabetes were not only a source of advice. Further, they provided a source of motivation during youths' pursuits in diabetes management.

Many youth discussed receiving *motivation* from family members such as their daughters, as well as deceased fathers and grandmothers. Such family members provided youth with reasons to continue to maintain and improve on their diabetes management behaviours. For example, Joyce described how her life has changed since becoming a new parent:

*It would be a lot different. With my daughter, is she like a support? Like I always think about her ... Yeah, because like my diabetes ... She's motivative ... I want to be healthy for her too. I don't want to be lazy when my sugars high.*

Despite the lack of physical presence in youths' lives, deceased family members continued to provide a source of motivation to manage diabetes. Two youth explained this experience; Mary stated *you try to deal with it for granny*, whereas Karen's father continues to provide motivation for acceptance with living with an illness:

*Cause ... I forgot what my dad always said. Like you shouldn't wish something like that, like you don't have it [diabetes] cause I guess it wouldn't have shaped into the person I am I guess. I don't know. I'll be someone different.*

Family members continued to provide support through *relieving feelings of loneliness*, providing the *ability to survive*, and instilling a sense of *motivation*. In this way, family members improved

what youth identify as mental and emotional support. Family members also provided other avenues of support for youths' physical health.

All youth discussed relying heavily on family supports to *administer insulin injections*, provide *reminders for medication/appointments*, *not purchase "junk foods"*, and *brainstorm ideas for activities*. Avery explained:

*Well it was a pretty hard change but I realized like, I had a realization that this [McDonald's and Burger King] is not healthy and I just, I made that change by just asking my grandparents not to get it for me and they seem to, they've done a really good job.*

Whereas Elaine received support in the following way:

*They encourage me to exercise and my mom tells me take my insulin.*

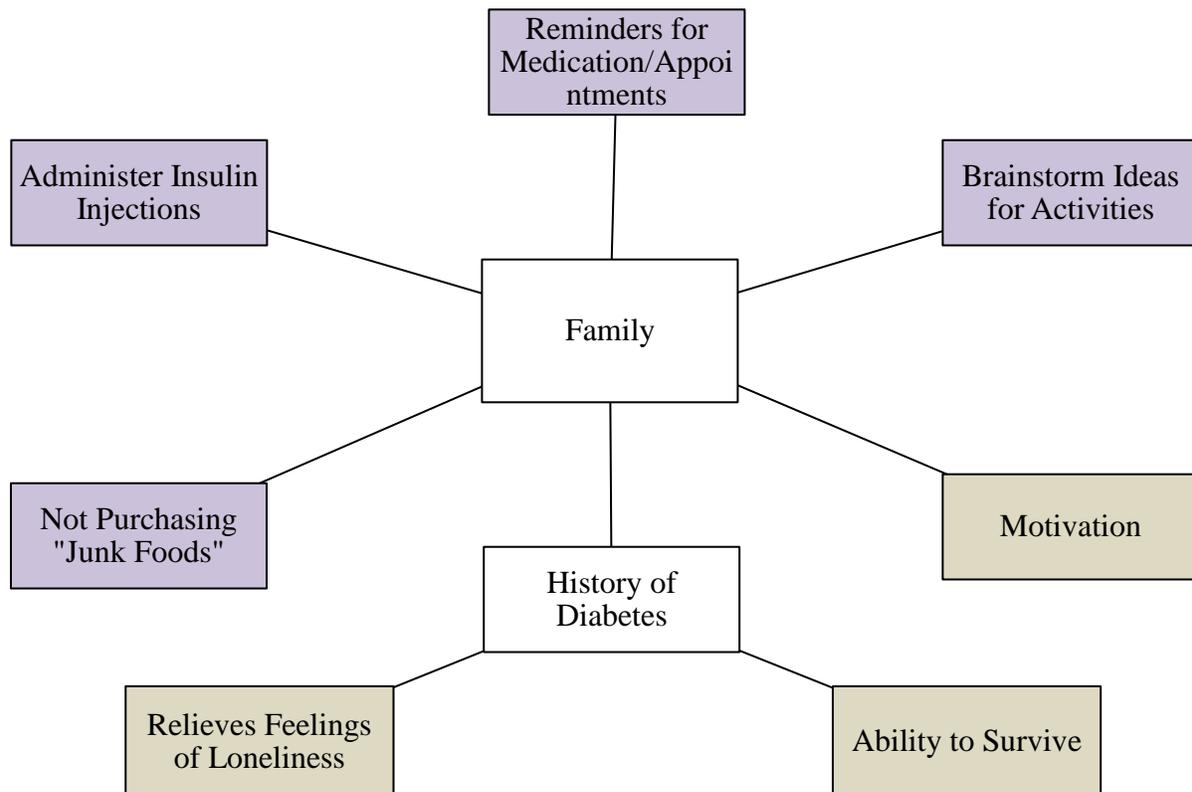
Although youth currently receive supports in these avenues, youth also discussed desiring more support for such avenues, as well as ongoing support. Karen explained:

*Yeah reminders are a big thing that I wanted. But ... Mostly with my mom, I want her to remind me every time but she hasn't been doing that since I've gotten older cause she thinks that I'm old enough to remind myself. But there's also things in my life that I kind of forget like check my blood sugar or take insulin and all that stuff.*

Similarly, Avery discussed the increase in responsibility to schedule doctor appointments with age, as well as having grandparents to support this transition. She explained:

*I guess as you grow older, you have to be more responsible for yourself because as a teen I get these appointments arranged for me. So when I'm older, I would have to do that for myself, which really isn't all that hard, I just think it's easier for me because I can get, I get my grandparents to make my appointments and all.*

**Figure 4.1 Family Supports** (■ Physical Health; ■ Mental/Emotional Health)



Thus, despite possessing various family supports, youth desired such supports on a continual basis and illustrated how critical these were to the attainment of successful diabetes management.

#### *Friends*

Five of the eight participants discussed requiring support from friends. They also illustrated where they would like to be better supported (Figure 4.2). As *adopting healthy food choices* alone is often difficult for youth, this endeavour was made easier with the support of friends. Avery illustrated this well:

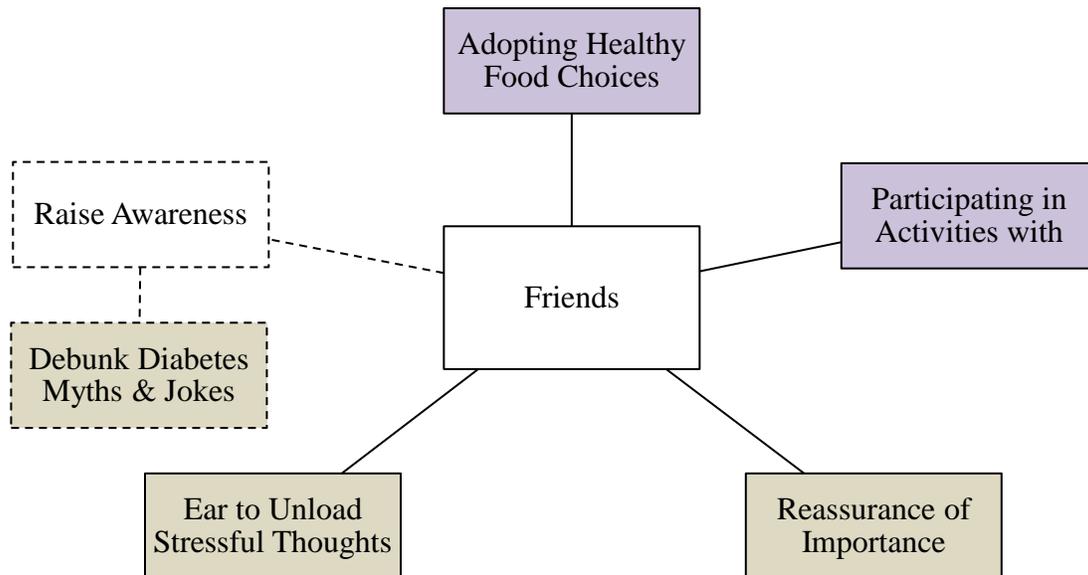
*Well they know I can't really have like very high sugar foods and all, and they know that, it can be hard for me sometimes not to have that sugar in me. But one of my friends, they're being really really supportive with me right now, she's trying to get me to the*

*gym and trying to get me to eat healthier. She'll bring me healthy snacks, she'll say "let's get a granola bar instead of getting chips" or "let's go get cafeteria food instead of going out to Mc Donald's" or whatever ... Yeah it really helps when we're having lunch.*

Similarly, the action of *participating in physical activities* or exercise was also made more enjoyable with the accompaniment of friends. As Elaine stated:

*They go for walks with me ... They do activities with me ... It's kind of boring doing these things alone.*

**Figure 4.2 Friend Supports** (■ Physical Health; ■ Mental/Emotional Health)



Along with providing supports for physical health, friends offered a light of *reassurance* in the *importance* of youths' lives. Friends also offered an outlet in the form of an *ear to unload stressful thoughts*. In particular, two youth – Karen and Stacy – discussed how critical it is to receive reassurance for their importance in others' lives and how it affects their diabetes management. Thus, knowing that one is cared about by valued friends was a strong incentive for

better diabetes management. For example, Karen explained:

*Sometimes we'll have a deep talk and then they'll ... Hmm ... And then they'll get me to start taking care of myself. They mean a lot to me so like whenever they say and tell me how much they care about me and all that, and they want me to be healthy usually helps, will keep me up while taking care of myself. Yeah.*

Stacy concurred how the expression of care and the willingness of her friends to provide help was reassuring both for her sanity and her diabetes.

*People constantly show me they care and willing to help me everyday with anything including my diabetes ... Someone who keeps you sane and never forgets to tell you or show that everything will be okay ... Support from people is very important to me because it shows that people care for me and I don't want to hurt them by neglecting myself.*

Comparably to 'maintaining sanity', Karen also discussed the importance of having friends who listen during stressful times in life. For Karen, it was especially important to be listened to when she felt unsuccessful in her diabetes management.

*And talking to my friends, like my close friends and family, if anything, releases stress for me – which is another part of my health I guess. Sometimes it's like personal problems and others are like ... I'm not able to do these things to keep myself healthy.*

Despite having friends to lean on in these situations, youth also discussed the concept of *raising awareness* as a required support. It was no surprise that youth spent time participating in online activities such as social media. In this forum, youth encountered online images reflecting diabetes in a negative light, with information that is often not true. Avery explained how off-putting such images are:

*These memes on Facebook and it'll be like a picture of like a bunch of desserts and stuff and it'll be like "oh I'm gonna get diabetes" you know. So just seeing that puts you off.*

*No one's ever like said those kind of things in front of me.*

Karen agreed, adding *those jokes about diabetes aren't true*. Having to face such things on online media, Avery described how liberating it was to explain her illness to those who will listen:

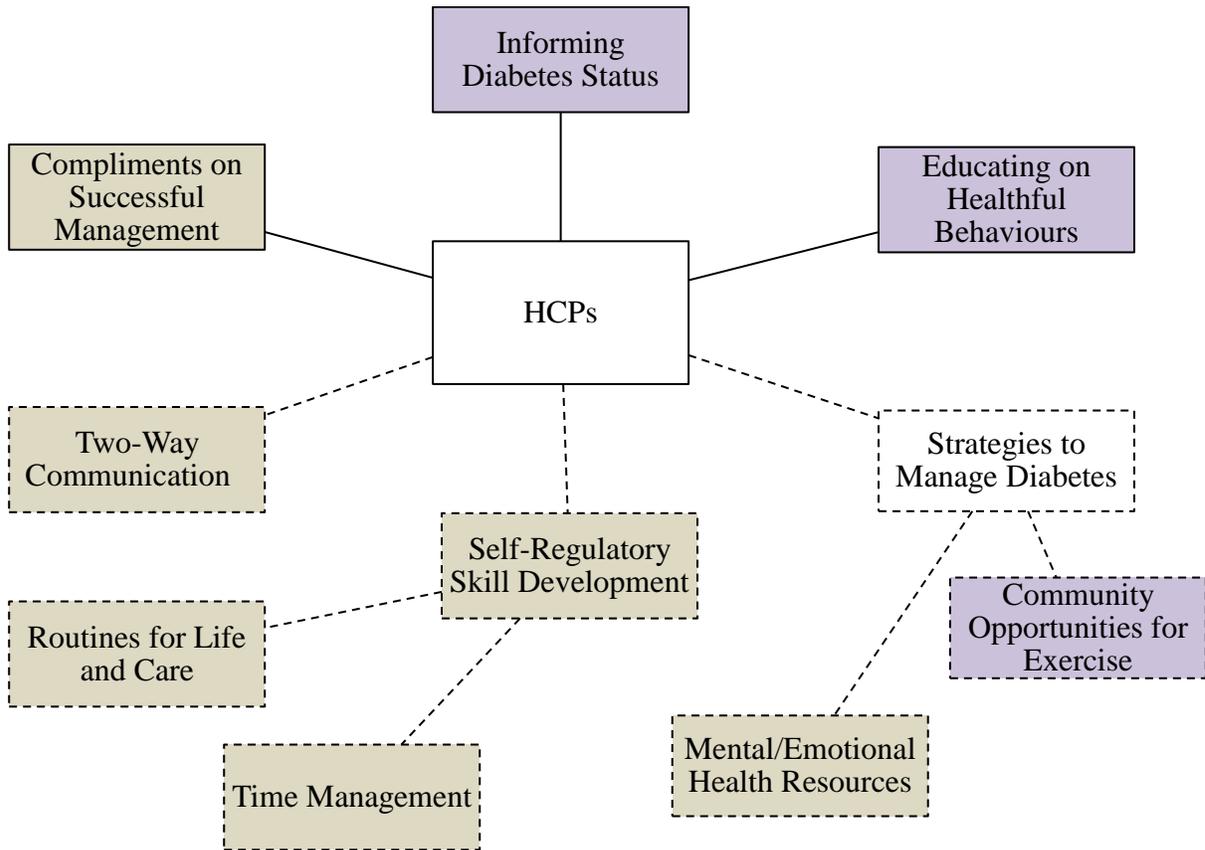
*Well it doesn't really affect me when I have to explain it to other people it just feels like I can express myself more because it's like, they'll listen. I don't know.*

Friends who listen and understand are an invaluable source of social support in the lives of youth with type 2 diabetes. The remaining three youth who did not possess friend supports for their diabetes management relied more on the support of family members.

#### *Health Care Professionals*

Health care professionals (HCP) were described as medical experts who youth have encountered due to their type 2 diabetes. As illustrated in Figure 4.3, HCPs offer various supports for youth, as well as possess many opportunities to support youth in other modes. All youth acquired support from HCPs in the form of updates on their *diabetes status*. Diabetes status updates included information pertaining to their blood sugar levels. As well, HCPs supported youth by providing *education on healthful behaviours* such as exercise and healthy eating. Michael explained how he receives support from HCPs in the form of compliments when he is successful in his diabetes management: *They kind of just congratulate me on my progress since I first started*. As well, Mary's mother described a similar experience: *Last A1c one was good, 6.5. So they were quite pleased*.

**Figure 4.3 HCP Supports** (■ Physical Health; ■ Mental/Emotional Health)



As youth perceive HCPs as experts in their illness, they hoped to acquire more information and advice in the following areas: *strategies to manage diabetes* and how to *develop self-regulatory skills*. Youth wanted support in terms of helping them develop strategies to explore mental and emotional health resources, as well as assistance with finding community based opportunities for exercise. Avery shared:

*So I would like to see more help with my emotions ... Yeah, that's something I would like to have some day. Except I will be turning 16 and I am having difficulty with my emotions lately. And to know if I am diagnosed with depression. I haven't been diagnosed so I do not know if I am.*

In contrast, Karen desired to be supported in the following way:

*They could motivate me I guess. Like suggest things to me of how I could manage my diabetes more instead of always saying like “if these numbers ...” Like giving me more options that I could do, like community stuff or getting involved in other groups.*

Further, Karen explained:

*For my diabetes. Other ways I could keep track I guess, or keep myself, or keep my levels normal instead of always like ... How do they always do it ... Like “if these numbers stay high, or this number is ... You’ll go through complications”.*

In this situation, Karen hoped to receive information or strategies on how to successfully self-manage her diabetes. She believed that establishing a routine may be helpful. Joyce, who is a new mother, identified her success in terms of managing her daughter. She explained how her daughter has a routine throughout the day, and, thus, she arranges her healthful diabetes behaviours accordingly. For example, Joyce stated:

*I have a routine actually cause my daughter sleeps all night long. So when she wakes up, I wake up and go have breakfast right away and then I take my insulin after that. And then I do my daily chores and I give her her nap and I’m actually on this medication so I only have to take it twice a day.*

Other youth, such as Stacy and Michael, struggled with competing interests. These competing interests included time spent in school work and time spent in healthful diabetes behaviours such as exercise. Stacy explained how she feels that she has the ability to obtain full control over her diabetes, but lacks the time management skills to juggle life priorities and diabetes:

*I think as people we have full control over our health and bodies. But, once you lose control, it’s hard to get full control back ... For my part if I manage my time a lot more,*

*form a schedule and stick with it, I can manage my health a lot better.*

Lastly, youth desired the opportunity to discuss personal issues with HCPs in a two-way communication. This was demonstrated by Avery and Karen's discussion previously (please refer to pages 40 and 50, respectively). Similarly, Elaine described the support she received as: *They tell me what I need to do and I do them.* As this support may be appropriate for Elaine, youth like Avery and Karen may require additional dialogue.

### *School*

Seven of the participating youth discussed the limited support they receive at school and how they would like to be better supported by the school, particularly in gym class (Figure 4.4). At school, some youth took comfort in the school's *preparedness of diabetic emergencies*. Youth discussed the plans that schools have in place if a diabetic emergency occurs.

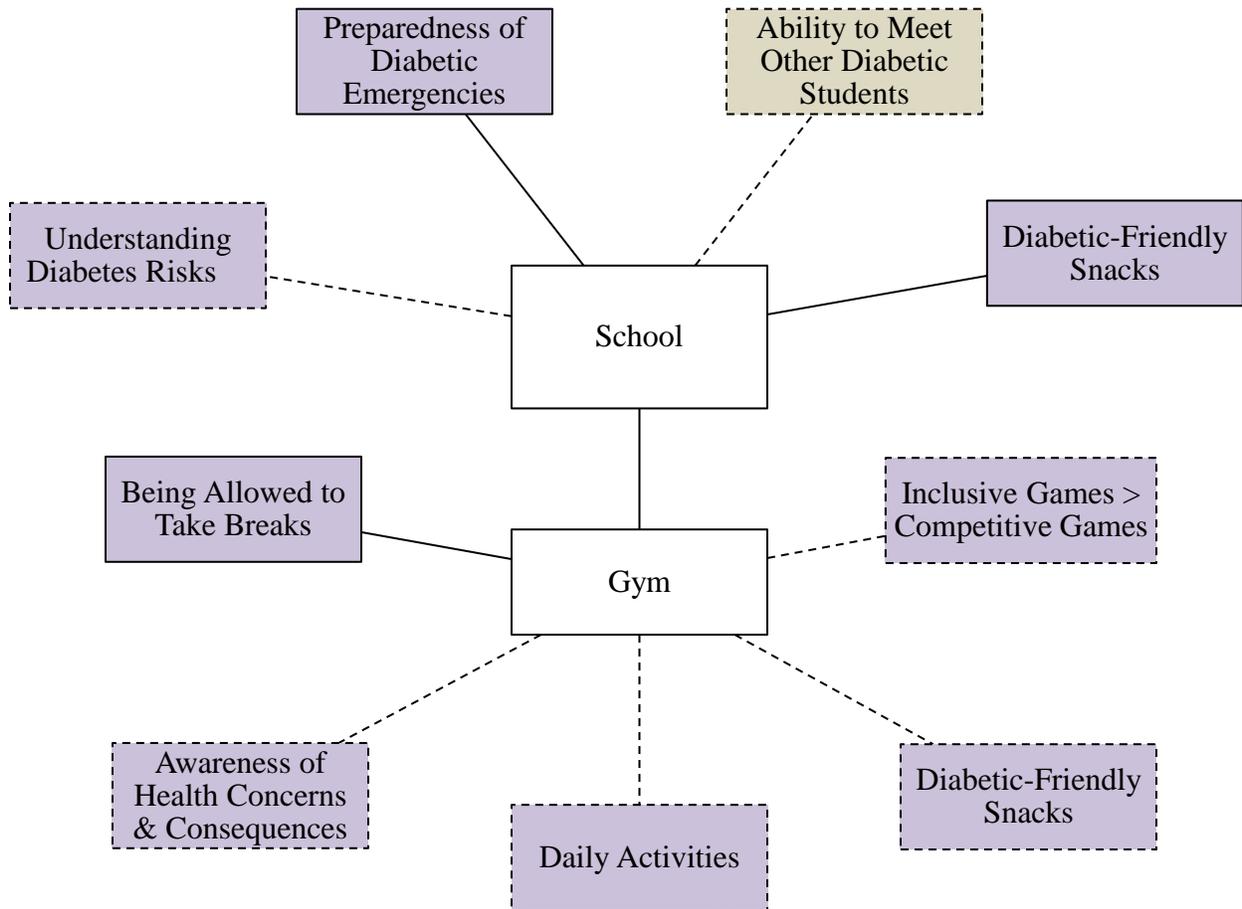
Joyce explained:

*Well hmm the positive thing was there was a nurse – they had a plan for me if my sugars went low or if I needed to monitor my blood sugars at lunchtime. Yeah they had a plan for that.*

Unfortunately, Karen discovered the school's plan the hard way:

*Even if I have to like, low blood sugars or high blood sugars, the school knows what to do like if I have low blood sugars, there will be a few teachers that tend to me right away. And if it's an emergency, they'll call 911. That happened a few times actually ... My emergency, I had like an emergency low blood sugar few times at school, where I felt like I was about to black out I guess. It was because of gym class I guess. I guess I was pushing myself too much and it's like first thing in the morning – so I just had breakfast or sometimes I skip cause sometimes I'm not, I don't have the appetite.*

**Figure 4.4 School Supports** (■ Physical Health; ■ Mental/Emotional Health)



However, other youth — such as Avery — were not confident in her school’s ability to handle a diabetic emergency. Avery discussed not feeling supported by her school at all. Her feelings resonated when she discovered that her medication consideration section – where she identified that she has type 2 diabetes – of her school register was crossed out. Upon registration, schools often have students and/or family members fill out an information form. Such information typically includes personal addresses, and emergency contacts, as well as information such as allergies and medical considerations. Although the purpose of these forms is to protect students, youth with T2D felt otherwise. Avery shared:

*Actually I absolutely do not feel like the school is supportive because, because I actually put it down on my school registration form where it says if you have any health concerns, and I put down type 2 diabetes but somewhere on that form, I don't know who wrote it or what, but it must have been some sort of ... Some principal or someone of power that actually wrote down that because it's type 2, and not type 1, there's no risk for hmm ... For danger or whatever.*

Youth also wished that schools would provide opportunities to connect with other diabetic students. Due to confidentiality issues, schools are currently unable to disclose students' illnesses to others. Karen explained:

*I think it's rare at my school. I think there's only a few kids that have diabetes ... They [the school] won't tell me their names or anything ... I don't know they said "classified" ... Like we can't tell you, yeah.*

As schools are not able to disclose such information, this limited the opportunity for youth to connect with peers within their own schools that are living with the same illness as them.

Another method school educators were able to support youth was by having *diabetic friendly snacks* available. Stacy appreciated having this option:

*One teacher knew that I was a diabetic and would always provide me with sugar free snacks as much as possible which I thought was very thoughtful for her to do.*

As previously mentioned by Karen, participating in gym has caused issues due to her illness. Despite the school providing diabetic friendly snacks, a different experience occurred in gym class. Many youth discussed at length the lack of support they feel in gym class. Joyce had an experience similar to Karen (page 51), where participating in first period gym class resulted in a negative outcome:

*Sometimes when my sugar was low, my sugar always went low cause in the morning I have never had breakfast and I wasn't really a breakfast person, I'd have tea in the morning. When I was younger, I would only have tea in the morning and my sugar would go low in gym class cause my gym class was always first period and when my teacher ... This one time she said "no more, no, you're not going to get something to eat." And I didn't like that so I stopped going. Cause she didn't understand like how I felt, yeah.*

Joyce further explained how she would have preferred her gym teacher to handle the situation:

*I probably wanted her to at least have candy in her office like suckers or something. Yeah. I would have been ok, I could have been running around with and eating that sucker at the same time.*

Despite the limited support received by youth in gym class, some educators are mindful towards youths' needs. Elaine experience in gym is described by *being allowed breaks*:

*I'm told to exercise but not to push myself ... They, they let me sit down for awhile.*

Additionally, Michael experienced something similar:

*And sometimes my gym teacher, he like compliments me when I do a good job.*

Interestingly, both Elaine and Michael discussed receiving support. However, both stated that their gym teachers were not aware of their illness. Another limitation to gym classes discussed by youth was the *lack of inclusion* in games. High level competition directed at youth who are not "natural athletes" created a barrier for Michael,

*The only barrier in me in playing sports for me is myself. Because like everyone, like majority of my school is like super sporty. I'm not a fan of competition cause some people are like crazy during competitions.*

Lastly, Mary has experienced the most negative reaction from her gym teacher. In

agreement with what the other youth have discussed previously, she felt that her gym teacher was neither knowledgeable nor considerate of her health concerns. She unfortunately explained:

*Like during gym, the teacher doesn't get it. I'm like trying to tell him, that I'm diabetic and he's like "I don't care". And he should know all the things about each student. He should be fired. You know one time ... in gym class and I was getting light headed and he was like "I don't care about your stupid blood sugar". And I'm like "if you don't care, I'm going to pass out and you're going to have to call an ambulance if I do." And he was like "I don't want to, it's not my job". I'm like "you know what I'm going to report you to the principal".*

However, despite informing her principal of this incident, the principal reacted with a lack of urgency to rectify the situation. Mary continued to explain:

*She's [the principal] like "oh hmm ... I'll try finding you guys a better gym teacher next year."*

### *Programming*

Due to the limitations and barriers to participating in gym class, programming appeared to be an attractive approach. Three of the eight youth previously participated in programming aimed to improve diabetes outcomes – Beating Diabetes Together (BDT). All three youth discussed wanting and waiting for such programming to continue in the future. Joyce explained the importance of BDT for her diabetes management:

*I like them because they can control my sugars better because when I was in BDT, I felt like ... The exercise helped me and I really liked it. At BDT, they encouraged me to exercise and it teach me more about my diabetes too actually. And what kind of food I can eat, and what foods will make my sugars go high. I didn't even know anything about*

*my diabetes before I went to diabetes, Beating Diabetes.*

As the remaining five youth have yet to participate in programming aimed to improve diabetes management, they discussed the following aspects to be included – illustrated in Figure 4.5.

The need for *reciprocal relationships with staff* was a recommendation for future interventions.

As youth have previously mentioned, they desired personal connections to be made with HCPs.

Michael provided the following description of desired program staff:

*They tell you stories and like there's struggles and motivation things. So people there that could tell you like, things that could like raise your spirits up to motivate you mentally and physically.*

In addition to building rapport with program staff, recommended staff are individuals who are able to facilitate inclusive games and activities. Joyce continued to explain her experience at BDT:

*Cause I really liked the way that BDT was. Because it was, like after we did all the activities, there was a lot of encouragement there. So nobody was like, nobody was ever like not running around, no one was ever sitting down type of thing. And I really like that. In high school, there's like these kids where they like, they like act like I couldn't do anything there because I was so shy to go out there and do stuff with the other kids but then with BDT, I felt like I could do stuff over there cause I wasn't shy. And I wasn't embarrassed to run around.*

Stacy and Avery, who have not participated in programming or an intervention, suggested that programming should include *mental and emotional health supports*. Avery stated:

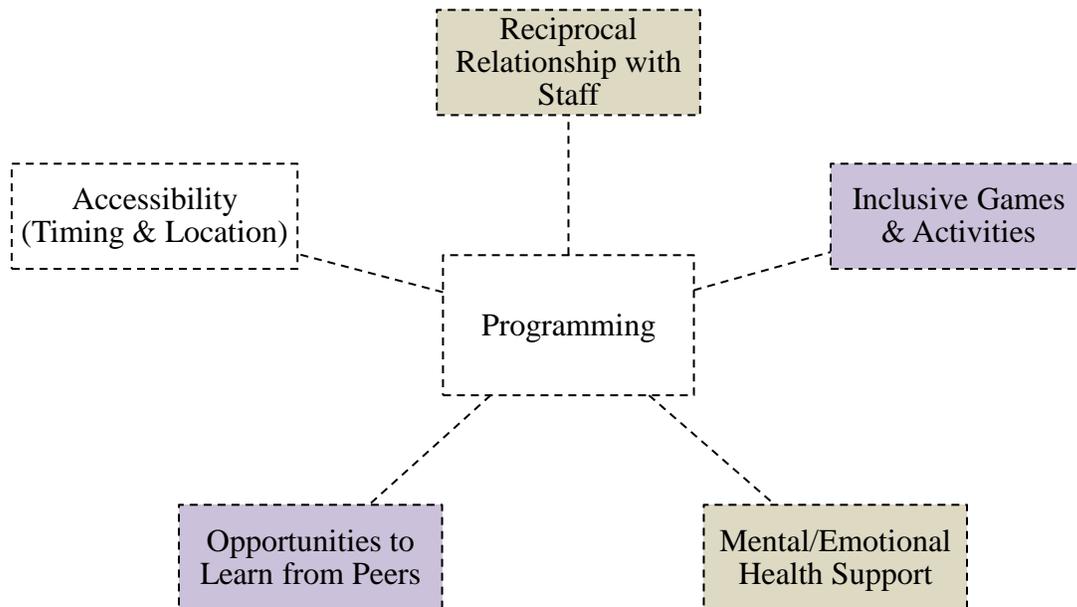
*Yes I think having someone there for as a leader, hmm ... to help us all with the emotional state and yeah.*

While Stacy concurred, she described:

*Programs such as ones that deal with mental health regarding diabetes and management class programs would be important to me. Because I think they are important to being able to manage my health a lot better.*

This was in alignment with youths' perception that they require additional mental and emotional health supports as mentioned previously, and that programming may serve as an appealing approach to provide this support.

**Figure 4.5 Potential Programming Supports** (■ Physical Health; ■ Mental/Emotional Health)



Additionally, programming offered *opportunities to learn from peers* in regards to strategies for diabetes management. Karen, a previous participant of programming, shared how she felt understood by other youth also living with diabetes and how she was able to learn from their experiences:

*Cause its kind of different with people that don't have diabetes cause its kind of hard for them to understand and how much you need – like how much activeness you need I*

*guess. Cause sometimes too much will cause problem like emergency low blood sugars and all that. Or too less will cause even more problems with high, or up and down blood sugars and yeah ... I met other kids like the kids at BDT that had the same thing as me and knew exactly what I was feeling and some of them say “you can still have sweets, but limit yourself” ... you can limit yourself with it, like limit yourself with chocolate or sugar. Or there’s also like diabetic candy and other stuff and if you have like, like the regular sugar, like try to hmm ... What’s it called? Work it out, like go to the gym or go swimming – like do something active for an hour.*

Those youths who had the opportunity to previously participate in programming found it to be invaluable. Those youths who have not, such as Mary and her mother, discussed the limited opportunities in programming that are *accessible* to their family and their desire to participate in programming within their community:

*Yeah if they were available in the community, which there isn’t. If there is, it’s like across town and to get from A to B, working shift work, that’s definitely hard ... Yeah I don’t think I would take a bus on my own.*

### **Living with Type 2 Diabetes**

As caring for diabetes and health are large aspects of youths’ lives, it was not surprising that youth discussed the lived experience of diabetes. Often times, youth identified health with diabetes, using these terms interchangeably. Youth described diabetes as being a treatable condition. However, they also felt that diabetes was a restrictive condition that posed limitations on what they can and cannot do. However, youth also felt that diabetes was not restricting when they are able to successfully manage it and during these circumstances. Numerous youth described diabetes as not ‘life ending’ or ‘life limiting’. Elaine wanted to inform others:

*It's not the end of the world. Because then they think it's the end of the world and they don't know what to do.*

As well, the following subthemes have been identified with respect to the lived experience of disability: identity, barriers, and burden of care.

### *Identity*

Many youth described something similar to Elaine's interpretation of diabetes:

*It's part of my life ... It makes life a little bit harder.*

After diagnosis, all youth struggled to understand the meaning of living with a chronic illness.

With time, youth learned to accept that their illness is an integral part of their life and identity.

Karen explained [continuing from her quote on page 45]:

*I guess it wouldn't have shaped into the person I am I guess. I don't know. I'll be someone different ... and I would have never met [friends]. That's like saying to someone "I regret meeting you, I wish we never met" or whatever. Yeah, yeah and I and I don't want to trade that ever. Yeah that's what my dad used to always say.*

Likewise, Stacy described how recognizing the lack of difference in her identity after her diagnosis has helped her cope with her illness:

*They [family and friends] help me through this all to manage my diabetes while they never make me feel any different from them. They still make me feel like me and not someone who is a diabetic ... They support me a lot but never single me out because of my health.*

As such, youth addressed the misconception that having diabetes results in a negative change in identity.

## *Barriers*

Despite youths' resiliency by accepting diabetes as a part of life, they discussed barriers when managing their illness. Barriers included a lack of financial resources and competing priorities. Forgetting to manage their diabetes was the more significant barrier that youth faced. Elaine – the only youth who identified the lack of financial resources as a barrier — shared how finances played a crucial role in the types of activities she was able to participate in:

*Well ... Everything cost a lot, especially the places I want to go ... [like] Lasertag. [And] I want to travel the world. Everywhere.*

Michael and Stacy similarly discussed having competing priorities as a barrier to managing their diabetes. They explained:

*Well at home I don't really do much, I'm usually doing a lot of school work and like, I usually do a lot of stuff that makes me happy on the inside, I don't really do stuff that's like ... Fun, physically, other than gym. [Michael]*

*I think I haven't been managing my diabetes as well as I like since I am a graduating student from high school and there has been a lot of added stress and pressure this year, that I feel it is just an extra thing I have to do that kind of adds to the stress I'm under. [Stacy]*

Lastly, many youth — including the three above — discussed how forgetfulness was the main reason for their lack of control in managing diabetes successfully. Similar to Karen's previous explanation on how she would like ongoing reminders provided by her mother [page 47], she shared how this was due to her forgetfulness:

*Cause me to forget? A lot of things [laughter] cause sometimes I zone out I guess and it's like ... Or sometimes I'm easily distracted by TV or someone else, the computer, like*

*anything, anything would distract me. Like really quick, like oh, and at the end of the day it's like I haven't checked my blood sugar today or I haven't take insulin – my evening insulin dose and realize how much sugar I ate or how much sugar is going in my body right now. Usually once I remember, I take it, as soon as I remember. Sometimes I feel like it's too late, it's like ... Cause I would feel like sick with those symptoms of high blood sugar.*

Comparably, Elaine clarified how she does not have complete control over her diabetes and explained why:

*I tend to forget things, [like] doing exercise.*

### *Burden of Care*

Notwithstanding the optimism that diabetes is not life ending, youth described the following burdens associated with diabetes and its care. Karen explained extensively the struggles she felt with managing her illness. She described the pressure to perfect her diabetes self-management. Also, she illustrated how there is a steep learning curve after diagnosis to the acquisition of healthful behaviours. Lastly, she often felt blamed and guilty when she was not successful in her diabetes management. Her description is as follows:

*It's something that is not easy to live with cause it's kind of difficult cause like if you make one mistake, everything goes down, and then if you like keep it like steady and keep it that way ... Hmm ... It'll be ok, you'll be ok if you keep it steady but if you, if you mess it up just a little bit, you just crash down I guess – like mess up your whole thing, your whole system I guess ... Then they give me all that negative crap. I feel bad at the end of the day, it wouldn't change anything ... And it's like that's not helping me, that's just going to keep my sugars the way they are now. So yeah.*

In line with Karen's story, many other youth illustrated other burdens they face as a result of living with diabetes. All youth described portion control of food as a critical pillar in their diabetes management. They defined portion control as 1) being aware of the type of food you are consuming, and 2) reducing the amount of foods that are less healthy. Mary and her mother described difficulties in managing portion control:

*But there's limitations cause you don't eat fish, you don't like eggs, you don't like certain things. She basically grew up on pasta ... You try to eat more ... Vegetables ... Salads and veggies, it's a little tough with the braces right?*

Lastly, Michael depicted the concept of diabetes being a social disadvantage. In his example, he illustrated a common difficulty diabetics face in a particular social situation – birthday parties.

*It's also socially bad too. Cause like some people who have diabetes, they're not allowed to have any sugar at all, I think that's like one? Is that right? No, nevermind. Cause like, let's say an example would be like a birthday party, you can't really have like, it's not really good for you to have like the birthday cake cause those really sugary cakes aren't good for you, they'll raise your sugar levels and then like ... Yeah cause some families like, they insist on you having the birthday cake and it's rude to like throw it out or like give it away.*

## **Negative Emotions**

As with complexities of living with diabetes, negative emotions were elicited. The following negative emotions were discussed by youth: fear, worry, shame, anger, regret, and lack of normalcy. Elaine shared how living with diabetes provoked a sense of fear and worry that is never-ending – no matter how much support she receives:

*Fear. It makes life a little bit harder. Yeah and there's worry. Whether or not I'm doing*

*enough or am not doing ... There's always going to be worry. You can listen but it's always going to be there.*

Additionally, Elaine also felt ashamed and reluctant to share her illness with others. She explained how part of the reason for this relates to avoiding being micromanaged by others. She shared:

*I hide the fact that I am diabetic. Because I don't like to be told when my limits are, when I already know them. It's helpful but it's also very annoying.*

While Avery experiences anger when she encountered online images, her experience was previously discussed in relation to raising awareness. To reiterate:

*These memes on Facebook and it'll be like a picture of like a bunch of desserts and stuff and it'll be like "oh I'm gonna get diabetes" you know. So just seeing that puts you off. No one's ever like said those kind of things in front of me.*

Karen shared similar sentiments to Avery, alongside feelings of regret. Both Joyce and Karen described the deep regrets they have on past food choices and wondered if improving past food choices would have resulted in a diabetes-free life. Each considered:

*Well ... If I could change how my diet was back then, I would change it actually, yeah.*  
[Joyce]

*Like I felt bad, like I felt really bad. I was like "oh no I shouldn't have eaten this much sugar, I should've controlled myself or eaten too much pasta". I should have tried to keep in shape but I wasn't cause I was pretty chubby. [Karen]*

Together with feelings of anger and regret, Karen also desired a sense of normalcy. She defined normalcy as having the freedom to choose when and what to eat and drink:

*Sometimes I wish I wasn't diabetic at all, just like a normal kid – that doesn't want to be*

*forced to eat or drink anything in the morning when you don't have an appetite, then get really sick and the ambulance has to come get you. Like a normal kid shouldn't have to go through that like a normal kid. Yeah.*

### **Things We Want You to Know**

*When I have to explain it to other people it just feels like I can express myself more because it's like, they'll listen. [Avery]*

Avery's sense of liberation to have her voice heard provided the purpose of this final theme. With this in mind, this section is dedicated to providing youth with a voice on diabetes matters they would like to share with others. Each youth was asked to share things they would like others to know about either their diabetes or their life with diabetes. Such things ranged from warning others, to educating others and addressing misconceptions. Their voices are shared:

*I would tell them that ... I have to look after my sugars everyday and like to warn them to eat better. And ... Try not to get diabetes. Yeah, I would encourage them not to ... To eat healthier and to exercise a bit more. Or exercise at least a little bit. I would warn them. [Joyce]*

*I think I would tell them that living with type 2 diabetes is not as difficult as you think it is but it's also not as easy. For instance, you definitely have to keep an eye on all these different things and you have to keep your health in check like getting check ups. [Avery]*

*It's restricting, that's all I'll say. It prevents you from eating an excessive amount of certain foods that lots of people eat, like slurpees which is very popular here in Winnipeg or like you can't really have a huge jug of ice cream when you're sad or else that will affect your health. A lot. [Michael]*

*If not managed well, it can really be damaging because it affects every part of your body if not taken care of. Well support is necessary to get through with it. And life is normal as usual*

*just with some extra precautions. And there are times when it is just really hard and complicated but it always gets better. [Stacy]*

*Lots of needles. [Rebecca]*

*I would say ... What are those things called again? Those jokes about diabetes aren't true. And the second one, that diabetes isn't an easy thing to control but it's also not hard – depends on how you do it. It's hard when you don't take care of yourself and ... For me it would be not getting enough support and advice and motivation, yeah. [Karen]*

*You can't have sugar. You have to do a lot of exercise, check your sugars. Because they need to know all the info, in case something does happen to you – like pass out. [Mary]*

*Staying active is fun and there's a lot more games out there other than the ones you know. There's a lot of things you could do that's fun and it doesn't have to be boring. [Elaine]*

## **Summary**

Youth struggle between the paradoxes examined earlier in this chapter. As illustrated by the mountain metaphor used to encapsulate my grounded theory, youth are “trapped” between their own perceptions of their illness and the perceptions that they believe their health providers have of their illnesses and lives. Youth continue to battle between expectations of what proper diabetes management is and their perceptions. As such, youth remain in limbo between whether they should embark on climbing the health mountain and its challenges or to find resources and strategies to return them safely to the ground. By sharing the experiences and voices of youth, in this chapter, I illuminated the complexities of social support and its role for youth living with diabetes in Winnipeg. Despite youths' current ability to request particular types of support, this chapter provided youth with a platform to seek additional supports they desire and require. To conclude, youth accessed and viewed social support in various ways, and, although youth receive

supports in some fashion, large strides are needed to ensure optimal disease management. The findings are discussed within the context of the literature in the next chapter.

## **CHAPTER FIVE – DISCUSSION AND FUTURE RECOMMENDATIONS**

The complexity of social support remains in regards to youth living with type 2 diabetes. The findings from this thesis have illustrated the various components to consider when supporting and managing this illness. It is evident that social support plays a critical role in the success or failure of management for such youth. The findings suggest that youth do receive support from their family, friends, school, health care professionals and programming. However, there are critical areas of social support which they believe require enhancement. Based on the findings presented in the previous chapter, this chapter contextualizes the findings within the existing research, as well as make recommendations for future research.

### **Diabetes Management Paradox**

I created the *Mountain of Health* to conceptualize a paradox in diabetes management grounded in the experiences of youth. This metaphor was derived from my conceptual framework – or grounded theory – of social support in type 2 diabetes. Although the concept of multiple domains of health has been discussed previously, the mountain metaphor underscores that youth with diabetes conceptualize their health in physical, mental, and emotional domains. Though youth discussed physical versus mental and emotional health, they also recognised that these dimensions are interconnected. Youth believe that health care professionals have differing perceptions when it comes to managing diabetes. This reveals an important disconnection between what youth believe HCPs expect of them and what they expect from themselves. As HCPs are perceived to be the experts in health and diabetes, youth look to HCPs for unquestioned instruction.

Youth discussed receiving advice and support from their HCPs largely for their physical health and desired similar supports for their mental and emotional health. Youth who participated

in Salamon et al.'s (2012) study were able to utilize psychological techniques when managing diabetes. For example, youth stated “when I get mad, I try and calm myself down cause I don’t want my blood sugar going way up” (Salamon et al., 2012, p. 550). Though, in this study, it was not identified how youth developed such techniques, the youth in this thesis discussed desiring support from HCPs to develop similar psychological techniques during difficult times in management. Thus, participants in this thesis felt ill equipped to handle situations of mental and emotional distress. As youth have prioritized mental and emotional health over their physical health in regards to their diabetes management, the struggle to manage their physical health first – as suggested by HCPs – continues to exist.

This difference in perceptions between youth and others in their social network is not uncommon. Rhodes et al. (2012) found that the perceptions between youth and their parents varied greatly, where parents perceived their youths’ physical functioning as more impaired than youth themselves. However, the finding that youth and HCP perceptions differ in my study is novel in that youth have illustrated how they perceive themselves and how they believe HCPs perceive them. These findings attest to advocating for improved communication strategies between youth and their HCPs. Communication may provide clarity for both youth and HCPs on how best to conquer the mountain of health – whether it be from a bottom-up (physical → mental/emotional health) or top-down (mental/emotional → physical health) approach (Figure 2). Dialogue should centre on priorities of HCPs and youth in regards to successfully managing diabetes to develop a strategy for improving physical, mental, and emotional health in harmony. Rather than a competing strategy between physical and mental/emotional health that appears to exist now as evidenced by this finding, HCPs and youth should work toward more harmonious and holistic ways of thinking about diabetic health. HCPs should also be interviewed to

understand their notions of health in type 2 diabetes.

### **The Complexities of Social Support**

The concept of social support in regards to youth and T2D has been discussed previously in the literature (Protudjer et al., 2014; Brouwer et al., 2012). It has been identified that supportive relationships are a crucial component for adopting healthful behaviours for diabetes management (Protudjer et al., 2014). As well, support has been distinguished between support for nondiabetes– and diabetes–specific behaviours (Brouwer et al., 2012). The findings from this thesis outlined the sources of support for youth, how these supports are interconnected, and the benefits and improvements associated with each type of support. Youth identified five potential sources of social support for their diabetes: family, friends, health care professionals, school and programming.

#### *Family*

The role of mothers as a primary support person has been documented in the literature (Auslander et al., 2010). However, the role and support of other family members remains scant. This study was novel in that it captured a more encompassing definition of family, which included fathers, grandparents, siblings, aunts, and daughters, in addition to mothers. A family history of diabetes is generally viewed in clinical and academic realms as negative. Thus, it was a great surprise to learn that youth felt a sense of strength, camaraderie and community associated with having a family member that is also affected by diabetes. Having a family member with diabetes was positive because it provided evidence of thriving and surviving with diabetes. This finding in relation to a family history with diabetes is novel and points to a strength based, rather than deficit approach. Based on the finding that a family history of diabetes can be perceived as positive by youth with diabetes, in the future, discussions should

centre around resiliency-based language. For example, the dialogue should speak to how those before youth have survived diabetes, and how youth can too. However, it is necessary to exercise caution with such an approach so that youth do not merely survive diabetes, but also thrive.

Many youths discussed forgetting as the main barrier to successful diabetes management. As a solution, youth rely heavily on family members to provide support through reminders, despite the notion that diabetes is an illness requiring self care (Orem, 1991). Attempts by parents to encourage youth to remember on their own have been discussed by participants. However, youth have also reviewed how such attempts have yet to be successful. In this regard, the finding from this thesis – that youth with diabetes have difficulty remembering diabetes treatment – is consistent with the literature. This suggests that both youth and their caregivers require education and skill development in order for youth to transition closer to self-care and become less reliant on their caregivers. Specific strategies to combat forgetting self-care are required, such as placing triggers throughout the home, and setting a daily alarm. Examples of triggers may be “post-its,” labelled with “take your insulin” or “check your blood sugars”. This finding demonstrates that youth seek family members for instrumental types of social support in the form of reminders.

A novelty of this study is that it included a patient with diabetes who is also a young mother. This dimension of the diabetes experience has not been previously captured. As a young mother, managing diabetes well goes beyond caring for oneself. As a participant discussed, it is important for her to be healthy in order to provide care for her child. The mothers’ health status must be maintained so that she is able to perform her responsibilities as a mother. The opposing notion is that if the mother’s health is compromised, in this case by diabetes, then she is unwell to provide care for her child. Such caregiver duties may include feeding the child, playing with

the child and taking the child for outings. This offers an indirect motivation to young mothers to continue to take action in managing their illness. Based on the finding that young mothers with diabetes are motivated to care for themselves in order to be a more effective caregiver to their child, it is evident that further research on the lived experience of being a young mother with diabetes is required in the future.

### *Friends*

Since adopting healthful behaviours such as eating healthy foods, and participating in physical activity are at the forefront for successful diabetes management, the support of friends makes these endeavours less challenging. Similar to Mulvaney et al. (2008), youth found comfort in friends who also adopted healthy food choices, such as the example of purchasing sugar-free snacks in their presence. Extending the experiences of youth conducted by Huynh et al., (2015), youth found physical activity to be more enjoyable with friends. These findings continue to reinforce the critical nature that friends play in increasing physical activity levels, and reducing the consumption of unhealthy foods for youth with diabetes. This may be viewed as friends providing appraisal social support, in that they remind participants of their ability to survive diabetes by participating in activities together. An extension to the roles friends play in the management of diabetes, participating youth reported a sense of reassurance in the importance offered by friends, as well as having someone who listens during stressful times. For a youth with diabetes, stress is inevitable. To have friends who can offer these avenues of social support demonstrates that meaningful support for youth goes far beyond adopting healthful behaviours. Friends who are successful in providing support are those who are able to listen and sympathize. This finding suggests that friends are critical in providing youth with diabetes emotional social support. Thus, information and education is needed for those who have friends living with

diabetes, and the types of social supports that are appreciated. For those who are friends with a diabetic, information should not be limited to the types of healthful behaviours and foods to engage with/in, or the symptoms of high or low blood sugars, but should also include information on how friends can help raise awareness to the public. Additionally, friends need to recognize the added complexities of stress for youth with diabetes. It is recommended that friends display sensitivity and support youth with diabetes through reassuring self-worth – by providing emotional social support. For example, friends who were successful in providing support often provided dialogue that fosters encouragement and a sense of purpose.

There were three youth who identified not having friend supports. Reasons discussed for not having such social supports relate to the intimacy of friendships. Youth chose not to share their illness with friends due to a low intimacy level friendship. Youth in this study without friends identified acquaintances in their social circle. The information they discussed with acquaintances included shared hobbies and interests, rather than intimate topics.

### *Health Care Professionals*

Diabetes is readily discussed in conjunction with health care professionals and health care spaces such as hospitals. In the medical field, health care professionals are deemed as experts in health and chronic illnesses. Thus, it was not surprising that youth seek informational social support from HCPs. However, Parkinson (2015) states that HCPs “own the concept of medical, but not health. Medical is acute and chronic illness that can be treated with pills or procedures. Health is an everyday series of decisions we all make” (para 1). This resonates well with the findings from this thesis. Though youth look to HCPs for expert opinions on behaviours to adopt in order to successfully manage their illness, there is disconnect in how youth perceive the notion of health in comparison to their HCPs. Largely, youth felt ill equipped in their ability to

participate in self-regulatory skills such as time management or establishing a routine for care.

Protudjer et al., (2014) was the first qualitative investigator to include perceptions of youth and their health care professionals in the management of diabetes. It was concluded that health care professionals prioritize obesity management (Protudjer et al., 2014). This was similar to the findings in this study where youth described substantial support in behaviours aimed to improve physical health. Though HCPs recognize that there are “intellectual challenges” in managing diabetes, these needs remain unmet (Protudjer et al., 2014). These findings build upon work done by Protudjer et al., in that it provides specific supports that youth would like to receive. HCPs who interact with this population should attempt to develop an individualized strategic plan for youth, their needs, and their aspirations (e.g. graduating high school). It is also important to note that strategies and processes such as the one previously suggested require engagement and dialogue with youth in order to be successful.

### *School*

School is an institution aimed at providing opportunities to learn. In Manitoba, the compulsory ages to attend school are 7-18, with kindergarten as an optional year of schooling (Government of Manitoba, 2016). As it is youths’ right to attend school, it is also their right to feel supported and comfortable at school. Unfortunately, a lack of school-based support was perceived to be the most significant support deficit in the lives of youth in this study. Schools who are aware and knowledgeable of diabetes and its symptoms provide comfort to youth. Youth felt relief when schools and teachers have developed a “diabetes plan” in the event of an emergency. Consequently, when schools lacked preparedness, it left youth feeling unsafe and unimportant. As a result, youth felt that schools were unable to provide the emotional social support that they needed.

The purpose of physical education (gym) class is to provide students with opportunities for physical activity. Thus, there is an expectation that youth with type 2 diabetes are to engage in and take advantage of such opportunities. However, the environment and nature of gym class in itself posed further barriers for this population and their participation. Huynh et al., (2015) was the first to report the lack of inclusion youth with diabetes felt in gym class. The youth in study shared similar sentiments as that reported in Huynh et al.'s (2015) work. Inclusion is the philosophy of supporting the general and physical educational needs of students with differing needs (Block & Obrusnikova, 2007). In Huynh et al.'s study (2015), youth discussed disliking the competitive nature fostered in gym classes. In building upon this, participating youth shared in depth scenarios leaving a distasteful feeling towards gym teachers. Why gym teachers were not able to provide inclusive supportive opportunities in gym class begs further study. For instance, potential reasons why gym teachers do not offer emotional social support might involve 1) the lack of education and experience, 2) the lack of knowledge relating to type 2 diabetes, or 3) a combination of both. This is a shame as environments in which physical activities occur offer countless potential benefits for the facilitation of integration for youth (Titus & Watkinson, 1987). These environments may also discourage youth from participating, especially if youth lack confidence and competence in their physical abilities. The findings from this study suggest that stronger advocacy within the school system is needed, and its considerations and expectations of educators who interact and engage with this population. This is of utmost importance as the purpose of gym class is to provide students with the opportunity to be active. Further, gym spaces have the potential to aid in diabetes management. When gym classes lack inclusion, youth are robbed of opportunities for growth, learning and development. The lack of opportunity to participate in meaningful physical activity – especially in an environment

specifically designed for this purpose – and its consequences are likely to transfer into other aspects of youths’ lives. Youth who do not have the opportunity to develop physical activity competencies are less likely to participate in physical activity altogether (Biddle, Whitehead, O’Donovan, & Nevill, 2005). As youth continue to experience such negativity in this environment, their willingness to participate in physical activities will not surprisingly continue to decline. Thus, greater awareness must be accomplished with regards to the health concerns and consequences for this population and their participation in gym class. We need to work toward different conceptual models in physical education that promote inclusion rather than competitive advantage. Education for gym teachers is paramount. Interestingly, youth who shared positive experiences at school and in gym were youth who also reported that their educators were not aware of their illness. This suggests that educators who are inclusive are likely to have inclusive attitudes towards all students, regardless of illness and ability.

### *Programming*

Interventions aimed at improving glycemic outcomes for this population may not be effective for families and youth with T2D due to the lack of awareness and consideration for psychosocial needs (McGavock et al., 2015; Protudjer et al., 2014). However, an after-school program designed for this population appeared to provide other benefits besides improving glycemic control (Huynh et al., 2015). Other benefits included the development of friendships, and a safe space to participate in physical activity. In this thesis, I demonstrated that such benefits continued to be felt by youth who participated in the previously mentioned program. This suggests that programming may be an attractive avenue to foster healthful behaviours, for both physical and mental/emotional health – so long as program delivery is mindful of this. Programming must encompass not only opportunities for youth to participate in physical activity,

but offer opportunities to learn to cope with their illness as well. The accessibility of programming discussed by a participant and her mother must also be taken into consideration, as accessibility is considered one of the best practices when delivering youth programs (Youth Agencies Alliance, 2013). Thus, this must be reflected during program design and delivery. Intentional programming may be a potential source of all four domains of social support for youth.

In order for youth to feel supported through programming, youth desire reciprocal relationships with program staff. Reciprocal relationships are characterized as a relationship in which youth feel that staff are mutually invested in their diabetes, but, more importantly, in them as a person. Thus, rapport must be built in order for youth to feel comfortable participating in the program. Similarly, to gym class, programming must be inclusive and sensitive to the needs of youth with diabetes. Nonetheless, the quality and components of programming are crucial in determining its success. The findings presented here extend the knowledge on the perceptions of programming for youth with diabetes, what ideal programming may look like, and offer components for future interventions/programs to consider including. Hence, future programs must incorporate the components outlined in Figure 4.5.

### **Living with Diabetes**

The lived experience of diabetes in youth has been investigated (Huynh et al., 2015; Protudjer et al., 2014; Salamon et al., 2012; Brouwer et al., 2012; Mulvaney et al., 2008). Previous literature discussed adjustments made during this experience (Salamon et al., 2012), feelings associated with living with diabetes (Huynh et al., 2015; Brouwer et al., 2012), and the development of problem solving and coping skills after diagnosis (Mulvaney et al., 2008). These findings extend this literature to include the concept of identity, barriers, and the burden of care.

*One of the most distinctive features of adolescence is that it is a time of thinking about who you are, where your life is going, what you believe in, and how your life fits into the world around you* (Arnett, 2012, p. 160). In this thesis, it was suggested that youth with diabetes grapple with developing an identity and whether that identity includes their illness. This finding suggests that there is a delicate balance between recognising that diabetes does not necessarily change one's identity and learning to accept the illness as part of life. Based on this finding, it is recommended to discuss diabetes as something an individual has, and not something an individual is. This may help youth during their transition and journey to discovering self-identity.

Building upon the concept of identity, barriers such as forgetting, the lack of financial resources, and competing priorities exist. As forgetting remains the largest barrier to youths' success in diabetes management, as previously discussed, efforts are needed to develop skills to overcome this barrier such as developing self-reminders. For example, youth who have cell phones may be encouraged to add a daily alarm which rings to remind them to check their blood sugar levels. Other devices, such as Fitbit Trackers that serve as a watch and step-counters, also offer a 'silent alarm' in which the device provides a time-set reminder through a quiet vibration. Future recommendations for research may be to study the effectiveness of similar devices and its potential to improve forgetfulness.

Financial concerns have been identified in preceding literature (Protudjer et al., 2014; Auslander et al., 2012). This entails an inability to purchase healthy foods due to socio-economic constraints that are needed for illness management. The limitations associated with financial concerns include the type of foods purchased (Protudjer et al., 2014; Auslander et al., 2012) and the types of activities youth can participate in. Similar to the previously discussed idea that youth require skill building, this should also factor in time management skills to aid in reducing

competing priorities such as school responsibilities. Though the barrier of finances may be that of a larger systemic issue, barriers such as skill development for remembering and time management are feasible for HCPs and programming. As light is shed on these barriers, social supports previously discussed may offer solutions to reducing such barriers.

After diagnosis, youth are expected to make drastic changes in their lifestyle and behaviours in a short amount of time. This concept is characterized as a steep learning curve. The notion that youth are to make behavioural changes immediately following diagnosis is contradictory to any behaviour change theory. This is because, according to behaviour change theories, “behaviour change is a process and not an event” (Canadian Society for Exercise Physiology, 2013, p. 31). For example, the popular transtheoretical model of change suggests that people move through a series of stages as they progress towards changing behaviour (Prochaska, DiClemente & Norcross, 1992). Perhaps health care professionals could focus on a particular behaviour to change for youth and allow youth to transition into others once they are confident in the previous change and are able to sustain it. As well, short-term goal setting immediately following diagnosis may allow youth to capture ‘quick wins’. Quick wins allow for improvements to be visible for youth by producing an immediate benefit, and are timely strategies that can be delivered (Parker, 2013). For example, rather than advising youth to eliminate junk foods altogether, perhaps asking youth to limit junk food intake to one portion each day is a more realistic and feasible approach.

An interesting and unexpected view emerged – living with diabetes poses as a social disadvantage. Social disadvantage has been linked as a determinant of type 2 diabetes (Protudjer et al., 2014). However, the idea that diabetes can result in social disadvantages is novel and has not been reported previously. This provides an added layer of complexity when discussing

behaviour change with this population. A potential recommendation may be to discuss strategies on how to navigate such social situations positively. Consequently, this may also elevate common negative emotions experienced by youth. Larger, systemic studies are needed in order to investigate whether there are objective social disadvantages associated with having diabetes.

Participating youth discussed a lack of normalcy as a result of their illness. In recent qualitative studies, Protudjer et al. (2014) and Brouwer et al. (2012) found that some youth feel like “outsiders” due to their diabetes. This view was articulated in greater depth by participating youth. Struggling to understand normalcy, youth fluctuated between feelings of acceptance with their illness – accepting a new “norm” and feelings of abnormality – differing from many of their peers. In light of the shame, regret, and anger associated with diabetes, youth struggled to prevent, manage and elevate such negative emotions, and also struggled with disclosure of their illness. Negative emotions have been evident for youth living with diabetes in the past (Huynh et al., 2015; Protudjer et al., 2014; Auslander et al., 2010). These findings extend previous research in this respect by providing greater understanding into the negative emotions experienced as well as illustrate how youth believe that these negative emotions are likely to never disappear. Stigma and disclosure among this population have also been reported. Brouwer et al. (2012) provided suggestions on how to ease the difficulty of disclosure to others. They offered ideas around providing youth with information brochures to distribute to their friends. Though there is potential in this suggestion, it perpetuates the view of self-responsibility for youth with diabetes, in that youth are expected to make efforts to educate others. Collective initiative is required in raising awareness and education to reduce stigma and thus reduce the fear to disclose. Schools may offer advocacy campaigns centred around not only type 2 diabetes, but perhaps chronic illnesses in general. This may be a feasible approach as schools often hold “around the world”

events and activities where, each day, students learn about a specific country, its customs and culture. A similar approach may be adapted to educating students on the various chronic illnesses their peers may face.

It is reported that 99% of Canadian youth have Internet access out of school (Global News, 2014). The Internet — in particular, social media outlets such as Facebook, Twitter and Instagram — offers a plethora of information and opportunities to connect with peers. It also equally offers exposure to inappropriate images and cyberbullying. Youth in this study discussed encountering negative imaging in online outlets. These images may have lasting effects on how youth perceive themselves and their illness. Though complete elimination of these images proves to be a herculean task, in addition to continued education and awareness of type 2 diabetes, resources such as health care professionals and educators may be called upon to also counsel youth through emotions evoked by online channels. As well, health promoting online technologies could be used in the management of type 2 diabetes, such as evidence based, monitored and private Facebook groups.

### **Things We Want You to Know**

Though it is not uncommon for qualitative investigations to capture the experiences and voices of this population, this study is the first to provide a platform for youth to share what they want others to know about their illness. In this way, youth illustrated “what I wish you knew” (Moola et al., 2011). As a youth mentioned, having the opportunity to express oneself is liberating and empowering. In 2014, the Nutrition Resource Centre in Ontario delivered a presentation titled “Harnessing Youth Voices to Change the Diabetes Conversation”. Though the purpose of this presentation aimed to reduce the risk of type 2 diabetes through engaging youth in education, there is still a need to include the voices of youth with diabetes. The diversity in

what youth choose to share to the public in the previous chapter illustrates the variability in how youth experience their illness and the differences and commonalities in the journey towards successful diabetes management. I hope that the voices presented here act as a catalyst for ongoing dialogue in matters pertaining to youth and their diabetes. Clinicians and researchers should harness the voices of youth in order to better manage what continues to be a very challenging illness to treat.

### **Summary**

As poorer quality of life has been reported among youth with type 2 diabetes (Hood et al., 2014), high-quality support may invoke resiliency against diabetes adversities. These findings illuminated the complexities of living with diabetes and social support, and discussed these findings in the context of the literature. Recommendations stemming from these findings were also made. As well, I have offered various avenues and opportunities to target for those hoping to improve quality of life in this population. By grounding this work in the voices of its participants, it is my hope that future researchers and interventions/programs continue to include youth in dialogue, matters, and processes that pertain to them. Social support is essential to helping youth become drivers of change in their own life. Lastly, these findings offer tangible and feasible strategies to move the needle towards high-quality support for this population.

## CHAPTER SIX – CONCLUSION

The relationship between social support and diabetes management has sparked interest to explore the meaning of social support for youth living with type 2 diabetes. Though the literature recognizes the importance of social support in facilitating diabetes management behaviours, youth continue to struggle to manage their illness (Protudjer et al., 2014). The purpose of this thesis was to answer the following questions:

- 1) What is the meaning of social support to youth living with T2D?
- 2) How do youth with T2D want to be supported?
- 3) What roles do parents and clinicians play in the management of T2D?
- 4) What is the perceived feasibility and acceptability of a behavioural intervention aimed to improve self-management skills?

Specifically, this thesis drew upon the grounded theory qualitative research tradition to explore the purposes outlined above.

As the rates of type 2 diabetes among youth continue to grow, the search for effective strategies to socially support youth persist. This thesis has offered insights grounded in the voices of its participants. The first chapter introduced the topic of T2D in relation to the Manitoba context, outlined the history of T2D, and provided definitions of terms readily used throughout this thesis. As well, in the first chapter positionality was established through the use of the reflexive process.

The second chapter surveyed and presented knowledge available in the current literature. This served as a basis for justification for the purpose of this thesis by bringing awareness to the gaps in the literature. Methodological considerations and methods were outlined in the third chapter. The methodology of grounded theory functioned as a framework to work with my

corpus of qualitative data, both by guiding how the data was collected as well as how the data was analyzed. Grounded theory offered an inductive approach to investigate the meaning of social support for youth with T2D. This chapter also described the process in which trustworthiness was established throughout this thesis.

The fourth chapter presented the findings of this thesis. Participant characteristics were described and a theory grounded in the voices of its participants was developed (Figure 2). Here, I theorized that a paradox exists between the perceptions of youth and the expectation youth feel in relation to diabetes management. I also outlined the various social supports that youth receive, perceived inadequacies in support, as well as what youth want others to know about their lives. The purpose of this chapter was to provide a platform for youth to share their illness experience and to offer suggestions to improve social supports. Lastly, the fifth chapter contextualized what was found in this thesis within the context of the existing literature. As well, I offered recommendations for the future.

### **Limitations**

Though findings from this thesis offer important insights to consider for supporting youth and their diabetes management, several limitations exist. One limitation of this thesis is that participants were not asked the age of diagnosis and the years spent with their illness. This poses a limitation, as the concept of time and its influences was not explored. Whether managing diabetes becomes easier or harder throughout time remains questionable. Future studies may aim to investigate the feelings associated with T2D in relation to time spent living with the illness. It may offer insights to the timing of appropriate types of supports.

Another limitation is the relatively small sample size, as well as the uniqueness of T2D rates in Manitoba. With a sample size of eight, the findings may not be generalizable to youth

living in other parts of the world. However, Hill et al. (2005) suggest that a sample size of eight is ample to understand experiences of participants through the use of open-ended interview questions and that the results may be transferable to other contexts. Although future studies are needed to explore the transferability of these findings, the concrete stories and commonalities among youth's experiences may suggest that concerns about sample size are not warranted.

Further, not all youth participated alone. In order to ensure autonomy and comfort, I allowed youth as much control as possible over the research setting. One participant – due to special considerations – had her mother accompany her during the interview. This was an unavoidable limitation. However, the presence of her mother appeared to have no effect on the information the participant shared. This was evident when stories were shared that the mother was not previously aware of. Though it may be considered a limitation, it may equally be argued that the presence of a caregiver provides comfort to youth discussing a sensitive topic such as living with an illness.

### **Knowledge Translation**

Knowledge translation (KT) is defined as “a dynamic and iterative process that includes synthesis, dissemination, exchange and the ethically-sound application of knowledge to improve the health of Canadians, provide more effective health services and products and strengthen the health care system” (Canadian Institutes of Health Research [CIHR], 2016). The purpose of KT is to close the gap between research and practice (Albrecht et al., 2016). It has been reported that 30-40% of patients do not receive care informed by current research (Freedman et al., 2011). Thus, effective strategies to raise awareness about research findings for its intended consumers is critical (CIHR, 2016). I am already engaging in typical KT activities, such as academic publishing and engaging in conference presentations.

The benefits and importance of multidisciplinary teams is not a new concept. Based on the findings from this thesis, it is strongly recommended that mental health counsellors be incorporated into the care of youth living with type 2 diabetes. Thus, with the knowledge that youth's mental health needs are neglected, hospitals and health care systems should invest in the hiring of psychologists or mental health counsellors to deal with the untreated aspects of pediatric type 2 diabetes. There has been a lot of traction on the effectiveness of peer mentoring. The concept of this is that youth can vicariously learn from peers who have lived experience, as well as success in the management of their illness. Thus, this may be an attractive approach to occupy mental health counsellors' vacancies. Clinics could establish peer mentoring by "buddying" new members in the clinic with members who are successfully managing their diabetes.

Specifically, health professionals may use the mountain of health as a tool to navigate an individualized management approach to caring for type 2 diabetes. HCPs can have youth place themselves on the mountain of health as a reference point. With this information, HCPs can begin the conversation of which mountain direction youth require to manage their diabetes successfully. Then, appropriate and relevant goal-setting that is both meaningful to youth and their diabetes may be established. This tool can be used with every clinical visit. It allows youth to visualize their diabetes journey, and help bridge the gap in communication between youth and HCPs. Therefore, clinics should consider adopting the mountain of health as a tool with clinical utility.

Knowledge transfer strategies are needed in educational settings, such as physical education classes. Evidence based interventions should explore the effectiveness of inclusivity training for educators. University educational departments should include students with chronic

illnesses in their definition of inclusion, and should be educated and trained on the considerations for this population. As youth feel isolated as a result of confidentiality policy in schools, schools may offer students the opportunity to consent to releasing this information for the purposes of meeting peers. This opportunity – so long as students’ desire – will allow students to build friendships and/or a support group that are accessible with those that are like them.

Knowledge transfer acknowledges that the users of research must benefit from the research. As well, youth who have participated in this thesis will be informed about these findings and the resulting KT strategies. The purpose of this is to empower youth to know that their input and stories matter and are affecting change in diabetes practice and education.

### **Future Directions**

With respect to future directions, it is necessary to discuss the disconnection between youths’ perceptions and how they perceive health care providers to conceptualize their health. Grounded theory allows researchers to develop theories from collected data. The participants in this thesis discussed the types of supports they receive from various sources, and the types of supports that are lacking. Participants identified the differences between the approaches to managing their illness (Figure 2). Future endeavours – may it be studies, programs or services – aimed to improve the quality of life for this population, should consider collaboration and engagement with youth during the earliest stages of study development. Since this thesis has revealed important differences in youths’ perceptions and how they believe health providers feel, it is all the more important to tap into youths’ experiences when clinicians and researchers are creating new programs.

The negative experiences youth discussed in regards to physical education classes was alarming. Future post-secondary teachers need improved education on the considerations

required of students living with a chronic illness. Further, future educators should remain sensitive to their ignorance on the lived experience of managing an illness during childhood.

As youth and family members rely heavily on the guidance and medical advice of health care professionals, the findings presented in this thesis urges health care professionals to redirect approaches to discussing T2D. Discussions with youth in relation to diabetes managements should move away from *what to do* and towards dialogue on *how to do it*. Youth are aware of the lifestyle changes to be made with regards to physical activity and food choices. However, youth struggle to navigate the terrain of adolescence, and this is made more difficult when attempting to also manage their illness.

*What we do for ourselves dies with us.*

*What we do for others and the world remains and is immortal.*

*– Albert Pike*

As this thesis concludes, I invite you to consider the impact you have on others, and the impact you wish to have. To contextualize this quote, it is my hope that through the production of this knowledge, I have had an impact on the pediatric diabetes community by identifying some of their unmet social support needs. As rates of type 2 diabetes continues to increase, there is a need to develop strategies to better support this population. In this thesis, I hope that I shed some clarity on the form and function of social support through the advancement of theory. As well, in this thesis, I aspired to compel educators, clinicians and researchers to collaborate and engage youth in finding appropriate social supports and in treatment plans. It is my hope that the stories shared in this thesis empower others to seek knowledge from youth living with type 2 diabetes.

### Appendix One

<b>Authors</b>	<b>Title of Article</b>	<b>Study Design/Tools</b>	<b>Participants</b>	<b>Outcomes</b>	<b>Findings</b>
Walders-Abramson et al (2016)	Benefits and barriers to participating in longitudinal research of youth-onset type 2 diabetes: Results from the TODAY retention survey	Longitudinal Survey	N = 337 Mean age = 13.8 Ethnicity = Non-Hispanic Black, Hispanic, Non-Hispanic White, Other	Perceptions of the benefits and barriers to sustained involvement	A supportive relationship with study staff was commonly endorsed as a benefit of engagement in the longitudinal study
Yi-Frazier et al (2016)	Whose quality of life is it anyway? Discrepancies between youth and parent health-related quality of life ratings in type 1 and type 2 diabetes	Cross-Sectional Questionnaires	N = 353 Mean age = 14.9 Ethnicity = Black, Hispanic, Other, Non-Hispanic White	Associations between discrepancies, PedsQL scores, and glycemic control (HbA1c)	Parents may often underestimate youths' HRQOL except in the youngest children
Chambers et al (2015)	A home-visiting diabetes prevention and management program for American Indian youth: The together on diabetes trial	Pre-Post Questionnaires	N = 263 Mean age = 13.2 Ethnicity = American Indian	Feasibility of a family-based, home-visiting diabetes prevention/management intervention	Family-based youth diabetes prevention interventions is feasible and acceptable
Sylvetsky et al (2015)	Buddy Study: Partners for better health in adolescents with type 2 diabetes	Randomized Clinical Trial Questionnaires	N = 10 Mean age = 15.8 Ethnicity = Non-Hispanic Black	HbA1c QOL	No change in HbA1c with intervention group (assigned "buddies"), and no differences in QOL

<b>Authors</b>	<b>Title of Article</b>	<b>Study Design/Tools</b>	<b>Participants</b>	<b>Outcomes</b>	<b>Findings</b>
Larkin et al (2015)	Effects of comorbid conditions on health-related quality of life in youth with type 2 diabetes: the TODAY clinical trial	Pre-Post Questionnaires	N = 685 Mean age = 14.0 Ethnicity = Non-Hispanic Black, Hispanic, Non-Hispanic White, Other	Association between health-related quality of life (HRQOL) and comorbidities	A significant correspondence between impaired HRQOL and number of comorbidities was noted, but was driven by the presence of depressive symptoms.
Hood et al (2014)	Psychosocial burden and glycemic control during the first six years of diabetes	Longitudinal Questionnaires	N = 281 Mean age = 14.1 Ethnicity = African American, Hispanic, White	Psychosocial burden and trajectory  Relationship between psychosocial burden and glycemic control	1) More depression and poorer QOL than T1D  2) Youth with higher A1c reported higher QOL
Protudjer et al (2014)	My Voice: A grounded theory analysis of the lived experience of T2D in adolescence	Qualitative Interviews	N = 8 Mean age = 15.3 Ethnicity = First Nations	Lived experience	Supportive relationships is an important determinant for adopting healthful-living self-management
Walders-Abramson et al (2014)	Relationships among stressful life events and physiological markers, treatment adherence, and psychosocial functioning among youth with T2D	Cross-sectional Questionnaires	N = 497 Mean age = 18 Ethnicity = Black, Hispanic, White, Other	Relationship between stressful events and physiological measures, adherence to prescribed oral medication regimes, depressive symptoms, and impaired QOL	Exposure to major stressful life events is associated with lower adherence to prescribed oral medication regimes and impaired psychosocial functioning

<b>Authors</b>	<b>Title of Article</b>	<b>Study Design/Tools</b>	<b>Participants</b>	<b>Outcomes</b>	<b>Findings</b>
Richards et al (2013)	Learning needs of youth with T2D	Cross-sectional Questionnaires	N = 191 Mean age = 14 Ethnicity = Non-Hispanic, Black, Hispanic, White	Learning needs	1) No difference in learning needs between genders  2) Scores on Teen Issues scale approached significance with girls reporting higher needs than boys
Salamon et al (2012)	Experiencing T2D – Qualitative analysis of adolescents	Qualitative Interviews	N = 8 Mean age = 13.5 Ethnicity = African American	Experiences with T2D	Three themes: 1) Concept of illness 2) Adjustment to self-care 3) Motivation to perform self-care behaviours
Rhodes et al (2012)	Health-related quality of life in adolescents with or at risk for T2DM	Cross-sectional Questionnaires Interviews	N = 44 Mean age = 15.5 Ethnicity = Non-Hispanic, Black, Hispanic, White	Perceptions of adolescents' health-related quality of life	1) Parents perceived their adolescents' physical functioning as more impaired than adolescents themselves  2) Burden of diabetes care inversely associated with parent PedsQL
Brouwer et al (2012)	Adolescents and type 2 diabetes mellitus: A qualitative analysis of the experience of social support	Qualitative Interviews	N = 8 Mean age = 13.5 Ethnicity = African American, Mexican American	Experience and perception of social support	Four themes: 1) Support for nondiabetes-specific behaviours 2) Support for diabetes-specific behaviours 3) Feelings of belonging 4) Disclosure

<b>Authors</b>	<b>Title of Article</b>	<b>Study Design/Tools</b>	<b>Participants</b>	<b>Outcomes</b>	<b>Findings</b>
Wilfley et al (2011)	Binge eating, mood, and quality of life in youth with T2D	Cross-sectional Questionnaires	N = 678 Mean age = 14 Ethnicity = Hispanic, Black, White, American Indian	Prevalence of binge eating and its association with adiposity and psychosocial functioning	Youth with clinical and subclinical levels of binge eating had higher rates of obesity, eating disorder, depressive symptoms and impaired quality of life
Auslander et al (2010)	Psychosocial resources and barriers to self-management in African American adolescents with T2D	Qualitative Interviews	N = 10 Mean age = 16.4 Ethnicity = African American	Psychosocial resources and barriers to self-management	Resources: 1) Mom as primary support person 2) Gaining self-efficacy and coping over time 3) Recognition of seriousness of diabetes 4) Supportive peers  Barriers: 1) Comorbidity 2) Dietary and other regimen challenge 3) Fitting in with peers 4) Financial concerns
Mulvaney et al (2008)	Self-management in T2D – The adolescent perspective	Qualitative Focus Groups	N = 24 Mean age = 15.2 Ethnicity = African American	Barriers and facilitators of self-management	Four themes: 1) Psychosocial development 2) Role of others with diabetes 3) Environmental influences 4) Problem solving/coping skills

<b>Authors</b>	<b>Title of Article</b>	<b>Study Design/Tools</b>	<b>Participants</b>	<b>Outcomes</b>	<b>Findings</b>
Allan et al (2008)	Quality of life in First Nation youth with T2D	Cross-sectional  Questionnaires	N = 28 Mean age = 15 Ethnicity = First Nations	QOL	1) Youth reported higher scores in all domains compared to parents – youth were more optimistic about health than parents  2) Youth and parents reported lowest QOL scores in school functioning, worry and communication

## Appendix Two

**Diabetes**

**Support**

## Appendix Three

### Interview Guide

#### *Introductory Questions*

- 1) Just so I can get to know you a bit better, what are some things you like to do for fun?
- 2) Who do you do those things with?

#### *Focused Questions*

- 1) How important is health to you?
- 2) How much control do you think you have over your health? How about your diabetes?
- 3) How do you manage your diabetes?
- 4) For you, what are things that help you manage your diabetes?
- 5) Are there things that would help you manage your diabetes that you don't have or would like to have? What are they? Why are those things important?
- 6) How about support from others? Is that important to you?
- 7) Whose support is important? Parents? Friends? Others?
- 8) If you were to describe what support meant for you, what would you say?
- 9) How important is support for your diabetes?
- 10) Do you feel supported? Why or why not?
- 11) If so, how did you achieve the support? If not, what are ways you think that could help you achieve this support?
- 12) What role do your parents and doctors play in your diabetes management?
- 13) What are your thoughts on programs aimed to help you manage your diabetes?
- 14) What would those programs look like for you? Why are these important?
- 15) What does diabetes mean to you?
- 16) What words or images come to mind when I say diabetes?

17) If there were one thing you could tell people about diabetes that they don't already know, what would that be?

*Concluding Questions*

- 1) If you could share three things about diabetes to another person, what would they be?
- 2) What do these things mean to you?

## Appendix Four



UNIVERSITY  
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Performance Research Institute

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### PARENTAL CONSENT FORM

**Research Project Title:** “A place where I belong”: Exploring the Meaning of Social Support Among Manitoban Youth Living with Type 2 Diabetes through a Grounded Theory Analysis

**Principal Investigator and contact information:** Elizabeth Huynh – Graduate Student,  
Elizabeth.Huynh@umanitoba.ca, [REDACTED]

**Research Supervisor (if applicable) and contact information:** Dr. Fiona Moola,  
Fiona.Moola@umanitoba.ca, 204-474-9742

This consent form, a copy of which will be left with you for your records and reference, is only part of the process of informed consent. It should give you the basic idea of what the research is about and what your child’s participation will involve. If you would like more detail about something mentioned here, or information not included here, you should feel free to ask. Please take the time to read this carefully and to understand any accompanying information.

#### **Purpose of the study:**

The purpose of this Masters thesis will be to conduct a qualitative investigation to explore what strategies, ideas and methods are most sensitive to youth living with type 2 diabetes (T2D) social and psychological needs. The research objectives are:

- 1) What is the meaning of social support to youth living with T2D?
- 2) How do youth with T2D want to be socially supported?
- 3) What roles do friends, parents, and clinicians play in the management of T2D?
- 4) What is the perceived feasibility and acceptability of a behavioural intervention aimed to improve social support?

*Your child is being asked to participate in this study. As your child is under the age of 18, your consent is required for his/her participation. Upon your consent, your child will also have the option to participate. Your consent must be obtained in order for your child to participate. If your child agrees to participate, his/her assent will be asked.*

#### **Procedures:**

Participants’ aged 12-17 diagnosed with T2D living in Winnipeg, Manitoba will be recruited to participate. Minimal risk will be posed on participants. Participants (your child) will be asked to engage in a one-time 45-90 minute interview. Participants will have the option to

meet in one of three ways: 1) face-to-face (in person), 2) face-to-face (Skype) or 3) over the phone. In person interviews will be conducted at the Children' Hospital Research Institute of Manitoba or at the Active Living Centre – University of Manitoba. Interviews will be audiotaped and transcribed verbatim by the Graduate Student (Elizabeth Huynh).

**Risks and Benefits:**

There are minimal risks from participating in this study. However, in the event that participants experience psychological or emotional distress during the participation of the study, all efforts will be made to manage them. This involves skipping over troublesome questions, letting the participants know about counselling services if required, or stopping the study if necessary. There may be no direct benefit to you or your child from being in this study. When the interviews are finished, we hope to understand what makes it easier or harder for youth and families to manage their diabetes with behaviour change, and what we can do in clinic to make it easier.

**Anonymity and Confidentiality:**

The interview will be tape recorded; however, your child's name will not be recorded on the tape. Your child will be given a code and that will be recorded on the tape and used when the interviews are written up. If your child wants the tape recorder turned off at any time, or prefers not to have it present, he/she can tell the study staff. As participants will identify themselves by name directly during the interviews, confidentiality will be maintained by naming each audio file with a code. Precautions such as password protecting transcript documents and folders will be undertaken when storing the data. Once data has been uploaded from the tape recorders, the file will be destroyed immediately from the tape recorder. All printed transcripts will have all names removed prior to printing and will only be labeled with a corresponding code. All materials collected will be saved for five years (November 2020), after which will be destroyed using a shredder and electronically. It will not be possible to trace the identity of the participants from the codes at anytime during the study.

**Remuneration:**

Participants will not receive any form of credit or remuneration for participating in this study.

**Withdrawal:**

Your child's decision to take part in this study is completely up to him/her. He/she may refuse to participate or he/she may quit at any time. Your child's decision to participate or withdraw from the study will not affect the health care he/she receives. In the event that your child would like to withdraw from the study, he/she may tell you or the researcher.

**Debriefing:**

Participants will be debriefed about the study findings, and provided with feedback immediately after the study. After data collection and analysis are complete, a report detailing the main study findings will be shared with you and your child. A 1-3 page summary of results will be provided to you and your child within six months after data collection (approximately between April 2016 – July 2016). You and your child will be given the choice of how they would like to receive these results (eg. mail, email).

**Dissemination:**

The dissemination of study findings will be in the form on a Masters thesis. This will be made available to users of the University of Manitoba libraries. Participants will be made aware of the dissemination plans and will not jeopardize their right to confidentiality unless they have explicitly waived this right. Academic publications may result from this Masters thesis. In this event, anonymous data from the study may be used for this purpose. This will also not compromise the confidentiality of participants.

Your signature on this form indicates that you have understood to your satisfaction the information regarding your child’s participation in the research project and agree to your child’s participation as a subject. In no way does this waive you or your child’s legal rights nor release the researchers, sponsors, or involved institutions from their legal and professional responsibilities. Your child is free to withdraw from the study at any time, and/or refrain from answering any questions your child prefer to omit, without prejudice or consequence. Your child’s continued participation should be as informed as your child’s initial consent, so you or your child should feel free to ask for clarification or new information throughout your child’s participation.

The University of Manitoba may look at your child’s research records to see that the research is being done in a safe and proper way.

This research has been approved by the Education/Nursing Research Ethics Board at the University of Manitoba. If you or your child has any concerns or complaints about this project you may contact any of the above-named persons or the Human Ethics Coordinator (HEC) at 474-7122. A copy of this consent form has been given to you to keep for your records and reference.

**Consent from the parent or legal guardian for participants who are under the age of eighteen years:**

By signing this consent form, I agree that I have read, understood, and agree to the above information.

**Print name of parent:** \_\_\_\_\_

**Participant's Parent's Signature:** \_\_\_\_\_ **Date:** \_\_\_\_\_

I confirm that I have explained the study to the participant's parent to the extent compatible with the participant's parents understanding, and that the parent has agreed to allow their child be in the study.

**Researcher and/or Delegate's Signature:** \_\_\_\_\_ **Date:** \_\_\_\_\_

If you have any questions or concerns regarding the participation of this study, please contact the Graduate Student, Elizabeth Huynh with the information provided on the first page. You may also contact Dr. Fiona Moola at [Fiona.moola@umanitoba.ca](mailto:Fiona.moola@umanitoba.ca)

If you have any concerns or complaints about this project, you may contact the Human Ethics Coordinator at 204-474-7122 or by email at [humanethics@umanitoba.ca](mailto:humanethics@umanitoba.ca)

## Appendix Five

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Performance Research Institute

### CHILD ASSENT FORM

**Research Project Title:** “A place where I belong”: Exploring the Meaning of Social Support Among Manitoban Youth Living with Type 2 Diabetes through a Grounded Theory Analysis

**Principal Investigator and contact information:** Elizabeth Huynh – Graduate Student,  
Elizabeth.Huynh@umanitoba.ca, [REDACTED]

**Research Supervisor (if applicable) and contact information:** Dr. Fiona Moola,  
Fiona.Moola@umanitoba.ca, 204-474-9742

This assent form, a copy of which will be left with you for your records and reference, is only part of the process of informed consent. It should give you the basic idea of what the research is about and what your participation will involve. If you would like more detail about something mentioned here, or information not included here, you should feel free to ask. Please take the time to read this carefully and to understand any accompanying information.

#### Why are you here?

We would like to tell you about a study about youth with type 2 diabetes (T2D). We want to see if you would like to be in this study. This forms tells you about the study. If there is anything you do not understand, please ask your parent, your guardian or the study staff.

#### Why are we doing this study?

We want to learn more about how youth with type 2 diabetes want to be supported. The main purpose of this study is to answer the following questions:

- 1) What is the meaning of social support to youth living with T2D?
- 2) How do youth with T2D want to be socially supported?
- 3) What roles do friends, parents, and clinicians play in the management of T2D?
- 4) What is the perceived feasibility and acceptability of a behavioural intervention aimed to improve social support?

#### What you are being asked to do.

If you want to be in the study, these things will happen:

- 1) The study will consist of a one-time interview. The interview will last 45-90 minutes. You will be asked to come to the Children’s Research Institute of Manitoba or the Active Living

Centre – University of Manitoba. If you are not able to meet at one of those places, you can also participate over Skype or over the phone.

2) The interviews will be audiotaped and transcribed word for word by the Graduate Student (Elizabeth Huynh). You are allowed to ask for the tape recorder to be turned off at any time during the interview. You can also skip over troublesome questions, or stop the interview if necessary.

3) Your decision to take part in this study is completely up to you. You may refuse to participate or you may quit at any time. Your decision to participate or withdraw from the study will not affect the health care you receive. To withdraw from the study, please tell your parent/guardian and/or the researcher.

There is minimal risk or direct benefit by participating in the study. Your name may be recorded on the tape. However, your name will be given a code and used on all electronic and printed materials. All materials collected will be saved for five years (November 2020) after which they will be destroyed using a shredder and electronically. All your information and interview responses will be kept private. The researcher will not share your responses with anyone who is not on the research team.

### **What happens after the study?**

When the interviews are finished, we hope to understand what makes it easier or harder for youth and families to manage their diabetes with behaviour change, and what we can do in clinic to make it easier. We will provide you with a summary of the results within six months after data collection (approximately between March 2016 – July 2016). You have the option of receiving the results by mail or email.

The study findings will be available in the form of a Masters thesis. This is will be available to users of the University of Manitoba libraries. This will not jeopardize your right to confidentiality. All data will remain anonymous.

Your signature on this form indicates that you have understood to your satisfaction the information regarding participation in the research project and agree to participate as a subject. In no way does this waive your legal rights nor release the researchers, sponsors, or involved institutions from their legal and professional responsibilities. You are free to withdraw from the study at any time, and /or refrain from answering any questions you prefer to omit, without prejudice or consequence. Your continued participation should be as informed as your initial consent, so you should feel free to ask for clarification or new information throughout your participation.

The University of Manitoba may look at your research records to see that the research is being done in a safe and proper way.

This research has been approved by the Education/Nursing Research Ethics Board at the University of Manitoba. If you have any concerns or complaints about this project you may contact any of the above-named persons or the Human Ethics Coordinator (HEC) at 474-7122. A copy of this assent form has been given to you to keep for your records and reference.

**Assent for participants who are under the age of eighteen years:**

I want to take part in this study. By signing this consent form, I agree that I have read, understood, and agree to the above information. I know I can change my mind at any time.

**Print name of child:** \_\_\_\_\_ **Age:** \_\_\_\_\_

**Child's Signature:** \_\_\_\_\_ **Date:** \_\_\_\_\_

I confirm that I have explained the study to the participant to the extent compatible with the participants understanding, and that the participant has agreed to be in the study.

**Researcher and/or Delegate's Signature:** \_\_\_\_\_ **Date:** \_\_\_\_\_

If you have any questions or concerns regarding the participation of this study, please contact the Graduate Student, Elizabeth Huynh with the information provided on the first page. You may also contact Dr. Fiona Moola at [Fiona.moola@umanitoba.ca](mailto:Fiona.moola@umanitoba.ca)

If you have any concerns or complaints about this project, you may contact the Human Ethics Coordinator at 204-474-7122 or by email at [humanethics@umanitoba.ca](mailto:humanethics@umanitoba.ca)

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