

MANAGEMENT EXPERIENCES OF ADOLESCENTS LIVING WITH TYPE 2  
DIABETES.

by

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## ABSTRACT

### MANAGEMENT EXPERIENCES OF ADOLESCENTS LIVING WITH TYPE 2 DIABETES

Although type 2 diabetes (T<sub>2</sub>D) is typically a condition that affects adults, it has recently been diagnosed in children and adolescents as well. Management is multifaceted, continual and involves diet therapy, exercise, blood glucose monitoring, taking medications and glycaemic control. While there is extensive literature on compliance issues in adults with T<sub>2</sub>D, no studies have examined how adolescents diagnosed with the condition manage their care. This study addressed this lack of information by using a qualitative research approach to explore the individual experiences of adolescents living with T<sub>2</sub>D.

Participants included adolescents with T<sub>2</sub>D (n = 8; Body Mass Index [BMI] = 22-34 kg/m<sup>2</sup>) attending the B.C. Children's Hospital diabetes clinic and health professionals (n = 2) working at the clinic. Each adolescent was interviewed for 60-90 minutes during which they described activities surrounding: dietary habits, activity, medication use and blood glucose testing. Likewise, two health professionals were interviewed for 60-90 minutes to obtain their perspectives on the challenges faced in this field. Interviews were tape-recorded and transcribed verbatim. Trustworthiness (rigor) was established using strategies such as member checks, peer debriefing, triangulation, and audits. Data was managed using the ATLAS.ti software and then analyzed using qualitative methods. Ethical approval was received from B.C. Children's Hospital and the University of British Columbia. Informed consent was obtained from the health professionals, all participants and their parents.

The adolescents with T<sub>2</sub>D encountered emotional, cognitive, and behavioural responses to the diabetes itself and each component of diabetes management. Self-care practices fluctuated depending on internal forces (i.e. personality, personal models and interpersonal relationships) and external forces (i.e. family, peers, community and health professionals). While health professionals acknowledged that emotions and cognitions play a role in management, treatment strategies focused on task completion, specifically blood glucose testing and the continuous reinforcement of information. Re-directing strategies that take into consideration how personality, understandings, and social context of an adolescent's life influence the implementation of diabetes management components are significant to their overall care.

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## **CHAPTER 1: INTRODUCTION**

### **1.1. Statement of the Problem**

Diabetes mellitus is a disease that affects 1.1 million Canadians and is associated with several complications including nephropathy, retinopathy and heart disease (Millar & Young, 2003). The Diabetes Complications and Critical Control Trial (DCCT) and the U.K. Prospective Diabetes Study (UKPDS) demonstrated the beneficial impact of improved glycaemic control on the long-term complications of type 1 diabetes (T<sub>1</sub>D) and T<sub>2</sub>D (DCCT, 1993; UKPDS, 1998). Treatment of T<sub>2</sub>D is complex and requires the integration of the following behaviours: altering eating habits, becoming physically active, taking medications and blood glucose monitoring.

The ability for adults with T<sub>2</sub>D to incorporate these new behaviours into their life has been a challenge. Therefore, eating behaviours, physical activity, medication use and self-monitoring of blood glucose (SMBG) remain the focus of diabetes management research. Obstacles adults with T<sub>2</sub>D experience when implementing diabetes management components have been explored, providing some knowledge base with regards to behaviour modification (Boehm, Schlenk, Funnel, Powers, Ronis, 1997; Maclean & Oram 1988; Plotnikoff, Brez, Hotz, 2000; Shultz, Sprague, Branen, Lambeth, 2001; Tillotson, 1996).

Although T<sub>2</sub>D typically affects adults, it has recently been diagnosed in children and adolescents. Research with adults with T<sub>2</sub>D may not be applicable to adolescents with T<sub>2</sub>D for many reasons. Adolescence is a period of transition from dependence to independence. Adolescents begin to adopt a multitude of new social and emotional roles and have to cope with altered bodily functions (Kyngäs, Hentinen, Barlow, 1998). The

addition of diabetes further complicates the situation. Diabetes influences many aspects of daily life and requires a life-long process of self-care (Kyngäs et al. 1998). Reports indicate that most adolescents do not perform self-care behaviours and also do not relate unhealthy behaviours with negative outcomes (Pender & Farchaus, 2001).

Taking in to consideration the physical, emotional and mental changes that occur during adolescence, along with diabetes management tasks, educational and counselling needs of adolescents' living with T<sub>2</sub>D may be different from adults living with T<sub>2</sub>D. Prior to establishing effective strategies for adolescents with T<sub>2</sub>D, their experiences with the diabetes management components and the context in which they respond must be understood.

## **1.2. Purpose and Rationale**

Health professionals play a role in assisting individuals with diabetes to achieve optimal health. Understanding the management experiences of adolescents with T<sub>2</sub>D is an important step to the development of diabetes education and counselling strategies that will enhance their health outcomes. Currently, there is no literature highlighting the management experiences for adolescents with T<sub>2</sub>D. The findings of this study will provide a foundation from which health professionals can draw upon.

## **1.3. Objectives**

The specific objectives of the study were to:

1. Describe the experiences of adolescents with T<sub>2</sub>D in implementing diabetes management components.
2. Understand the factors that shape diabetes management for adolescents with T<sub>2</sub>D.

## CHAPTER 2: LITERATURE REVIEW

Until recently, children with diabetes were diagnosed with T<sub>1</sub>D. This is the autoimmune form of diabetes that includes permanent deficiency in insulin secretion (American Diabetes Association [ADA], 2000). Conversely, T<sub>2</sub>D, characterized by insulin resistance and a relative decrease in insulin secretion, has been considered a disease of adults. Historically, only 1-2% of children diagnosed with diabetes were considered to have T<sub>2</sub>D or other rare forms of diabetes (ADA, 2000). However, recent reports indicate that 8-45% of children and adolescents with newly diagnosed diabetes have the non-immune mediated diabetes (ADA, 2000). Management involves diet therapy, medications, physical activity and blood glucose monitoring. While there is extensive literature on compliance issues in adults with T<sub>2</sub>D and adolescents with T<sub>1</sub>D, data are lacking on how adolescents diagnosed with T<sub>2</sub>D manage their care.

This review of the literature will begin with an introduction to the classification of T<sub>2</sub>D in children and adolescents. A summary of the epidemiological data illustrating the increased incidence and prevalence of T<sub>2</sub>D in children and adolescents will be presented. Current literature on treatment and management strategies will be reviewed, including research on adults living with T<sub>2</sub>D, and adolescents with T<sub>1</sub>D. Lastly, a review of the trajectory theory and its application to chronic illness experiences will be described.

## **2.1. Definition and Classification of Diabetes Mellitus**

Diabetes mellitus is a metabolic disorder characterized by the presence of hyperglycaemia due to defective insulin secretion, insulin action, or both (Meltzer et al., 1998). Chronic hyperglycaemia of diabetes mellitus is associated with significant risk for long-term damage, dysfunction and multi-organ failure (Meltzer et al., 1998).

T<sub>1</sub>D includes diabetes that is primarily a result of pancreatic beta-cell destruction, either due to an auto-immune process or unknown aetiology (Meltzer et al., 1998). Typically, children with T<sub>1</sub>D (immune-mediated) are not overweight and experience weight loss, polyuria and polydipsia. In addition, they usually experience a short duration of symptoms such as ketosis and approximately 30-40% experience ketoacidosis (ADA, 2000). After metabolic stabilization, they may have an initial period of diminished insulin requirement after which they require insulin in order to survive and are at continual risk for ketoacidosis. Furthermore, of the children diagnosed with T<sub>1</sub>D, it is estimated that approximately 5% may have a first or second-degree relative with the same disease (ADA, 2000).

T<sub>2</sub>D may range from predominant insulin resistance with relative insulin deficiency, to a secretory defect with insulin resistance (Meltzer et al., 1998). Children and adolescents diagnosed with T<sub>2</sub>D (non-immune-mediated) are usually overweight or obese and experience the following: glycosuria without ketonuria, absent or mild polyuria, polydipsia and little or no weight loss (ADA, 2000). The mean age of diagnosis of T<sub>2</sub>D in North American children is between 12 and 14 years (Dabelea, Pettitt, Jones, Arslanian, 1999). The majority of children diagnosed are female and are predominantly from ethnic minorities (ADA, 2000). At the time of diagnosis, insulin C peptide levels

are normal or are often raised. In addition, they do not have auto antibodies to  $\beta$ -cell proteins (ADA, 2000). A healthy person without diabetes will have a hemoglobin A<sub>1c</sub> (HbA<sub>1c</sub>) value of 4% to 6 % (Lincoln, 2001). Researchers have found children and adolescents diagnosed with T<sub>2</sub>D to have a HbA<sub>1c</sub> value of 10% to 13% when initially diagnosed (ADA, 2000; Fagot-Campagna et al., 2000). In addition, some children and adolescents with T<sub>2</sub>D may have hypertension, hypertriglyceridemia, albuminuria, sleep apnoea, and depression.

Gestational diabetes mellitus refers to glucose intolerance that manifests during pregnancy (Meltzer et al., 1998). Lastly, a range of "other specific types" exist and include specific genetically defined forms of diabetes, diabetes associated with other diseases, or diabetes induced by medications (Meltzer et al., 1998).

## **2.2. An Epidemiological Review**

While T<sub>2</sub>D has traditionally been considered a disease that occurs in adulthood, recently this disease has manifested in children and adolescents (Fagot-Campagna et al., 2000; Rosenbloom, Young, Joe, Winter, 1999). Cases of paediatric T<sub>2</sub>D have been reported in children and adolescents from the United States, Canada, Japan, Hong Kong, Australia, New Zealand, Libya and Bangladesh (Dabelea et al., 1999; Dean, 1998; Dean, Moffat, 1988; Dean, Mundy, Moffat, 1992; Fagot-Campagna et al., 2000; Harris, Perkins, Whalen-Brough, 1996; Kadiki, Reddy, Marzouk, 1996; Kitagawa, Owada, Urakami, Tajima, 1994; Kitagawa, Owada, Urakami, Yamauchi, 1998; Neufeld, 1998; Pinhas-Hamiel et al., 1996; Young, Dean, Flett, Wood-Steiman, 2000; Young, McIntyre, Dooley, Rodriguez, 1985). The first documented case of T<sub>2</sub>D in youth originated from

the study on the Pima Indian population. The Pima Indians represent a northern extension of a group of American Indians, who live in an area of southern Arizona and north-western Mexico (Rosenbloom et al., 1999). The 1991-1992 Navajo Health and Nutrition Survey revealed that the prevalence of diabetes (type unknown) among 142 American Indians aged 12 to 19 years was 14.1 per 1000. In the years 1992 to 1996, the prevalence was 22.3 per 1000 for 10 to 14 year olds and 50.9 per 1000 for 15 to 19 year olds (Dabelea et al., 1998). In Arizona, 125 of 5274 Pima Indians initially aged 0 to 19 years developed T<sub>2</sub>D over a 30-year period (1967-1996) (Dabelea et al., 1998).

Approximately 13 years after the first appearance of diabetes in the Pima Indians, reports of T<sub>2</sub>D (both in adults and adolescents) were described among the First Nations in Manitoba, Canada. Approximately 10-20% of these new cases of diabetes in youth were classified as T<sub>2</sub>D. The age range for this group was 5 to 14 years, with a prevalence of 0.8:1000 (Dean et al., 1992; Dean et al., 1998). A similar finding occurred in 15 year olds, in northwest Ontario. However, this group had a higher age specific prevalence of 2.5:1000 of T<sub>2</sub>D (Harris et al., 1996). In addition, the gender ratio was 4 to 6 female patients for every male patient diagnosed (Harris et al., 1996).

In 1996-1997 a cross-sectional screening survey was conducted in a remote aboriginal community (Ojibwa-Cree) in northern Manitoba. The purpose of the study was to determine the prevalence of obesity and investigate its association with fasting glucose and insulin among children and adolescents in a population at high risk for T<sub>2</sub>D (Dean et al., 1998). Among 717 school youths the prevalence was 11.1:1000 for 4 to 19 year olds. In females the prevalence was 36:1000 for 10 to 19 year olds (Dean et al., 1998). These

trends coincide with the rising prevalence of overweight and physical inactivity worldwide (Rosenbloom et al., 1999).

The appearance of T<sub>2</sub>D in youth is not limited to North America. For instance, the incidence of T<sub>2</sub>D has been found among Japanese school children (Kitagawa et al., 1994; Kitagawa et al., 1998). Between 1976 and 1995, the incidence of T<sub>2</sub>D increased from 0.2 to 7.3: 100,000 (Kitagawa et al., 1994; Kitagawa et al., 1998). Research has also revealed a higher incidence of T<sub>2</sub>D amongst Japanese youth in junior high school. The incidence ratio index was 13.9:100,000 whereas the incidence ratio for children in grammar school was 2.0:100,000 (Kitagawa et al., 1994; Kitagawa et al., 1998).

A comprehensive literature search revealed no published statistics on the incidence or prevalence of T<sub>2</sub>D in adolescents in British Columbia, Canada. Over the past five years, 15 adolescents have been diagnosed with T<sub>2</sub>D at B.C. Children's Hospital. Due to the specific needs of this age group and the demanding lifestyle interventions required for diabetes management, a clinic was formed to provide services and address their needs.

### **2.3. Treatment and Management of Diabetes Mellitus**

The results of the DCCT (1993) and the UKPDS (1998) revealed that maintaining tight glycaemic control with any of the several available therapies has the potential to significantly reduce the risk of long-term microvascular complications of T<sub>1</sub>D or T<sub>2</sub>D. Subsequently, health professionals aim to guide their clients to incorporate the diabetes management components in order to maintain tight glycaemic control. For individuals with T<sub>1</sub>D, the approach focuses on balancing food intake, specifically carbohydrates, and insulin dosages to control blood glucose (Meltzer et al., 1998).

Management of T<sub>2</sub>D can involve many different approaches that may change throughout time. Initially the approach is non-pharmacologic management consisting of diet modification and weight loss when appropriate (Meltzer et al., 1998). However, if desired blood glucose levels are not achieved within 2-4 months, oral anti-diabetic agents are added (Meltzer et al., 1998). Sulfonylureas and biguanides are commonly used but studies are needed to evaluate the long-term safety and efficacy in youths. The side effects of other agents limit their use in youth. Some youths may need insulin when multiple oral anti-diabetic agents are ineffective (Rosenbloom et al., 1999).

Of all the components in diabetes management, individuals living with diabetes indicate that diet and physical activity are the most difficult part in managing their diabetes (Meltzer, 1998). Traditionally, education programs focused on adherence and compliance to recommendations. However, the goal of diabetes control through such a perspective has been elusive (DCCT, 1993). Many personal, interpersonal and societal factors contribute to and shape one's behaviours. By understanding how they are shaped health professionals may better improve the quality of care provided.

### **2.3.1. Management Experiences of Adults with Type 2 Diabetes**

Researchers examining the management practices of adults with T<sub>2</sub>D have explored use of medications, blood glucose monitoring and the alteration of eating habits and exercise levels. There have been conflicting studies with regards to medication use by adults with T<sub>2</sub>D (Donnan, MacDonlad, Morris, 2002; Grant, Devita, Singer, Meigs, 2003). Adults with T<sub>2</sub>D prescribed a single medication were more likely to take their medication than adults prescribed multiple medications (Donnan et al., 2002; Grant et al.,



2003). The common reasons for non-adherence with medications include side effects and a lack of confidence in immediate or future benefits (Donnan et al., 2002; Grant et al., 2003).

With regards to making Self-Monitoring Blood Glucose (SMBG) useful, it is recommended that an individual with T<sub>2</sub>D be educated on the role of blood glucose testing and the interpretation of the results (Meltzer et al., 1998). A cross-sectional study in the United States found that most individuals reported SMBG levels. However, of these 67% of them reported practicing SMBG less frequently than recommended by the ADA (Karter, Ferrara, Darbinian, Ackerson, Selby, 2000). The cost of glucometer strips deterred adults with T<sub>2</sub>D to SMBG (Karter et al., 2000). In a population-based study with adults with T<sub>2</sub>D, SMBG was correlated with better metabolic control for insulin treated individuals (Franciosi et al., 2001). In contrast, for individuals not taking insulin, a higher frequency of SMBG was related to higher HbA<sub>1c</sub> levels. This suggests that individuals with poor metabolic control have a great tendency to self-monitor.

Although there are some studies on adherence to medications and SMBG by adults with T<sub>2</sub>D, most research has focused on exploring the obstacles that individuals faced with the alteration of eating habits and activity levels. Researchers have focused on trying to answer the question, “Why don’t patients do what they should?” (Goodall & Halford, 1991). In attempting to answer this question, researchers have focused on obtaining a better understanding of the factors that influence the management practices of adults with T<sub>2</sub>D. Psychological models such as the Health Belief Model (HBM) emphasize that attitudes and beliefs are major determinates of health behaviour and constructs from these models have been associated with diabetes management. In a

sample of over 2000 adults with T<sub>2</sub>D, beliefs about treatment effectiveness followed by beliefs about seriousness appear to be strongly associated with self-management behaviours (Glasgow, Strycker, Hampson, Ruggiero, 1997). The adults with T<sub>2</sub>D who believed that dietary changes, medication adherence and physical activity were going to make a difference in their blood glucose levels were more likely to follow through with the diabetes management recommendations.

While these factors do play a role, social support, psychological stress and anxiety, competitive demands and setting variables have also been shown to be predictors of dietary adherence (Hunt, Arar, Larme, 1998a; Hunt, Valenzuela, Pugh, 1998b; Travis, 1997). For example, in the study conducted by Travis (1997) over 50% of adults with T<sub>2</sub>D found holidays to impact greatly on their diet plan. In addition, participants made many comments concerning their emotions and how these influenced eating patterns such as: “I eat more when I am anxious or nervous” and “I eat when I am upset” (Travis, 1997). Maclean and Oram (1988) interviewed 18 people with T<sub>2</sub>D and found dietary restriction to be a common “irritation” among participants in the study. Each individual missed eating certain foods (Maclean & Oram, 1998). One of the most common and frequent comments from participants was: “If I didn’t have diabetes I would eat” ... and completed the sentence with the food or foods they missed the most (Maclean & Oram 1998). Food habits are closely linked to family histories and cultural norms. If the diabetic diet conflicts with values that are learned over a long period of time, then making dietary changes is difficult (Maclean & Oram, 1998).

To further expand on health behaviours, Kleinman (1980) proposed that personal illness models are predictive of adherence with dietary intake and physical activity in

adults with T<sub>2</sub>D. By examining patients' illness model, educators and clients can work towards developing goals that may improve adherence and satisfaction (Kleinman, 1980). Hampson et al., (1990) investigated the personal models held by 46 females living with T<sub>2</sub>D. The study discovered that the personal model strengthened the prediction of diet change and exercise level (Hampson et al., 1990).

Likewise, Garro (1995) has used the concept of explanatory models and has conducted research on how individuals diagnosed with diabetes living in three Canadian Anishinaabe communities (Ojibway) accounted for their diabetes and the increase in cases of diabetes within the community (Garro, 1996; Garro, 1995). The initial research discovered the theme that diabetes is a "new" illness that was not present "in the old days". In addition, many explanations for the diabetes were based on individual actions.

For instance:

*"Maybe it is from what someone eats, they do it to themselves... it is their own fault because of what they eat." (pg44)*

*"I always tell my kids, you know, sometimes they drink so much cold stuff. I tell them, don't drink so much of that maybe you'll get diabetes too, if you drink too much. I was never one to drink soft drinks. The only thing I used to like was pastries." (pg.44)*

However, the study has also shown that there are times when participants had doubts about their explanatory model. For instance, one participant who commented on how her diabetes came from eating too many sweets during the holidays later stated:

*"But some people I know eat lots of candy, like chocolates, and they don't get sugar diabetes". (pg.44)*

Lastly, many remarks focused around the change of their diet patterns. Many of the participants' comments suggested that diabetes emerged when it did because of the

“unhealthy” foods they were eating presently and the lack of “healthy” wild foods that they used to have access to and ate in the past (Garro, 1995).

Likewise, a study conducted by Schoenberg, Amey and Coward, (1998) looked at the relationship between perspectives on aetiology and adherence to dietary approaches for adults with T<sub>2</sub>D. The study demonstrated a significant relationship between the causal explanation for the onset of diabetes and an individual’s adherence to a prescribed dietary regime. Participants who attributed the onset of their diabetes to their past eating habits, being overweight, or having a medical “malfunction” were more likely to adhere to the dietary recommendations. Those who attributed the onset of their diabetes to family history, being female, and/or getting older were less likely to follow through with recommendations (Schoenberg et al., 1998).

Other researchers have examined adherence to dietary recommendations from practitioners’ perspectives. For example, Williamson, Hunt, Pope and Tolman (2000) interviewed dietitians to identify factors that contribute to the barriers to dietary adherence in individuals with T<sub>2</sub>D. The factors that dietitians identified included lack of time, lack of symptoms, lack of education, poor self-esteem/lack of empowerment and misinformation from family, peers and others with diabetes.

Other research on T<sub>2</sub>D in adults examined how motivational interviewing techniques may be related to behaviour modification. For example, Brown and colleagues (1998) interviewed dietitians to identify motivational strategies used most often when counselling individuals with T<sub>2</sub>D. In addition, the study identified barriers perceived by dietitians as being the most significant obstructions to dietary adherence experienced. The study revealed that obstructions to adherence were related to appreciation of

diet/disease relationship, lifestyle parameters and lack of valid information (Brown et al., 1998).

Smith, Heckeymeyer, Kratt and Mason (1997) conducted a study to determine whether the addition of motivational interviewing techniques to a behavioural obesity intervention program improved dietary adherence and blood glucose control. The motivational interviewing sessions looked at ambivalence about behaviour change, elicited personal goals and self-motivational statements from each individual, formulated personal goals in behavioural terms and problem-solved barriers to change. The study found that the addition of the above motivational strategies significantly enhanced adherence to the program recommendations and blood glucose control (Smith et al., 1997).

Overall, research in management experiences of adults with T<sub>2</sub>D has identified barriers to implementing components of diabetes management. While adults with T<sub>2</sub>D are more likely to adhere to medications (i.e. single medication) and monitor blood glucose levels, changing dietary habits and physical activity have been most commonly cited as the most difficult aspect to implement. The factors that shape behaviours include emotions, stress, personal illness models, holidays, competitive demands and work environments.

### **2.3.2. Management Experiences of Children and Adolescents with Type 1 Diabetes**

Studies of management experiences in children and adolescents have been limited to those with T<sub>1</sub>D. For children and adolescents, there is some evidence that self-management activities vary with age and that adherence worsens with transition into adolescence (Hanna & Guthrie, 1999; Weisberg-Benchell et al., 1995). Researchers have found that treatment adherence and metabolic control deteriorate during the adolescent years (Anderson, Auslander, Jung, 1990; Anderson et al., 1997; Hanson, Henggeler, Burghen, 1987; Johnson et al., 1992; La Greca, 1990; Schafer, McCaul, Glasgow, 1986; Weisberg-Benchell et al., 1995). Studies have shown that in adolescents with T<sub>1</sub>D, mismanagement has been higher for diet than for insulin administration and glucose monitoring (Hanna & Guthrie, 1999). Weisberg-Benchell and colleagues (1995) reported that approximately 56% of adolescents indicated that they missed meals and snacks on a regular basis. Likewise, Peveler et al., (1993), found that 24% of adolescents missed breakfast, 54% missed morning snacks and 69% missed afternoon snacks. In order to understand the reasoning behind lack of dietary adherence by children and adolescents with T<sub>1</sub>D, researchers have focused on understanding their attitudes and beliefs surrounding their diabetes and behaviours with regards to their disease.

As with other chronic illnesses, an individual's family and friends play a pivotal role in disease management. Adolescents with T<sub>1</sub>D and their families have to manage multiple insulin injections, frequent blood glucose monitoring, dietary plans and regular exercise. This sometimes requires that family members take an active role in the management process. In addition, less parental involvement in diabetes care has been associated with poorer diabetes outcomes (Anderson et al., 1990; Ingersoll et al., 1986).

However, increased parental involvement in the management of T<sub>1</sub>D with children and adolescents has been shown to create family conflict (Miller-Johnson et al., 1994).

Subsequently researchers have focused on developing an understanding of the adolescents' perceptions of family support.

Miglani and colleagues (2000) evaluated the degree of comfort adolescents with T<sub>1</sub>D living in India, had with discussing their illness with other individuals in their life. The study revealed that the majority of children (87.5%) in their study were willing to talk with their family either completely or partially only when they believed they were attempting to achieve blood glucose control (Miglani et al., 2000). While this study was conducted in India, this study reveals that children and adolescents with T<sub>1</sub>D may avoid communication with family members in order to avoid disappointing family members and/or feeling ashamed.

In contrast, a similar study conducted in the United States by Jacobson et al., (1986) found different results. The study revealed that the majority of children (55%) did not talk to their parents about their diabetes, 57% generally did not share concerns about their diabetes with friends and 40% reported that they did not tell their teachers that they had diabetes (Jacobson et al., 1986). This contrast may be due to the differences between the socio-economic and cultural environments of these two studies (Jacobson et al., 1986; Miglani et al., 2000).

Other studies on T<sub>1</sub>D have focused on examining whether or not poor adherence to diabetes care is related to variables such as self-esteem, self-efficacy, depression and bingeing behaviour in adolescents with diabetes. Littlefield et al., (1992) recruited 193 adolescents with T<sub>1</sub>D and assessed the frequency of bingeing, self-efficacy using the

Rosenberg Self-Esteem Scale, depression using the Children's Depression Inventory and measured degree of adherence using a seven item measure of adherence scale. The study concluded that treatment adherence in adolescents with T<sub>1</sub>D was associated with behavioural psychological variables, as adolescents who reported lower adherence tended to report lower self-esteem and self-efficacy, more depressive symptoms and bingeing and had higher HbA<sub>1c</sub> than those with high adherence scores (Littlefield et al., 1992).

Remley and Cook-Newell (1999) explored situations that impacted dietary adherence for adolescents with T<sub>1</sub>D. Adolescents living with T<sub>1</sub>D reported that adhering to their diet was difficult during holidays (i.e. birthdays, Christmas); during social situations (i.e. eating meals with a group of friends); times when they were upset (i.e. they had a fight with one of their friends or family members); and lastly, when they were told that they had to give up a lot of foods that they really liked in order to follow their meal plan (Remley et al., 1999). On the other hand, very few reported that the amount of time it took to prepare their meals according to their meal plan affected whether or not they followed their plan. However, this response may be justified if the parents were taking an active role in assisting or preparing their meals.

Similarly, Schlundt et al., (1994), interviewed 20 adolescents to understand problem situations that create obstacles to dietary adherence. The study identified 10 categories of obstacles to dietary adherence: being tempted to stop trying; negative emotional eating; facing forbidden foods; peer interpersonal conflict; competing priorities; eating at school; social events and holidays; food cravings; snacking when home, alone, or bored; and social pressure (Schlundt et al., 1994).



Taking into consideration that adolescence is a developmental stage for a young individual, there may be many factors contributing to adherence and compliance to their nutritional care plan. There are some similarities and differences with regards to the factors that shape diabetes management for adults with T<sub>2</sub>D and adolescents with T<sub>1</sub>D. Both adults with T<sub>2</sub>D and adolescents with T<sub>1</sub>D have identified emotions, competing priorities (i.e. either school for adolescents with T<sub>1</sub>D and work for adults with T<sub>2</sub>D), social events and pressure from being around friends as obstacles to implementing dietary recommendations. Health professionals also play an important role in the management experiences of adolescents with T<sub>1</sub>D and adults with T<sub>2</sub>D. Health professionals have focused on the long-term severity and consequences of diabetes. In contrast, individuals are more concerned with how components of diabetes management are going to impact their daily lives.

A pilot study was conducted with four adolescents with T<sub>2</sub>D at B.C. Children's Hospital (Cairns, 2002). Barriers to dietary changes identified included emotions, peers and social events. In addition, the pilot study revealed that adolescents with T<sub>2</sub>D were scared of insulin (Cairns, 2002). Lastly, the study also found that these particular adolescents with T<sub>2</sub>D were more likely to incorporate activity into their life if they were somewhat active prior to their diagnosis. While the study mainly focused on dietary management issues, it reinforced the complexity of incorporating health-promoting behaviours into one's life and highlighted the role that close friends and family members play in the process of incorporating dietary changes (Cairns, 2002). With further details on the management experiences of adolescents living with T<sub>2</sub>D, health professionals will be able to develop interventions to improve their care.

## **2.4. The Illness Experience: A Phased Process**

Numerous researchers have described that living with a chronic illness is a phased process in which the person follows a trajectory or illness course (Paterson, 2001). This framework is not new and was developed from extensive research on dying and refined with other chronic illnesses such as myocardial infarctions, stroke rehabilitation and cancer (Corbin & Strauss, 1992). The trajectory model also applies to adolescents living with T<sub>2</sub>D. Adolescents with T<sub>2</sub>D will experience an illness course and each phase of the course will shape their management of diabetes. Understanding the phases may assist with addressing concerns and developing strategies to help them incorporate components of diabetes management into their life.

Generally, trajectory models consist of the pre-trajectory phase, which occurs before the onset of symptoms. The trajectory proceeds when signs and symptoms appear and pose a threat to the individual (the crisis phase). As the symptoms intensify, individuals seek intervention to prevent the worsening of symptoms (acute phase). Depending on the illness and intervention it is assumed that individuals reach a stable phase where their health improves (Burton, 2000). Interventions may be unsuccessful and the individual may have a relapse or deteriorate to a downward phase (Burton, 2000).

This type of framework is not rigid and the concept of a trajectory has been applied to other areas of the illness experience. The Illness Constellation Model (ICM) provides another view of the illness experience and addresses how the experience affects the individual with the illness and his or her significant others (Morse & Johnson, 1991). In the ICM, the illness experience is defined as a four stage process (Morse & Johnson, 1991). Stage I is the stage of uncertainty, and in this stage the individual detects or

suspects signs of illness and attempts to make sense of these symptoms by determining their severity and meaning. Those closest to the individual may observe that the individual is unwell. In other cases, the individual may need to inform others of their symptoms. Stage II, the stage of disruption, occurs when the individual makes a decision that the symptoms are serious and decides to seek help. This is comparable to the crisis phase in the trajectory model (Morse & Johnson, 1991). During this stage, individuals may distance themselves from others and/or become totally dependent on health care professionals and family members. Significant others become aware and intervene (Morse & Johnson, 1991). During stage III, the person is striving to make sense of the illness. The individual examines reasons that may explain the illness and may require support from family and friends for commitment to take care of themselves (Morse & Johnson, 1991). In stage IV, termed the stage of regaining wellness, the individual regains balance and takes charge, learning to live within the limits set by the illness (Morse & Johnson, 1991).

## **2.5. Summary of Literature Review**

Currently there are an increasing number of children and adolescents being diagnosed with T<sub>2</sub>D. While the aetiology of T<sub>1</sub>D and T<sub>2</sub>D differ, treatment may involve the following components: dietary modifications, exercise, taking medications, SMBG and glycaemic control. There has been limited research on the issues influencing the implementation of the diabetes management components for adolescents with T<sub>2</sub>D. In order to gain an understanding of the management issues faced with implementing

diabetes management components, I reviewed the literature surrounding management experiences of adults with T<sub>2</sub>D and adolescents with T<sub>1</sub>D.

A number of barriers were identified to implementing the diabetes management components for both adolescents with T<sub>1</sub>D and adults with T<sub>2</sub>D. In both adults with T<sub>2</sub>D and adolescents with T<sub>1</sub>D the social context influenced diabetes management. For the adult, one's work environment and personal family demands influences their eating habits. Many studies have examined how family members influence diabetes management behaviours of adolescent with T<sub>1</sub>D. Studies have found that family members involvement with diabetes management task may create conflict and adolescents may not adhere to diabetes management components. However, at the same time, lack of parental involvement has also been shown to result in lower metabolic control. In contrast, there is limited research on the influence of the family on disease management for adults with T<sub>2</sub>D.

For adolescents with T<sub>1</sub>D literature has focused on understanding the role that peers and friends play in their management experiences. Adolescents with T<sub>1</sub>D will not follow through with diabetes management tasks such as blood glucose testing and may alter eating habits when they are with friends.

While management experiences of adolescents with T<sub>1</sub>D and adults with T<sub>2</sub>D are shaped by similar factors, the nature of the disease and the way in which these factors influence the implementation of the diabetes management components may differ. Thus examining the responses of adolescents with T<sub>2</sub>D and the factors that shape the implementation of the diabetes management components will provide insights for their care.

## **CHAPTER 3: DESIGN AND METHODS**

The purpose of this study was to examine the diabetes management experiences of adolescents with T<sub>2</sub>D attending B.C. Children's Hospital, Vancouver, Canada. This study was exploratory, as there is a lack of information on how adolescents diagnosed with T<sub>2</sub>D experience this condition and its management. The goal was to describe their responses to implementing components of diabetes management. This chapter begins with a brief rationale for a qualitative approach and a discussion of the surrounding assumptions. Next, procedures used in the study are presented consisting of sample selection, recruitment, data collection and data analysis. Finally, criteria used to ensure rigor and ethical considerations are explained.

### **3.1. Qualitative Methods**

The design and methods used in this study were qualitative. The term qualitative implies an "emphasis on processes and meanings that are not rigorously examined, or measured (if measured at all), in terms of quantity, amount, intensity or frequency" (Denzin & Lincoln, 1991, p. 13). Although quantitative data are useful in explaining certain health issues, especially the cause and effect of a disease, they do not fully describe aspects surrounding human values, culture and relationships. Quantitative data do not reveal an individual's interpretations, understandings, and interactions with others (Rice & Ezzy, 1999).

A qualitative approach provides the opportunity to examine phenomenon beyond linear relationships and a look into its complexity (Thorne, 2001). In this study, the ethnographic technique consisting of semi-structured interviews was used to understand

and capture the particular social situations, events, roles, and group of interactions that shape how adolescents with T<sub>2</sub>D manage their condition. In addition, as individuals experience events differently, this qualitative approach allows for description of more than one truth that will assist us with understanding the situation. People live and understand their experiences differently, as they are exposed to different cultures, lifestyles, and environments.

Diabetes management involves making lifestyle changes and incorporating new behaviours. To help health professionals counsel adolescents with T<sub>2</sub>D, it is important for them to understand the context in which adolescents manage their diabetes as well as the impact of the different components of diabetes management. It is also necessary to have the adolescents define and explain aspects of counselling that they believe to be effective and ineffective. The utilization of a qualitative approach in this study provided a means by which the context of the situation could be explored.

### **3.1.1. Theoretical Perspective**

My beliefs surrounding how and why people behave as they do have been shaped through my education, personal relationships, understandings of society and work experience in nutrition counselling for adults with T<sub>2</sub>D. It is through these experiences that my ideas surrounding diabetes management experiences fit with a constructivist perspective. Early on in my practice, as a dietitian I used common diabetes management tools and based my teaching on the basic tools and requirements for diabetes education. Through experience, I realized that individuals make sense of their experiences in their own way and learn to manage their diabetes in their own way. I came to learn that the ideal model of what I think I should teach a client is different from what the client needs.

Subsequently, my perspective is that there is never any “right or wrong” way of managing one’s condition, rather many different views exist. Diabetes management practices are shaped by numerous conditions (i.e. personal, psychological, societal, family, and environmental) and they may change according to situations and time. By using an interpretive approach in research we will gain an understanding of how these conditions relate to the management practices of adolescents with T<sub>2</sub>D. Better understanding of these processes will help professionals working with these clients to provide care that is more sensitive to client needs.

### **3.2. Research Procedures**

The following sections describe the research procedures including sample selection, participant recruitment, ethical considerations, data collection, and data analysis. Although these procedures are discussed separately, they occurred concurrently.

#### **3.2.1. Sample Selection**

Participants between 12–17 years of age, diagnosed with T<sub>2</sub>D and attending B.C. Children’s Hospital T<sub>2</sub>D clinic, were included in this study. Participants met the criteria for T<sub>2</sub>D based on the 1998 clinical practice guidelines for the management of diabetes in Canada (Meltzer et al., 1999). Individuals living with other diseases that could influence dietary adherence and/or their ability to discuss their needs and experiences living with T<sub>2</sub>D were excluded.

As the number of potential participants was small (n= 15), the aim was to try to recruit all the adolescents that were attending the T<sub>2</sub>D clinic. Of the 15 potential participants, 4 were interviewed by a graduate student conducting a similar study and thus were not

eligible for participation in my study. Initially, adolescents that were diagnosed with diabetes for at least one year were interviewed. It was assumed that individuals that were diagnosed for at least one year would have had numerous experiences to share. After I interviewed three participants who had been diagnosed for at least one year, I sought participants who had been diagnosed for less than one year, to see if their experiences with management varied.

In qualitative research, the main goal is to ensure that the data collected are rich and credible therefore, the actual number of participants in the study is flexible (Creswell, 1994). Usually sample size is determined on “theoretical saturation” which occurs when further data collection reveals no new information. However, in this study I was only able to recruit 8 participants who met the inclusion criteria and were willing to be interviewed. Given the small sample size, theoretical saturation for all concepts was not likely reached. The limitations to the size of the sample will be addressed in the discussion chapter.

The health professionals providing counselling to the adolescents with T<sub>2</sub>D at the clinic were also interviewed. The idea to interview the health professionals emerged from three sources 1) discussions with the thesis committee, 2) data from initial interviews suggesting that health professionals play a role in certain management experiences, and 3) illness related studies suggesting that health care professionals have different meanings and understandings of experiences from the clients who are actually experiencing the illness (Hunt et al., 1998b; Pasquier-Fediaevsky & Tubiana-Rufi, 1999).

Initially, the intent was to interview all health professionals (i.e. physician, nurse and dietitian) to obtain their perspectives on the experiences of adolescents living with T<sub>2</sub>D.



In the end, the primary physician was not interviewed because this person was a member of the thesis committee and was aware of emergent findings. Subsequently, the health professionals who conducted the diabetes education in the T<sub>2</sub>D clinic (i.e. nurse and dietitian) were interviewed.

### **3.2.2. Participant Recruitment**

I was introduced to the Registered Dietitian at the T<sub>2</sub>D clinic through a colleague (i.e. Registered Dietitian) who was conducting a pilot study on “The Counselling Needs of Adolescents with T<sub>2</sub>D” at the clinic. I met with the Registered Dietitian at B.C. Children’s Hospital and discussed my interest in exploring the area of T<sub>2</sub>D in adolescents further through a qualitative study. Access was obtained after I discussed my interest with the physician heading the T<sub>2</sub>D clinic and received ethical approval from B.C. Children’s Hospital and The University of British Columbia. While gaining access to the clinic proceeded smoothly, the recruitment process was a challenge. Recruitment took place between August 2001 and July 2002. Initially, posters were displayed at the diabetes clinic at B.C. Children’s Hospital. As very few individuals responded to this approach, the physician heading the T<sub>2</sub>D clinic was asked to refer individuals. This second source of recruitment proved to be successful as all individuals that I spoke to were willing and interested in sharing their stories. Although individuals agreed to participate in the study, arranging and following through with the interviews proved to be an additional challenge. There were times when interviews did not take place and were rescheduled, as competing events in the participants’ lives took precedence. For instance, interviews were cancelled as participants had school events to attend. This process

reinforced the complexity of interviewing adolescents and reminded me of the importance of understanding the group I was studying.

To further assist with the recruitment process, I attended the clinic every month (2 clinic visits per month) and introduced myself to potential participants and family members. I explained the purpose of the study to potential participants and determined their interest in participating. I found this useful as it allowed the participants to get to know me and feel comfortable with taking part in the study.

Once written consent was received from the parent and the adolescent, an interview time and location was arranged. Both the health professionals and seven out of eight adolescents were interviewed at the B.C. Children's diabetes clinic. One interview was conducted at the participant's home, as he was not available after clinic visits.

### **3.2.3. Ethical Considerations**

The study protocol was approved by the University of British Columbia Behavioural Sciences Screening Committee for Research and Other Studies Involving Human Subjects (Appendix A) as well as the Ethics Committee for Human Studies at B.C. Women's and Children's Hospital. In addition, parents signed consent forms along with the adolescents and the health professionals interviewed in the clinic (Appendix B & Appendix C). Adolescent participants were given a gift certificate at a value of \$25 for Cineplex Odeon Theatres for their participation.

To protect the confidentiality of the participants, transcripts and computer files were coded numerically and a pseudonym was used in place of the participants' name.

However, as the population of adolescents with T<sub>2</sub>D at B.C. Children's Hospital is small, it might have been possible for participants to be identified. Participants may be recognized by a number of identifiers such as age, ethnicity, BMI, and year of diagnosis (Morse, 1998). Morse (1998) recommends that participant "identifiers" are grouped to prevent individuals from being identified based on their demographic characteristics. Subsequently, the participants are described in terms of ranges for each characteristic in the Result chapter. To further protect the identity of the participant, Morse (1998) suggests that researchers not attribute each quotation to a particular participant as a means of reducing the risk that a health professional reading the thesis could identify an individual from the quotation used. Therefore, in presenting the results of the study, the participants' pseudonyms and other identifying information are not attached to quotations (Morse, 1998).

#### **3.2.4. Data Collection**

As the primary researcher, I conducted all the interviews. Initially, demographic information was collected using the medical charts at the diabetes clinic. However, once the first two interviews were conducted and discussed in peer debriefings, I found that having prior participant information led to my assumptions about the participants with regards to their management of diabetes (e.g. "compliant" versus "non-compliant"). In addition, it also reduced the opportunity to get to know the participant during the interview as I assumed that I "knew" certain aspects of this individual's life from the medical chart. Therefore, I decided not to review the participants' medical chart before

an interview. Once the interviews were completed, data such as HbA<sub>1C</sub> and body mass index were recorded from the participants' medical charts.

The purpose of qualitative interviewing is to build meaningful theories out of the interviews (Spradley, 1979). The preliminary interviews were conducted to obtain themes and ideas from the subjects concerning their perspectives of living with T<sub>2</sub>D. A semi-structured interview guide (Appendix D) was developed to ensure that each adolescent participant was asked the same basic set of questions surrounding the following areas: a) eating and dietary habits, b) exercise and lifestyle changes, c) medication(s) used, d) blood glucose testing and e) glycaemic control.

The semi-structured interview guide contained a list of topic areas and general open-ended questions to be addressed during the interview. The guide contained "grand tour questions" such as: "Could you tell me what a typical day is like for you?" and led into specific questions such as: "Tell me about when you were diagnosed with T<sub>2</sub>D?" Participants were encouraged to tell their stories in their own words to provide "rich" accounts. Non-leading probes were used to limit bias and to allow participants to respond and illustrate concepts that emerged (Creswell, 1994). At the onset of the interview process, probes regarding influences of family, school and friends allowed participants to explore how others affect their diabetes management process. As the interviews were completed and analyzed, probes changed and included questions about the impact of school trips, social occasions and parents' reactions to management. In addition to the topics and probes identified by the interview guide, the interview proceeded into new and unexpected directions if participants raised issues pertinent to the research question (Creswell, 1994).

The interviews were transcribed verbatim and interview transcripts reviewed. Notes were made after each interview to allow for alterations and further development of the interview questions. This allowed for emerging themes and hypothesized relationships to be tested with other participants. In addition, literature surrounding the perspectives of health practitioners was reviewed and used to develop the semi-structured interview guide for the health professionals. These interviews covered the following issues: their philosophy, their perspective on challenges faced by adolescents with regards to diabetes management principles, and strategies used by the clinicians (Appendix E). In addition to the interviews, descriptive and reflective field notes were written after each interview to record observations such as body language, demeanour and facial expressions.

### **3.2.5. Data Analysis**

Initially, data analysis was facilitated using the qualitative computer software program ATLAS.ti (Muhr, 1997). I started by dividing the transcripts into three general open codes, “pre-diagnosis”, “initial diagnosis” and “post diagnosis”. These open codes came from the structure of the interview. Participants were asked to express their experiences before their diagnosis and after their diagnosis.

These broad categories assisted with the management of the data as it allowed me to focus on specific experiences and to compare and contrast these experiences. The broad categories were examined by conducting line-by-line coding for the first five transcripts. The initial codes used came from words and/or phrases that participants used (“in vivo codes”) (Appendix F). At the initial stages of open coding, many codes were utilized to ensure that all areas were examined. For instance, within the “pre-diagnosis” chunk

some of the initial codes included: “not feeling anything”, “feeling sick”, “having a tummy ache”, “feeling weird” and “going to the bathroom a lot”. The initial code list consisted of more than 100 codes. These codes then were condensed and sorted into categories that contained many of the initial codes. A category is an abstract concept that describes the phenomenon occurring (Strauss & Corbin, 1990). For instance, the above initial “in vivo” codes were grouped into a category termed “ways of finding out”. To examine the phenomenon of “ways of finding out”, causal conditions were identified that led to the participants finding out they had diabetes and how they responded to these conditions. Also, this process led me to develop the concept of “reading the body” and characterizing the pre-diagnosis time as a time of uncertainty.

Categories and sub-categories were named according to the topic area of the question. For instance, some of the sub-categories related to the diabetes management principles (i.e. diet and eating habits, activity/exercise habits, medications (anti-diabetic), and blood glucose testing and glycaemic control). As this process occurred, questions were refined and further concepts were documented that required exploration with future participants. As coding was refined and categories developed, the last three transcripts were not coded line-by-line. Rather, the broad categories and sub- categories were defined in these transcripts and each category was explored by using the refined coding list.

Throughout the process of data analysis, strategies such as memoing and diagramming were used to conceptualize how categories related to each other. Memos were used to describe categories, themes and personal reflections (Appendix G). Reflective memos captured my accounts of the analytical process. Questions that were reflective in these memos included the following: “What is happening here?”, “What is their story?” and

“What is missing from what they are telling me?” Diagrams helped to organize, and compress information by schematically linking categories (Strauss & Corbin, 1990) (Appendix H).

As more interviews were completed and transcribed, comparisons between the transcripts were made to compare the concepts and categories between the participants. To aid in the constant comparison between participants, matrices were developed and summarized. A matrix “aids in defining conditions that take place and the consequences related to the phenomenon” (Strauss & Corbin, 1990). For example, to explore their “eating and food habits” a matrix was created and the adolescents’ experiences surrounding food and eating were categorized according to the three phases: “pre-diagnosis”, “diagnosis” and “post-diagnosis”. Summaries were written on specific categories and themes that emerged.

The process required a continuous flow between analyzing data and collecting data. The process of writing memos, summaries, documenting ideas linked the concepts and themes evolved. The process continued and a comprehensive summary was written.

### **3.3. Strategies for Maximizing Research Quality**

The value of research is partially dependent on the ability of the researcher to demonstrate the credibility of his or her findings (LeCompte & Goetz, 1984). Rigor in qualitative studies is achieved by assuring “fit”, and transparency in contrast to quantitative research that strives for replicability and generalizability (Guba & Lincoln, 1985). These basic assumptions coincided with the qualitative strategies of

trustworthiness, authenticity, reflexivity and my theoretical sensitivity. These strategies will be discussed in the following sections.

### **3.3.1. Trustworthiness**

The goal of trustworthiness of the findings is to ensure that the participants' experiences are accurately identified and described (Creswell, 1994). Strategies used to build confidence in the data included member checks, peer debriefings, audit trails and triangulation. These methods will be discussed below.

#### **3.3.1.1. Member Checks**

Member checks involved asking the participants for clarification of interpretations during the interviews and reactions to the findings. By sharing interpretations with participants verbally during clinic sessions and getting their feedback, concepts, categories and themes were refined. This provided the opportunity for the participants to review my interpretation.

#### **3.3.1.2. Peer Debriefings**

Peer debriefings were conducted throughout the course of data collection and analysis with a group of graduate students conducting their own qualitative research and one of my thesis supervisors. Through group discussions, I reflected on emerging issues and identified concepts that required further exploration (O' Connor, 2001). For instance, initial peer debriefings assisted me with identifying the role that the family plays within the management process. This led me to develop questions for participants that examined their relationships with family members and understandings behind the role of family members in the diabetes management process.



### **3.3.1.3. Audits**

An audit involved going through the process of data analysis with one of my thesis supervisors who had experience in qualitative research. Random transcripts were provided to this supervisor. Sections of the data were audited by going through the data trail and the concepts, categories and themes were reviewed to illustrate the interpretations made.

### **3.3.1.4. Triangulation**

Triangulation refers to the use of multiple data analysis or data collection techniques to provide more than one “line of sight” on the phenomenon of interest (Manning, 1997). In my study, interviewing the health professionals and the adolescents provided two perspectives on the management experiences of adolescents with T<sub>2</sub>D.

### **3.3.2. Authenticity**

Authenticity refers to the strategies researchers use to ensure that the findings of the study are genuine. As the researcher, I am interpreting the experiences they share and attempting to identify some patterns or concepts emerge. Assumptions regarding the interviews, participants, and questions were made. Documenting assumptions clearly in the form of field notes allows another researcher to understand and make their own judgment on the nature of the data obtained. One of the most important considerations in interview research with young people is to develop a natural context for the interview (Eder & Fingerson, 2003). The natural context is important as it allows for individuals to feel comfortable and thereby would be willing to tell their stories without feeling intimidated. Because of my assumption in this area, I took certain measures to ensure that

participants felt comfortable with me and that they would feel I was not there to judge them but to hear their experiences. Firstly, I dressed very casually, usually wearing jeans and bringing along my knapsack. Secondly, as suggested by Briggs (1986), I avoided using clinical jargon. For instance, I used the term “blood sugar control” in place of “glycaemic control”. I also described myself to the participants and included questions in the interview that focused on getting to know the interests of the adolescents and establish a rapport. Lastly, I spent time with the adolescents and their family members at one or two clinic visits before interviewing them. This time was spent in the waiting room where I talked to the participants about the study and had time to develop a rapport with the adolescents and their families.

### **3.3.3. Reflexivity**

Depending on the research aims and the theoretical perspective of the researcher reflexivity can be used as a tool to reflect critically on the process of data collection, analysis and writing. As the researcher, I was the “human instrument” in the field collecting data (Guba & Lincoln, 1985). To actively reflect on my role and perspectives as a researcher, I wrote field notes to document my impressions of the adolescents on the days that I visited the clinic (i.e. how I perceived the adolescents’ relationships with their parents and the health professionals). In addition, I documented my response to comments that were made by health professionals during the clinic sessions as I found them to lead to certain biases. For instance, there was a common perception that one individual would not be a good candidate to be interviewed based on their “non-compliance”. I started to question my decisions with regards to the participants I was

asking to be in the study and how my uncertainties would prevent me from further exploring the situation for a variety of individuals. Writing and reviewing these assumptions that I created helped me bring these ideas to the conscious surface. Subsequently, it provided me with the opportunity to ask individuals to be interviewed whom I initially may have potentially excluded.

Lastly, the relationship that developed between the researcher and the participants is a factor that may affect the process of data collection (Sandelowski, 1993). At the beginning of the interviews, I introduced myself to the participant and described my educational background. Since I had previous experience in diabetes education I documented my thoughts and my experiences with the participants. I brought these to the forefront and wrote about my beliefs and understandings of what my thoughts were before the study. As the study progressed, I also made note of some of the ideas that I had with regards to certain areas of research that I had trouble understanding using reflective memos.

#### **3.3.4. Theoretical Sensitivity**

Theoretical sensitivity refers to a “personal quality of the researcher” (Strauss & Corbin, 1990). The dependability of the findings also depends on the skills of the researcher. These characteristics include methodological skills, ability to give meaning to data and the ability to recognize and understand what is relevant (Strauss & Corbin, 1990). Several personal experiences played a role in enhancing my theoretical sensitivity. Firstly, there was no literature surrounding management experiences of adolescents with T<sub>2</sub>D. Exploring the experiences of adolescents with T<sub>1</sub>D and adults

living with T<sub>2</sub>D expanded my understanding of the factors that may influence management. Secondly, I am a registered dietitian and have counselled adults living with T<sub>2</sub>D for one year. This experience provided me with an understanding of the events and actions that take place in adjusting behaviours and in the process of managing diabetes. However, most of these experiences were with adults living with T<sub>2</sub>D and hence I made note of these. Lastly, documenting the research process and reasons for asking certain questions and reflecting on questions I asked also assisted in bringing my ideas to the forefront.

### **3.4. Transferability of Findings**

Transferability refers to whether findings from a particular qualitative study can be transferred to another similar context or situation and still maintains the meanings and interpretations from the study (Lenniger, 1994). Qualitative research “seeks depth over breadth and attempts to learn subtle nuances of life experiences as opposed to aggregate evidence” (Ambert, Adler, Adler, Detzner, 1995). Hence, the goal of qualitative research is not to produce generalizations, but rather to gain in-depth understanding and knowledge of a phenomenon (Leninger, 1994; Whittemore, Chase, Mandle, 2001).

Guba and Lincoln (1985) stated that transferability is dependent upon the data set and provision of a description of the sample, environmental conditions, and/or the circumstances. To ensure transferability, qualitative researchers suggest that the researcher indicate how the data were collected, the conditions under which they were collected, and from whom they were collected. Each of these areas has been described in depth in this chapter, and further description of the participants is provided in the next chapter.

## CHAPTER 4: RESULTS

The findings that relate to experiences of adolescents managing T<sub>2</sub>D are presented in this chapter. The study participants will be described. Following this, two areas of the findings are presented. The first area is descriptive, specifically looking at the responses towards the components of diabetes management, which included dietary changes, getting active, medications (i.e. oral anti-diabetic agents), blood glucose monitoring and glycaemic control. The second area provides an overview of how the participants' responses were shaped by personal factors, their outlook, family members, friends, social events, community members and the health professionals.

### 4.1 Participants

Four male and four female adolescents between 13-17 years of age were interviewed. Participants had been diagnosed at least 4 months prior to their interview (range 5 months to 1 year). The youngest age of diagnosis was 11 years and the oldest age of diagnosis was 16 years and 10 months. The participants were from a variety of ethnic backgrounds that included: Indian-Pakistani, Asian, Aboriginal-Canadian, and Caucasian. The participants' BMI's ranged between 22-34 kg/m<sup>2</sup>. At the time of the interviews, participants' HbA<sub>1C</sub> levels ranged from 5.3% to 6.9% (normal range 4% to 6%). All participants were taking an oral anti-diabetic agent (i.e. metformin) and two participants were also taking insulin. All participants had a family history of T<sub>2</sub>D with at least one first-degree family member diagnosed with T<sub>2</sub>D. Their family household varied, including at least two siblings, one or both parents, one grandparent and young niece living together.

B.C. Children's Hospital currently has the only T<sub>2</sub>D clinic in British Columbia. Prior to the development of this clinic, all adolescents with T<sub>2</sub>D were counselled during T<sub>1</sub>D clinic days. The clinic is composed of the following health professionals: the physician, dietitian and nurse. When required, the clinic seeks consultation from psychiatry and social work. The two health professionals interviewed were the nurse and registered dietitian. The nurse practitioner had worked at B.C. Children's Hospital for the past 17 years. She had over 10 years of experience counselling children and adolescents with T<sub>1</sub>D and was recently involved in counselling adolescents with T<sub>2</sub>D. The clinical dietitian was a certified diabetes educator who also had over 20 years of experience at B.C. Children's Hospital. Over those 20 years, she worked with children and adolescents with T<sub>1</sub>D and was involved with dietary counselling of adolescents with T<sub>2</sub>D.

#### **4.2. Participants' Experiences of Implementing Components of Diabetes Management**

Managing diabetes requires performing many self-care behaviours such as altering eating behaviours, taking part in physical activity, taking medication(s) (i.e. insulin or anti-diabetic agents), testing blood glucose levels and achieving glycaemic control. The participants' narratives illustrated a process of incorporating these behaviours, which varied through the course of managing their diabetes. The following sections describe the participants' experiences with each of the aforementioned components of diabetes management.

#### 4.2.1. Altering Eating Behaviours

Prior to being diagnosed with T<sub>2</sub>D, participants had well-established eating habits and food choice patterns. Initially, in a group educational session, participants were provided with general dietary recommendations regarding diabetes management. According to the health professionals, some of the basic dietary principles discussed included the following: trying to eat three meals a day, distribution of carbohydrates, protein and fat, consuming complex carbohydrates, consuming at least five fruits and vegetables a day and decreasing refined sugars. It was during the individual counselling sessions that nutritional recommendations were tailored.

All participants stated that their initial thought of making changes to their food choices and eating behaviours was unpleasant. They thought they would have to say “good bye to their favourite foods” and would “not be allowed to eat sugar.”

*“Because I thought, you know, I can’t eat my favourite foods.”*

*“Yeah there were like food wise like umm. Like umm ... the first time I got diabetes ... I couldn't eat ice cream, chicken McNuggets at McDonalds and stuff like that ... It was kind of depressing.”*

*“Just the no junk food thing because it sort of sucks.”*

Most of the participants knew that sugar is found in a variety of foods such as fruits and vegetables, breads/pasta/cereals and candies. However, one participant thought that sugar was only found as raw sugar, so learning that sugar was found in different foods was received with frustration.

*“So when I thought that I can’t have sugar. It’s like I just can’t eat sugar... like when you first think of it like you can’t eat spoon of sugar that’s, that’s what I thought like you can’t eat. Not like ... I thought you can still eat pop, candy, juice, chips stuff like that but ... I came here and they started explaining that I can’t have stuff with sugar in it.”*

Participants described altering eating behaviours as being the “most difficult thing to do.”

The older participants commented that changing eating behaviours was going “to take time.”

*“It takes a lot of time because of your habits ... I used to eat a lot, and big meals, the habits stuck with me.”*

Three participants initially thought that it was impossible to change eating habits. As one participant stated: *“How is anyone humanly able to do that ... it’s not possible.”*

Subsequently these three participants described, “doing nothing” to alter their eating behaviours after their diagnosis.

*“When I was first like this I didn’t listen to nobody.”*

Four participants described how the dietary changes took place slowly and how they were still in the process of making changes when they were interviewed.

*“Well it has been really hard and I am still in the process of trying to find out what kind of foods that I should be eating and maybe like getting recipes of stuff of what I should ... we should be cooking at home.”*

They acknowledged that the support of their family and health professionals influenced them to change their eating habits.

*“I think if it wasn’t for my parents and the clinic I probably wouldn’t do anything to change my eating habits.”*

Overall, altering eating behaviours was received with unpleasant thoughts and emotions. The process of altering eating habits varied through the participants’ experience, but a variety of strategies they used to help them make dietary changes were apparent. These included eating less “unhealthy” food and eating more “healthy” food,



eating less overall and eating regularly. The following sections present each strategy and the challenges participants faced.

#### **4.2.1.1. Eating Less “Unhealthy” Food and Eating More “Healthy” Food**

Participants described eating less “unhealthy” food and eating more “healthy” food. Participants’ defined “healthier” foods as foods that were low in fat, high in fibre and low in refined sugars. “Healthy” food items included fruits and vegetables, meat, cereal grains, milk and water. “Unhealthy” food items included candies, chocolate bars, juice, pop, chips, burgers, French fries and pizza. Strategies used to accomplish this shift towards eating more “healthy” foods included: eating more “healthy” foods, trying to avoid the “unhealthy” foods (i.e. cut them out) and eating less of the “unhealthy” foods.

Most examples of attempts to increase intake of “healthy” foods involved trying to eat more fruits and vegetables. Participants who enjoyed eating fruits and vegetables prior to the diagnosis found that this behaviour change was “easy”.

*“Trying to eat more fruits and vegetables ... It hasn’t been as hard because I like my fruits and vegetables a lot.”*

As well, all participants cited that they tried to eat “healthier” by drinking water with meals and not drinking soft drink beverages. Eating less frequently at restaurants and fast food places was also mentioned. One participant described that this was something her family was attempting to do but they were not always successful in accomplishing.

*“Something we are working on is trying to not go to fast food places as much ... it’s so hard because it’s so convenient and my mom doesn’t always have time to start a meal or whatever so we’ve been trying to work on that.”*

Making this shift from “unhealthy” foods to “healthy” foods was a challenge for most participants. They often felt frustrated and angry that they “can’t have certain foods” or that they “are not allowed” to eat certain foods. Some participants responded by avoiding foods and described themselves as being “off certain foods”, “cutting them out” or “getting off certain foods”. For some participants it was easier to make a commitment to omit certain foods from their life than trying to include them in moderate amounts.

*“I just try to avoid sugars ... I try not to eat ... anything with sugar like junk food and stuff. I’m avoiding that. Like no more candy foods.”*

*“I am eating a lot more vegetables and fruits and following the food pyramid and just cutting out the junk food and sugary stuff.”*

The two health professionals also had similar ideas surrounding the types of foods that participants would try to “avoid” or “get off”.

*“One of the things that they wouldn’t drink regular pop or they wouldn’t be drinking as much juice in the same way and all the drinks that are high in sugar.”*

Another way participants attempted to avoid “unhealthy” foods was by staying away from certain restaurant locations (e.g. Boston Pizza, McDonalds and Burger King) and convenience stores. Three participants talked about avoiding these places by not walking by them when they would go to school and come home. While they attempted this they also noted it was a challenge as fast food items and convenience food items were “good tasting” foods.

Through experience, participants found that trying to “cut out foods” was not working. They were more successful with strategies aimed at reducing the intake of these “unhealthy” foods. These strategies included: eating “unhealthy” foods less often,

reducing portion sizes, balancing “unhealthy” foods and “healthy” foods, substituting and “thinking twice” before eating “unhealthy” foods.

Some of the participants described eating “unhealthy” foods less often by commenting that they had these foods “once and a while” and “not often”. For instance, most participants cited that they ate chips and chocolate bars occasionally and referred to them as “treats” they gave themselves after they had a hard day at school or after they achieved a goal. On the other hand some participants incorporated the “unhealthy foods” into their diet and reduced the portion size.

While some tried eating less and decreasing portion sizes other described balancing “healthy” and “unhealthy” foods. This allowed participants to incorporate some of their favourite foods. For instance, one participant said he included ice cream into his life and decided to eat it “only once and a while” or “not often”. Another participant said that when she ate “junk foods” she balanced it out throughout the rest of the week by eating more carefully and avoiding “junk foods”.

*“Well it is like going to the movies I have to have popcorn. But I sort of know that I don’t go to the movie every week or anything. But, this week I am not going to have chocolate or chips or so I try to do it that way.”*

For another participant this process involved balancing her desire to eat the food item and how she was feeling at the moment. Participants said that if they were concerned about the effect the food item had on their blood glucose, they would avoid it. However, if they were hungry and craved the food item at the time they felt that it was to their benefit to eat the food item.

Another strategy involved substituting “foods to avoid” with alternative foods. Every participant cited that soft drink beverages were the “easiest” foods to substitute.

Although the change was gradual, participants did not miss shifting from regular pop to diet pop. One participant described sourcing out “sugar free” ice cream in place of regular ice cream. One participant made an effort to carry “healthier” foods such as an apple or a banana with them in order to prevent them from eating “unhealthier” foods.

In order to eat “healthier”, participants described changing the types of restaurants they ate at. Fast food restaurants such as McDonald’s and pizza places were considered to have “unhealthy” food options.

*“Normally we would go out for hamburgers ... but now basically we’ll go out and having something more healthy.”*

Other participants mentioned that they would “think twice” before eating certain foods in order to avoid the foods. Participants described that this was one way that they would be able to control the amount of certain foods they would eat, especially if it was a food item that they were supposed to avoid. Usually participants would think twice about eating a certain food item if it were believed to be an unhealthy food item such as a chocolate bar, chips, burgers and fries.

*“I love chocolate and stuff but I know that I shouldn’t have it so I think twice of eating it and then I try not to. But if I do eat it, I don’t eat it as much.”*

One participant recalled that she had to think twice about foods she ate when she was feeling sad or depressed in order to follow through with the principles. For some participants, ‘thinking twice’ involved looking at the amount of sugar in the food item.

#### 4.2.1.2. Eating Less Overall

In addition, to the above strategies for changing the quality of their diets, some participants also described decreasing the quantity of food they ate. Participants commented that they “did not eat as much as they did before”, by “having less of it”, by reducing the portion size of the foods (specifically unhealthy foods) and by having fewer portions. By reducing the portion size of certain foods, participants were able to include food items that they thought they were not allowed to eat or they perceived as being “unhealthy”.

*“Are there any other experiences with dietary changes that you would like to talk about?”*

*“Well definitely umm ... like even like eating less. Like from what I was eating like say if it was a sort of a healthier meal ... instead of over eating, just eating till I am full.”*

*“And the healthier foods if I was to eat meat or pasta I always had seconds and third servings. Well, now I finish one serving but that’s about it.”*

A few participants recognised the effect reducing the portions of their foods had on their weight. Most participants noted that they were “bigger” than their peers. Most female participants described noticing a weight loss by having reduced their overall food intake. Although one of these young women indicated that her goal in decreasing intake was to feel “healthier” rather than to lose weight, she had lost weight anyways. In contrast, another young woman talked about trying to lose weight. When I asked her to explain her reason for losing weight she asked me to change the subject.

*“I don’t eat as much food as before. Because even though I was trying to lose weight before I never actually stuck to the diet plan that I was trying to aim for.”*

Two male participants commented that since they reduced their food intake they noticed some weight loss. They also focused on how their physical activity performance improved as well.

*"I find that it's just made me feel better because I have not been eating as much I have lost a lot of weight. I can do generally more things than I used to be able to do."*

Overall, participants noticed that a decrease in their food intake resulted in some weight loss. While one female wanted to lose more weight, as she believed it would be "healthier", the other participants wanted to lose the weight so that they would be able to improve how they felt about themselves and their physical performance and health.

#### **4.2.1.3. Eating Regularly**

The third category of diet changes that some participants talked about was eating regularly. The concept of eating regularly was described in general as having three meals a day and/or specifying the three meals as breakfast, lunch, dinner and a snack. In order to eat regularly participants described having to alter lifestyle behaviours. All participants noted that skipping breakfast was something that they had to stop doing. One participant described that if she did skip breakfast she would be hungry during mid morning and she would grab something quick to eat, which she described as an "unhealthy" food item. Participants noted that eating regularly was a difficult task to perform, as their previous habits did not fit with having three meals. Some participants

described not waking up until the afternoon on a weekend and this would influence their eating habits.

#### **4.2.1.4. The Meal Plan**

For the most part, when the participants discussed the food related strategies they used to try to manage their diabetes, they referred to broad principles of balancing healthy and unhealthy food, eating less and eating regularly throughout the day as discussed above. However, some participants also made some comments about trying to follow a structured meal plan. Two participants commented that they appreciated having a meal plan as it provided guidance and helped them change their eating behaviours.

*“I was actually thankful for it (i.e. meal plan)... Cause I didn’t know how to control my diet. I was thankful I had something to follow”.*

However, both participants described gradually not using the meal plan as written and making adjustments on their own. One participant commented that at times she felt the meal plan got “so mundane”. The other participant described that his meal plan had to be adjusted according to his activity level and his preferences. For instance, sometimes he did not want to drink milk at lunch and would choose to drink water instead.

*“At the very beginning I was staying exact. Now I am sort of trying to stay as close to it as I can but...I’ve started to do a whole tonne of different activities so I am getting a lot more exercise now so I find certain times I am going to need more food to be able to keep my blood sugar up.”*

Some participants cited that they did not find the meal plan helpful. One participant stated that she found the exchanges difficult to understand. Food items such as a slice of bread or a cup of milk were “simple” to determine the number of exchanges. Other foods such as stew or casseroles posed a problem.

*"I could not follow it I guess. And you don't know exactly...like which foods have this amount in it. Like they only do the very simple foods I guess... like bread or something but how do you know that this kind of bread doesn't have that in it... and the dietitian discussed not doing one of those because I found that I wouldn't follow it. "*

Likewise, the health professionals acknowledged that the meal plan was not effective for all participants and used it as a teaching tool. However they noted that it was more important for participants to make changes with some of their habits than to restructure their entire eating style.

#### **4.2.1.5. Crashing & Bingeing**

In contrast to the strategies described above, which involved participants making dietary changes that helped them towards an eating pattern recommended by the health professionals, some participants also described instances and strategies that were counter to these recommendations. One participant described not eating any food items that contained sugar and followed recommendations a week before her appointment to the clinic. After the clinic visit, she would eat any food item that she wanted that had sugar.

*"I eat whatever most of the time and then before a visit like a few days before I try to not eat the sugary, fat stuff and then after like the day I eat whatever I want."*

This participant believed that this strategy worked best for her and was not concerned about it. Another participant said that trying to avoid foods sometimes resulted in her overeating those food items. This behaviour caused her to feel guilty and sad. The health professionals were aware that participants would overeat if they were restricting certain foods. They encouraged participants to take part in achieving a "balanced" eating lifestyle and incorporating all types of foods in moderation.



In summary, participants tried different strategies in order to make changes in their eating behaviours. The majority of participants attempted to shift from eating less “unhealthy” food to more “healthy” food items. This shift consisted of eating more “healthy food”, trying to avoid “unhealthy” food and eating less “unhealthy” foods. The successful strategies consisted of balancing “unhealthy” and “healthy” foods, reducing the portion size of “unhealthy” foods, eating out less frequently and thinking twice. These strategies were also inline with recommendations made by the health professionals. However, participants also described “losing control” and therefore did not follow through with these strategies consistently. The conditions that led up to “losing it” for most participants dealt with certain emotions and life events such as a stressful day or a social situation.

#### **4.2.2. Getting Physically Active**

Participants’ experiences with physical activity following their diagnosis with T<sub>2</sub>D depended on their previous activity and lifestyle. Three participants described themselves as being “somewhat” active in their life. They described the process of incorporating activity into their life as “not difficult” or “not a big deal” as they were not “lazy” when they were diagnosed.

*“Not really because considering before that I was trying to lose weight so it just helps me on that path... I was trying to exercise more.”*

*“Well I wasn’t exactly lazy to begin with so they told me I should continue with exercise and that’s not a big deal. It’s actually okay with me because it’s helped my game.”*

On the other hand, most of the participants defined their previous lifestyle as relatively inactive or “lazy”, and believed that getting active would be “boring”, “difficult” and would mean having to “sweat it out in a gym” As a result, these participants received the advice to become active with dissatisfaction.

*“Like I have to exercise all the time. I didn’t like that.”*

Participants who were inactive when they were diagnosed described that it took them a long time to get active. One participant noted that she thought that she had to go to the gym, which was something that she did not feel comfortable doing. She commented that her weight made it difficult for her to take part in “heavy” sports (e.g. running) and that she had no extracurricular activities. Some participants cited that they tried by making small changes to their daily plan. For instance, two participants stated that they started by just walking home from school instead of taking the bus.

Health professionals also noted that it was difficult for participants to become active, especially if they were not active when they were diagnosed. They acknowledged that one of the obstacles for these participants was their perception of exercise and their self-esteem. Subsequently, they described that they tailored their recommendations to each participant. For instance, the male participants who were active in sports such as football and rugby were encouraged to start weight lifting. Participants who were not at all active were encouraged to take walks after lunch and dinner. The role of the family was not addressed when it came to getting active.

*“We often just encourage them to get out there, get the roller blades on or to go for a walk with their friends or to go to the beach and just be active um... just whatever they are interested in doing. But it’s not always easy. It’s just every week asking them what they have been doing and it might be a once a week kind of thing.”*

In summary, participants who were previously active were more likely to increase physical activity levels than non-active participants. Participants' beliefs, interests and health capabilities influenced their responses to becoming active. Health professionals' acknowledged the challenge of getting individuals active and their role as a motivator.

#### **4.2.3. Medications**

##### **4.2.3.1. Oral Anti-diabetic Agents**

All the participants were prescribed an anti-diabetic agent (i.e. metformin) and two participants were taking insulin. All participants described that taking the anti-diabetic medication was the "easiest" management strategy to implement into their life. Most participants described it as "just popping a pill" and not "being a big deal". Some participants admitted that they needed reminding to take their medication when they were first diagnosed.

Participants taking oral anti-diabetic medications also were "thankful" that they were not on insulin. As stated by one participant: "Thank god, I am not on insulin.... That would be the worst thing." Two participants commented that insulin represented diabetes progressing to T<sub>1</sub>D and meant they would have to live with it for life. Some participants described that the "thought of having to take insulin" motivated them to attempt to make changes in their life and follow all the principles. One participant commented that it would just be "more hassle" and "one more thing to figure out".

#### 4.2.3.2. Insulin

Two participants were taking insulin daily and both stated they noticed consequences if they did not take their insulin. However, one noted that when he was first diagnosed, he had a hard time remembering to take his insulin and needed reminders from his family.

Both of the participants commented that they were initially scared of taking insulin because of the “pain” of the needle. They did not like the thought of “poking” themselves but described that they got used to the pain of the needle and the thought of the pain over time.

*“Everyone is always sometimes scared of needles. You don’t like the pain. You just sort of get used to it. The pain of the needle you get used to the thought of it and is just I do it so regularly right now.”*

They both described that they get worried and anxious about taking insulin. Insulin was noted as a driving factor for these participants to follow through with the components of diabetes management. As this participant noted:

*“The thought of just not having to take any insulin keeps me motivated to do all my stuff I am supposed to do.”*

One participant said it would be one less thing he needed to incorporate into his daily life. He did not want his friends to know that he was taking insulin and responded by planning everything that he did around his insulin injections.

*“Because you got to be a lot ...more worried where you are going, what you are going to do. Because you can’t do things that other people sometimes want to.”*

The other participant also did not want to share this experience with her friends or sister. When she went out on social occasions she felt uncomfortable taking her insulin injection in front of others. She found different remote locations to follow through with her insulin injection.

*“Like when you don’t feel like poking yourself with insulin and needles and stuff. ... When you go out with friends and if you want to go out for dinner. Like to eat with them like after a movie you have to bring your insulin along so you can take it like after the movie. It’s just so annoying because you have to hide in the washroom. You don’t want anyone to know.”*

In summary, participants only taking oral anti-diabetic agents were scared of taking insulin. Participants prescribed insulin described this as being a driving factor to managing their diabetes by implementing new health promoting behaviours.

#### **4.2.4. Blood Glucose Monitoring**

Most of the participants noted that after their diagnosis they tested blood glucose levels on a daily basis because they had to provide the values to the health professionals. However, they did not use the information to alter diet and activity patterns as illustrated by this quote:

*“I didn’t care. I had to test them. I did and I did not look at them at all. I just did it and had to bring them into the clinic.”*

Three participants stated that they monitored their blood glucose levels but “not as often as I should”. They learned to read their body and described recognizing high blood glucose levels without having to monitor on a regular basis. One participant referred to blood glucose monitoring as a “measuring tool” that he used to figure out if he had to modify his eating and exercise habits.

*“Whether I need to change certain things... am I eating too much ... am I eating too little am I eating the right things or the wrong things. Could I use, if I went and did a little bit more exercise could I drop my blood sugar levels a little more.”*

Some participants disliked the thought of having to “poke” themselves and did not test their blood glucose because it “just hurt”. Some participants said that it was “easy” to do their blood glucose testing but they did not want to go through it. Reasons participants commonly cited for not monitoring blood glucose levels included it being a hassle to carry the equipment with them and having to explain to others why they were doing it to people. For one participant, it was easier not to monitor her blood glucose as it was one more thing to think about doing. She had to figure out when to do it and was concerned about how she would explain it to her friends. Participants who did not conduct blood glucose testing described that they thought of reasons to tell the health professionals that they would accept.

The health professionals commented that participants did not frequently monitor their blood glucose levels. They believed that the primary obstacle was that the participants were young. One health professional described that participants came up with many reasons to not test their blood glucose levels such as forgetting their meter and losing their meter and strips.

#### **4.2.5. Glycaemic Control**

Participants were asked to describe how they believed they were doing with regards to their glycaemic control. Some cited the following as indicators that they were in good glycaemic control: having more energy, not feeling tired, and not experiencing hyperglycaemic symptoms. Other participants referred to their blood glucose levels and

cited their “usual range”. These participants commented that they wanted their levels to be “low”, at the “right level” or at the “safe level”. Everyone cited that the “safe level” was 4-7 mmol/L. One participant described that he did not like the thought of having high blood glucose values and he became concerned about the potential complications he could suffer, as illustrated by his quote:

*“I personally like to see them down there because it kind of in a way makes me feel better knowing that okay well if I can keep them this low...or at the right level that it will prevent me from having the liver problems and vision problems.”*

Most participants did not know what the HbA<sub>1C</sub> value represented. One participant commented that she did not understand the level that she had received. After reading the information to me during a clinic visit she realized that her HbA<sub>1C</sub> level was in a good range. She thought it was confusing as to how that could be because she sometimes felt that she was not eating well. But knowing that her HbA<sub>1C</sub> was in the normal range did make her feel good about herself and what she has been doing in changing behaviours.

*“I don’t think my sugars are very good then I come and have my haemoglobin done and have 5.9 and that’s pretty low. Sometimes I eat too much or think I had too much candy but I guess not.”*

During the research interviews, the health professionals noted that they focused on blood sugar control in order to reduce the risk of potential complications.

*“You know we try to go at it from the point of view of the blood sugar so that it has a mathematical kind of tact rather than just a weight point of view because really that is so difficult to address for anybody.”*

In order to control their blood glucose levels, the health professionals commented that they stressed the importance of changing behaviours. The process of changing behaviours differed for all the participants and the health professionals recognized that

sometimes all they could do was wait until the participant was ready to implement the changes.

In addition, health professionals commented that they tried to get participants to understand when their blood glucose levels were not in control by assessing how they were feeling. By having the participants connect the symptoms of hyperglycaemia with their blood glucose level, the participants will know when they may have to take action.

*“If the blood sugars are high you are feeling tired. You feel kind of lazy you don’t feel like you want to get up and go so if you can get your blood sugars down you can feel a lot better. So I think that they know it’s a medical thing and if they can fix that then they don’t have to feel that lazy. So maybe that’s part of it.”*

In summary participants were aware of the safe blood glucose range. However, many did not understand the meaning behind their HbA<sub>1c</sub> value. The health professionals focus on blood glucose control in order for participants to change their behaviours. They reinforced the importance of having the adolescent recognise symptoms of hyperglycaemia as a means of understanding their blood glucose control.

#### **4.3. Factors that Shape the Participants’ Experiences of Managing Type 2 Diabetes**

The research interviews revealed how the participants’ experiences of diabetes management varied and did not occur in isolation. They were shaped by personal characteristics, diabetes itself, family members (i.e. parents and siblings), friends, community, social events and health professionals. These are described in the sections below.



#### 4.3.1. Personal Characteristics

Although all participants noted that they required support to manage their diabetes, the majority believed that they were primarily responsible for making the necessary changes and that they had to do things for themselves.

*“Definitely I know that if I want anything done that I have to like change for myself.”*

*“I just figured that I better do the best I can to change things.”*

*“Well knowing that I can only change things for myself, no one can do it for me.”*

Personal factors that shaped their experiences of making these changes for themselves included their pre-existing eating and physical activity patterns, their time management skills and their outlook towards the diabetes itself. While all participants went to school, some also juggled working, being part of a sports group and responsibilities at home. Trying to change their behaviours and manage the diabetes disrupted aspects of their life. Most noted that the most important factor with managing their diabetes was time management.

*“For anybody with diabetes, the most important thing you have to learn is time management. If you can’t manage your time, you can’t do anything. You know you can’t take it... you will be too depressed. Let’s say at five o’clock you have to take a walk but you are eating at that time you know, it gets too complicated. You have to manage it.”*

Specifically, some cited that they could not manage their homework, studying and diabetes management. Some commented that they needed a schedule or a way of incorporating their new behaviours in their life.

*“It was pretty hard to manage it before because of, the schoolwork. You don’t know how to put the work time then the school time you know the exercise time. It was a headache.”*

*"I don't really manage my time very well. So, it's really just I have to practice my time management to help me manage my schedule. I need a schedule."*

Overall, though, most of the personal factors that shaped participants' experiences of diabetes management related to their personal outlook or mindset towards the diabetes.

*"I think it depends on your set, like you how you set your mind to it. Like if you think that diabetes is that bad you will never be going to manage your weight but to me diabetes is nothing at all. It won't really hinder you from doing things. It's not like you got into a car accident and you are crippled or something. I don't make much of it."*

Participants' mindset and emotional responses to their diabetes varied between individuals and over time. Almost all said that they were depressed with the diagnosis and the changes they would have to make in their life. Once diagnosed, some had unpleasant thoughts of the diabetes and spent their time being angry, arguing with their parents and taking it out on themselves. Other participants described reconciling their emotions and accepting the diabetes. Three participants commented that they "don't dwell" on their diabetes as much as they used to and decided not to "freak out" with their diabetes. Their viewpoints changed in terms of how diabetes will influence their life. As one participant stated, *"I don't make a big deal about my diabetes. It is just there. I don't dwell on it much."* She shared the same recognition that life has obstacles and this is one of them, so she chose to try to cope with her diabetes.

#### **4.3.2. The Diabetes Itself**

The participants' outlooks were shaped by their experience of finding out that they have T<sub>2</sub>D, their understandings of why they got diabetes, consequences of diabetes, belief

in control over the diabetes, and the adolescents' perceived progress with the diabetes management.

#### **4.3.2.1. Way of Finding Out**

Most participants described a variety of triggers that caused them to be suspicious that there may be something wrong with their health including physical changes such as frequent urination, profuse sweating and dizzy spells.

*"I wasn't feeling right ... and I said I have to go. I was drinking a lot. I was going to the washroom a lot ... I was tired. Like I used to be able to go to sleep and wake up at a certain time...it makes you so tired."*

*"I felt sometimes I got tired and sometimes I had to go to the washroom a lot at night."*

These participants described that they were very shocked about the diabetes and felt quite sad and depressed with the diagnosis. They described that they were unsure of what diabetes was and the impact it was going to have on their life.

*"I didn't know what it was going to mean to me and my life."*

Two other participants who shared similar symptoms attributed them to other problems that they had. In one case, a family member who had diabetes was concerned about her daughter's risk of diabetes. Initially, this participant dismissed her mother's concerns until the physical symptoms were difficult to manage.

*"My mom has diabetes and she was concerned about me because I was overweight. I was concerned too because I was getting dizzy and stuff like that. Therefore, we had a blood test done and we found that I was diabetic. She always like said oh we should test you every couple years or something like that we should get you tested. And I was like, oh no no... and then finally I was like getting dizzy and I was like and that's never a good feeling to be dizzy or anything like that and so I was like I told her I think we should go get tested to see if I have diabetes."*

These participants responded by saying that they were shocked but not too shocked with the diagnosis. The diagnosis clarified their uncertainty as they could put a name to what they were physically feeling and what was happening to them. For participants who had some perceived notion of their risk for diabetes, finding out supported and clarified their suspicions. Participants that were not too shocked with the diagnosis noted that they accepted the diagnosis and did not “beat themselves up” as participants who were shocked. Participants who were shocked felt quite sad and depressed with the diagnosis.

#### **4.3.2.2. Reason for Having Diabetes**

Participants described the process of seeking causal explanations for the diabetes. The two questions that participants struggled to answer were: “Why me?” and “What did I do to get this?” Participants initially identified and described poor eating habits and lifestyle for the onset of their diabetes. All participants described that past dietary practices included food high in sugar, starch and calories and this caused their diabetes:

*“I would eat lots and I used to eat lots of junk foods.”*

*“Well because of my bad diet.”*

*“I used to eat a lot before. You know, I grew up and I used to eat a lot and big meals and the habits stuck with me and I didn’t control them.”*

*“Well I used to eat junk food... lot of it. If I had healthy stuff... I would eat a lot of it.”*

*“Just like lots of juice and too many gummie candies...because that’s what I ate before.”*

In addition, the four female participants cited that being overweight was responsible for the onset of diabetes. However, they all commented that they had always remembered being overweight in their life and cited other reasons that might be reasons

for the onset of diabetes. Participants implicated past lifestyle as contributing to developing diabetes. Participants who described themselves as “lazy” or “not active” cited their lack of activity in their life increased their risk for the diabetes.

*“Before I was lazy. Too much homework and not enough time to go out.”*

Participants who described that eating and lifestyle were the only reasons that they got diabetes described feeling guilty for the diabetes. In addition, some participants reflected on their parents’ previous lectures regarding their habits. Participants described blaming themselves for the diabetes. For some participants the guilt resulted in unsafe behaviours.

*“I used to beat up myself...I was supposed to be cautious before I got diabetes...I said why should I do things to manage it so forget about it.”*

Three participants cited their family health history for the onset of their diabetes. Many of the participants discussed their long family history of diabetes.

*“My dad the carrier passed it on to me.”*

*“Mainly because of the hereditary with diabetes and the mixture of the weight problem.”*

The youngest male participant came up with his own understanding to try to make sense of how he could have gotten this illness. He described his mother’s gestational diabetes.

*“My mom I think the reason why I got it was because when my mom was pregnant ... and she, she had diabetes. Just a little bit. And so I probably got it I don’t know when I was born.”*

*“No she (referring to his mom) said I had diabetes when I was pregnant right and I said maybe that when you were pregnant it you probably gave it to me ... then I told the doctors and the doctors said maybe that could be it.”*

Attributing their family history with their development of diabetes helped participants deal with feelings of guilt and incorporating the diabetes management strategies, as illustrated by the following quote:

*“But after I learned ... the facts about it ... It’s not entirely my fault. It’s a genetic thing. After that I was like oh okay I have to change things. Do my best to do that. If I can do that I will still have the same life just with a couple extra pills and needles. Like it is but not in the sense that I thought it was being my fault.”*

One participant attributed her ethnicity to the onset of her diabetes:

*“Oh because I am native like before ... like Europeans came I guess we ate like just staple foods like corn like stuff that you could grow or like catch or hunt or whatever we would just eat those foods and we didn’t like have that much fat and stuff and we were exercising because we were hunting and stuff... so ... I guess and then ... I guess we weren’t like really ... used to like all that kind of fatty food so... I guess we couldn’t handle it or something...so that yeah and then... I guess ... I don’t know that’s what I think.”*

The health professionals had a similar perspective on the aetiology of diabetes noting past eating habits, lifestyle choices and family history as contributors.

#### **4.3.2.3. Severity and Consequences**

Participants identified various physiological and social/personal consequences of diabetes that influenced their diabetes management. Physiological consequences included not living as long, loss of eyesight and loss of limbs.

*“Basically the biggest one is that my life is now shortened by a few years.”*

*“First of all, I was sad because I thought that okay now my life was going to be really short.”*

For some participants, understanding and acceptance of these consequences influenced them to take an active role towards implementing some of the diabetes management principles.

*“Well... just knowing that I can lose my limbs makes me want to make some changes.”*

However, not all participants responded to the physiological consequences in the same manner. One participant cited that he knew the potential complications of diabetes but just did not care about the risks. He stated that he followed diabetes management strategies after learning that he may need to go on more medications.

While the physiological consequences were acknowledged, participants focused more on the personal and social consequences of diabetes. Some participants were concerned with the things that diabetes interfered with. For instance, many said that their diabetes got in the way of their school.

*“I find that school, like it gets in the way with how I manage because I get all that homework and stuff and studying and you may not manage your time more around it. It’s just more cumbersome with school.”*

Others cited that they had to worry more about what they were going to be able to do and how they would have to plan things around their diabetes.

*“Because you got be a lot more worried where you are going and what you are going to do. Because you can’t do things that other people sometimes want to.”*

Participants stated that they wanted to try to figure out a way to incorporate the recommendations despite times when they were stressed or busy with school.

Some participants were scared that they would not accomplish future goals if they did not follow the recommendations, increasing their motivation to manage their diabetes.

*“You have to take it to prevent and to accomplish any goals you have.”*

One participant described that the thought of not meeting his goal motivated him to adjust how he looked at his diabetes. At first he thought his life was over but then he decided to change his outlook and made changes.

*“You have to look at the roads you want to go. I look at diabetes as one of the roads in the straight path. You have to somehow twist it and then go to a straight path to become what you want to become. You will get more obstacles as you grow up. But for me this is one of the small obstacles I have to cross over. I may have more obstacles in the future and at that time I will just have to deal with it.”*

These concepts were supported in the interviews with health professionals, who recognized the physiological consequences as aspects that were driving adolescents to manage the diabetes. Also, personal and social issues such as peer pressure and developing an identity were identified by the health professionals as areas that need to be reflected on in counselling.

#### **4.3.2.4. Having some control over it**

Everyone had different opinions about their ability to manage the diabetes and which principles they could handle. A few participants noted that knowing that they could control the diabetes motivated them to incorporate components of diabetes management. One participant described how this also made him feel better about himself and therefore just looked at the diabetes as a way of living healthier.



*"Knowing that ...if I can do everything that I can do take care of it that makes me feel better."*

Another participant described that diabetes was something that had to happen to "wake them up to how they were living" and noted that they were thankful that they had it because they were concerned that they would get it now, and it would be easier to change their behaviours now than later. Moreover, they believed that they would have time to change their behaviours and make a difference to their health. Having the sense of control and the ability to change their behaviours provided the participants with a sense of calmness and allowed them to balance their fear and anxiety with hope.

#### **4.3.2.5. Seeing a difference**

The participants' experiences with the diabetes itself changed throughout the course of their illness. As participants experienced living with the diabetes and attempted components of diabetes management, they noticed physical and/or emotional changes. Positive changes in themselves or in their glycaemic control motivated participants to continue with attempting to implement diabetes management components.

*"Well seeing that my blood sugar control is good makes me want to continue to do things...cause it's working."*

One participant noted the difference in terms of his social relationships at school. As well, he described how managing his diabetes made him feel better at school and do better with his schoolwork.

*"I actually think since I got [it] I have become more active ... more popular communicative... I don't know. I found that since I got it I have actually got more I do better in school ... I do more activities I do more to help out around the house and stuff ... it's really only that I have been eating different but I have found that besides not being allowed to eat the stuff that things have just gotten better really."*

*"It's kind of an emotional thing but at the same time it's physical. We were doing running at school like cause we have to do runs every day. I found it would take me forever to do the run and I will never be able to run the whole way. Now I can run the whole way and be one of the first people back physically I can do more."*

When questioned about whether or not they felt normal, many reflected that they really did not feel any different.

*"You know it's not a big deal. You are still a human being, you still have the same insides except one part isn't really working. You know it's not a big deal. You are still human."*

Overall, the diabetes itself shaped how the adolescents managed their diabetes. Initially, participants who were shocked with the diagnosis described not incorporating any components of diabetes management. Coming to terms with the diagnosis and the reasoning behind the diabetes also influenced diabetes management for some participants. Participants who had difficulty with dealing with the diagnosis were less likely to incorporate the components and struggled with their emotions. In addition, the participants understanding of the consequences and severity of the diabetes influenced the changes they made in their life. While the physiological consequences of diabetes motivated some participants to make changes, the personal and social consequences of diabetes influenced how they managed different aspects of their diabetes. Finally, integration of the diabetes management tasks was shaped by how the participants felt they were doing with their diabetes. Participants who noticed positive changes at school or with friends were more likely to follow through with health-promoting behaviours.

### 4.3.3. Family Members

Each participant's family context was diverse (i.e. siblings, parents, family history of diabetes and socio-economic status) and influenced their responses to managing the diabetes components. Most participants noted that their parents were shocked with the initial diagnosis and tried different strategies to help them manage the diabetes. They described these strategies as either supportive or obstructive.

Three participants described how their mothers took an active role in helping them with the diabetes management. They described the constant reminders and the planning of meals.

*"Well she used to put my stuff out and make sure that I take it."*

Participants described that being reminded to take their medication(s), and test their blood glucose levels after they were initially diagnosed was supportive as these were new behaviours that they had to learn.

*"I think I could of but I think I needed her (referring to mother) in the beginning ...being able to remember. Sometimes I need a little bit of reminding because I am fifteen years old. What do you expect?"*

Participants recognized that they may have "ups and downs" with managing their diabetes in the future and would need their parents' reminders. While some participants noted that they found the reminders helpful, I observed different responses at the clinic. For instance, one participant was going in for a counselling session and his mother kept reminding him to ask the health professional or the clinician a question. The participant's tone and body showed that he was frustrated with being reminded.

Another participant was annoyed by his mother's "over vigilance" once he was diagnosed. He sometimes felt that she hovered over him and did not trust him. On certain occasions, his mother asked him to prove his compliance through blood glucose tests and she followed up on his eating habits.

*"My friends are like my mom's little snitches they will tell her what I eat. My mom says: Did he eat a lot? And I am standing in front of the hallway saying you if you tell and stuff like that and he goes on and tells my mom and then my mom says: You didn't you eat that?"*

Some participants commented that their parents lectured them to change their eating habits and become more active. One participant described his father's lecture as "threatening" but he understood that his father cared about him. He stated that this technique "inspired" him to get active and reinforced the negative physiological consequences.

*"My dad from the beginning was like go out, go out, go out. I wouldn't listen to him. He used to force me a lot. I wouldn't get up. You know. He used to yell. He got all these magazines with deformities and I got kind of scared. You can hear my dad saying: This is what can happen to you."*

However, lectures were not always perceived as being helpful. One participant described that no matter what his mother said he did not make any changes to his eating and lifestyle behaviours, as illustrated in this quote:

*"After I used to beat up myself, my family they basically they kept telling me and telling me to stop what I was doing because I was killing myself I was eating so much... but I just didn't listen to them."*

One participant described how his parents watched over him to make sure that he ate healthier meals. His parents used this approach on a regular basis and he responded by either swearing or yelling back at them. This participant commented that he felt

restricted. He didn't understand why he had to restrict his food intake when other members in his family did not.

*"Like when we go out to eat... I just want to get that and that that's all. Like a plate of Chinese food ...but they won't let me have it... and that's when I get mad. It's like as soon as I just put like that much (showing with hands a fist) on my plate they say "oh that's too much now you are getting carried away."*

*"Sometimes we get McDonalds or Burger King and I have to get a small burger and they get big burgers."*

Most participants cited that it was difficult to follow eating recommendations when no one in the family was changing their eating habits. One participant described planning meals with his parents, but the meals only applied to him.

*"My dad and my mom sat down and arranged some stuff. Like I can eat this and I can eat that. If you find something that's sugar free you can have it. But not so much."*

In this case, the participant found it difficult to be motivated and follow through with suggestions because his siblings taunted him with "junk foods".

*"I see my brother and sister and they eat a bunch of chocolates and ice cream and drinking a lot of coke. And that makes me feel like I want some of that too. I can be motivated but sometimes I can lose my motivation."*

He described how his parents would not let him have treats at home or when they went out to eat. He often responded by getting angry and swearing at his parents.

*"Like usually they would go out to buy McDonalds and they'll buy me like ice cream, slurpee when they come back. But now when they come back they only have like three slurpees for my two sisters and my brother. And like I got nothing and that's when I get mad and say where's mine and they say 'aren't you diabetic you can't have this.'"*

One participant lived with her sister and commented that her sister would “usually upset” her eating habits. Her sister found it inconvenient to prepare two meals.

*“When my sister is around because she doesn’t care about her diet and she sort of upsets mine. Cause she eats whatever she wants. We live together and we have to waste time to get her thing and my thing. So I sort of go along with her.”*

Participants cited that altering eating behaviours and becoming active was facilitated when family members made changes along with them. For example one participant described that changing his eating habits was “not a big deal” because his entire family changed their eating habits. His mother changed the entire family’s eating habits by reading food labels, reducing simple carbohydrate foods such as sweetened cereals, cooking from suggested diabetic recipes, reducing convenience foods, not going to fast food restaurants and preparing homemade meals at home.

*“My mom ... she just basically just changed everything right away. She changed what she bought, she changed where we go, she has completely changed where and what we ate.”*

Other participants described small changes that involved members of their family. One participant described it as helpful when his father joined a gym with him and when they became involved in a cricket club. Another participant described working together with his family to make changes to their eating patterns.

Likewise, health professionals noted that the family responses to the dietary and lifestyle principles influenced the participants’ responses to diabetes management.

*“But if it’s not being done in the family that’s the thing ... it’s got to be embraced by the rest of the family if they have the same you know body build... because not all the family’s have that. They either have one child that’s different from the rest of the family.”*

In the interviews, the health professionals noted how dietary and lifestyle changes were implemented when they were acknowledged and experienced by all family members. The greatest challenge they faced was getting to know each family in order to help the participants.

#### **4.3.4. Close Friends and Peers**

With the exception of one participant, all participants indicated that they were comfortable letting their “close friends” know that they were diagnosed with T<sub>2</sub>D. This one participant stated twice “It wasn’t anyone’s business to know” and it was a “personal health issue”. However, she decided to let her “close friends” know about her diabetes as a precaution.

*“But I told a few just in case, if anything happens like they know why and they can help me. People that I have most classes with or I hang out with the most. I tell them, but that’s about it. Like three people know.”*

One participant responded with frustration when her teachers and classmates found out that she was diabetic. In the research interview she cited that she didn’t want to be “singled out by other students”. When asked to expand on this topic she refused.

*“All my teachers, which I didn’t want them to know. But the nurse told them... they blabbed it to some students. I didn’t want them to know. Because then... she was talking to a total stranger ... this person in this other class who had do a study project about diabetes. This teacher asked me questions about it. It was rude because I didn’t want anyone to know. I just don’t want anyone to know...I don’t want to be singled out.”*

She described being annoyed with students’ questions regarding her medical alert bracelet. She avoided answering questions by walking away and “laughing it off” and telling them “It’s nothing not a big deal.”

*"I have this thing right (pointing to the bracelet), the medical alert thing... and it can be for anything. They (referring to students at school) were asking about what it's for right and they were like... for bee stings? For allergies? And they were like if you drop or something we need to know.. But then I am like... Umm. It's nothing and just laugh it off."*

One participant shared his experience with his friend who had T<sub>1</sub>D. He described this as being beneficial as he could share his frustrations with someone who would understand what he was going through. Some respondents cited that they skipped blood glucose monitoring when they were around their friends or at school, took their blood glucose test in the washroom or hid their insulin injections. One participant let her friends know she felt uncomfortable managing her diabetes in their presence. One participant noted that he didn't care who knew that he was diabetic and "did not feel ashamed" about it. Some participants did "not mind" that other students knew that they had diabetes but they altered their responses to the diabetes management in their presence. One participant described that some of his peers at school knew as he was involved in extracurricular sports but they were not his close friends and he did not share any of his experiences with them. One participant commented that she did not let people in her school know because she gets picked on by peers at school, especially by boys, as she is a big person. She described not having many peer relationships at school, and said how she takes on a 'tough stance' in order to ward off the negative comments.

The participants' experiences with diabetes management varied when they were with their close friends. Some participants noted that it was "difficult" to follow the dietary recommendations when they were socializing with their friends. The youngest male participant described his friends' behaviours as not supportive and as a bad influence on his diet. He described these times to be "very difficult" and sometimes gave in and went



along with their friends. He also described his personal conflict to follow the dietary principles when he was tempted by friends to eat the “sugary” foods:

*“Yeah sometimes like when my friends eat something with sugar and they say: Don’t you want any, it tastes good” and I say back: I don’t want any. But to myself I am saying: Oh I really want that so bad to myself but I am just saying that I don’t want that to them.”*

He also commented that his friends did not understand what it was like to have diabetes.

One occasion he tried to explain the importance of the disease and how he didn’t like being made fun of but his friends still did not understand.

*“My friends they don’t worry but they’ll worry when they have it. When they get it. Well like I say to people like them: maybe that you might get it... It’s not funny for me; it’s funny for you guys.”*

The older participants noted that they occasionally “lost control” with dietary management when they socialized with their friends but found ways to try to follow the recommendations. They chose healthier snacks that they enjoyed eating. Some examples of alternative choices participants made consisted of the following: substituting regular pop with diet pop and substituting chocolate bars and chips with a granola bar.

Overall, participants noted supportive friends were important to their diabetes management, including friends who they could go for walks with and friends who would not influence them to eat “unhealthy” foods. Recognising that friends are not always going to be supportive, some participants described taking more control of their own behaviours by not being influenced or by listening to their friends, as illustrated by the following quote:

*“ I would say don’t listen to your friends that say just go out and eat. You see, it’s easy for them, they don’t have diabetes people like us we have it.”*

In response to non-supportive friends one participant wished she had a friend with T<sub>2</sub>D. She felt that if her friends had T<sub>2</sub>D they would be more understanding of the difficulty behind the behaviours and would alter their lifestyle. Another participant suggested having peer discussions with other adolescents with T<sub>2</sub>D, as noted in the following quote:

*“I will make a book in my own words say talking to them or like if they want to make an appointment to talk to me then I would talk to them about it.”*

In summary, peers can be both supportive and non-supportive. The nature of the relationship and the maturity level of the adolescent influences diabetes management practices of the adolescent with T<sub>2</sub>D. Older participants with strong identities or belief in themselves described more coping skills with dealing with sharing their diabetes and tasks. On the other hand, younger participants described times when they did not follow through with their diabetes management in the presence of friends.

#### **4.3.5. Social Context**

Most participants commented that it was “most difficult” to follow the dietary recommendations when they were at a social event or special occasion. One participant described that when he was diagnosed he had missed events, as he did not know how to incorporate the diabetes management at that time and found it easier to miss events. He did not know how to incorporate his physical activity and insulin and did not want to explain his condition to anyone.

Many of the difficult events involved a gathering of friends and centred around food and eating. Some participants reported that these occasions contained the typical “junk food” and they felt tempted to eat “high sugary” foods. After describing these events, participants remarked with statements such as “Well it only happens once and a while”

and “Well, it’s only once a year.” One participant shared her experience of going to the fair.

*“You see like the PNE is open and so you go there and they sell all that junk food and stuff and you automatically want to try it out cause that’s we would do. We would go to check out the junk food. It’s so tempting. But I know I shouldn’t, but it’s so tempting.”*

However, some noted that there were times when they felt guilty for not following the recommendations during these events. One participant went on a trip to Edmonton and decided not to follow the dietary principles or monitor her blood glucose. She described eating pizza, ice cream and cotton candy and by mid-afternoon felt dizzy and realized her blood glucose level was too high. She described, “feeling bad” and guilty for her behaviour but found it difficult to follow dietary principles when she was out in a different city. She also noted that she thought that there was no point to test her blood glucose because seeing the value would have made her feel worse about herself.

#### **4.3.6. Community Members**

Two participants described receiving support from members in the community. The youngest female participant received support from all of her teachers at her school. They ensured that she walked during recess and monitored blood glucose levels during the day and provided her with words of encouragement. This participant noted that her teacher’s attention was helpful and encouraging. However, living in a small community where others knew she was diabetic had its downside. She noted that she was not able to buy chocolate from the corner store because she was scared that her mother would find out.

The oldest participant looked for support outside of his family and friends and joined the local diabetes chapter to learn about diabetes. Attending diabetic group meetings at

the Canadian Diabetes Association allowed him to share his experiences with teenagers with T<sub>1</sub>D. Although he noted that the conditions were different he found it helpful to talk to someone besides his family who had to make life changes. Participants who did not extend into groups cited that they would like to have someone to share their experience with but were not familiar with existing groups. The youngest participants noted that they would like to go to a camp with other adolescents who have T<sub>2</sub>D and are learning to change their life. Lastly, one female participant wanted to attend the Canadian Diabetes Association cooking classes. The health professionals were aware that some participants sought support from the Canadian Diabetes Association. However, they were not aware that some participants shared their diagnosis with their teachers at school.

#### **4.3.7. Health Professionals**

The participants identified certain actions by health professionals as being supportive and non-supportive in their management. All participants cited that after their diagnosis they followed some of the recommendations because they had to show the results to the health professionals at a future clinic visit.

*“If it wasn’t for the clinic (referring to health professionals) I wouldn’t actually do any of this stuff. I would be like I don’t need to know.”*

The health professionals were perceived as being knowledgeable and providing informational support. Some participants stated that one on one counselling allowed them to ask questions about their diabetes without their parents around and to clarify information that their parents had provided them with.

*“It’s because they tell me more, that my mom can’t tell me. Like when my mom tells me stuff she’s not too sure about it. That when I talk about it to them and tell them they tell me that doesn’t happen and then I feel better.”*

Participants described that the health professionals helped them deal with family conflicts surrounding eating behaviours. One participant described how the health professional intervened and tried to get his mom to understand his responses to diabetes management.

*“But the dietitian said to my mom that like the reason why he eats sugar is because you guys have a bigger amount than him it makes him feel mad and he like eats whatever he wants and she said that if you guys change your dieting and stuff like that she say maybe he won’t swear or throw fits. Now they kind of understand.”*

Specifically, participants noted that clinic visits motivated them to monitor their blood glucose levels and modify eating behaviours. The comment that many participants made was similar to the following quote by this participant:

*“If it was just for me I might just do like it once a day or twice. Like when I went to school I was supposed to test it every... every time before lunch right. If it wasn’t for everyone at the clinic.”*

Others stated that the health professionals helped them get back on track when they lost control or lost their motivation to work on managing their diabetes. This is something that they described to be important initially when they were in the process of learning about diabetes and how to manage it. Some participants stated that they tried to follow management components because they didn’t want anyone to be upset with them. They found that getting feedback from the health professionals provided them with reassurance and support even if they were not following through with all the management components.

*“Well I try to control my sugars because you don’t want anyone mad at you.”*

While most participants perceived the health professionals' actions as supportive, two participants believed that the health professionals did not understand the difficulty behind the dietary recommendations.

*"There are some of them that do understand you and think that you should go on it slowly ... but there are some that think that you should get off it like you know like it was nothing it's kind of like smoking you can't quit just like that you got to take it one step at a time."*

One participant believed that the health professionals' expectations were different from what she experienced. She believed that she was doing well and described that the health professionals may not necessarily approve of her practices and she did not look to them for motivation.

The findings illustrated that there were some similarities and differences in the role of health professionals in the management of their diabetes. Being experienced in the field of diabetes education and counselling, the health professionals reinforced the importance of tailoring their counselling strategies to each individual.

*"We try to look at it from the individual and work with each person."*

Subsequently, the health professionals suggested that they play several roles in the education of the adolescents. The health professionals indicated that initially their role was to provide information and evaluate the progress of the adolescents. Their roles expanded and included being a motivator, problem solver and teacher. They described situations when they did not focus on any of the principles, but instead focused on family dynamics. Moreover, the health professionals realised that these tasks take time and stressed the need to follow up with clients regularly. Thus, they would be there to "catch" them when they were "ready" to take action with their diabetes.

*“Well we know that with type 2 we can’t just see them once in awhile and give them directions. It’s a lifestyle kind of thing and it depends on whether what stage of change they are at. Whether they are ready to make changes, whether they aren’t ready to make changes and when we can help them.”*

To the adolescents, some of the health professionals’ actions did present as being beneficial to the management process. The adolescents commented that being part of the process in negotiating goals was essential to the success of implementing behaviours. Developing strong relationships between the health professionals and adolescents played a significant role in the implementing of the diabetes management components.

#### **4.4. Summary of Findings**

This chapter examined the participants’ experiences with managing T<sub>2</sub>D. Diabetes management involves a combination of altering food choice and habits, getting active, medication(s) (i.e. oral agents or insulin), blood glucose monitoring and glycaemic control. In order to alter their eating behaviours participants described eating less “unhealthy food and eating more “healthy” food, eating less overall and eating regularly. Some successful strategies included: eating out less frequently, reducing portion sizes, balancing “healthy” and “unhealthy” foods, substituting foods and thinking twice. Attempting to “cut out foods” entirely from their life was not a successful strategy.

While all participants described a shift in their eating behaviours, not all participants incorporated activity into their lives. Participants who were active prior to the diagnosis integrated different activities into their life. Participants who were not at all active prior to their diagnosis had negative thoughts towards becoming active and experienced difficulties with this component of diabetes management. In contrast to the activity

component of diabetes management, the majority of participants noted that they took their oral anti-diabetic agents on a regular basis. Participants taking oral anti-diabetic agents were scared of being prescribed insulin and thus were motivated to manage their diabetes. Lastly, participants described variable responses to measuring their blood glucose levels. Sometimes participants commented that they found it helpful, as they knew how they were managing their diabetes. However, SMBG was not always adhered to on a regular basis.

Personal factors, family members, friends, social context, community members and the health professionals shaped the management experiences of this group of adolescents with T<sub>2</sub>D. Personal characteristics such as pre-existing eating and physical activity patterns, time management skills and their outlook toward the diabetes itself shaped how they managed their diabetes. In addition, family members' involvement in diabetes management shaped their experiences. Participants who had family members that implemented changes along with them were more likely to incorporate lifestyle changes. On the other hand, participants whose family members did not incorporate changes in their life found making the changes difficult on their own.

Peers and close friends were shown to be both supportive and non-supportive with incorporating components of diabetes management. As well, participants sought assistance from members in their community such as teachers and diabetes support groups to help them manage their diabetes. The health professionals motivated the participants to incorporate behaviour changes. Lastly, the health professionals acknowledged the difficulties in changing these participants' behaviours, particularly in terms of their family environment.



## **CHAPTER 5: DISCUSSION**

The purpose of this study was to try to understand the management experiences of adolescents with T<sub>2</sub>D. As there is no literature addressing this area, literature will be drawn from management experiences for adolescents with T<sub>1</sub>D and adults with T<sub>2</sub>D. This discussion focuses on understanding diabetes management behaviours and the factors that shape the incorporation of the diabetes management components. Limitations of the study and implications for research and practice are presented at the end of the chapter.

### **5.1. Understanding Diabetes Management Behaviours of Adolescents with T<sub>2</sub>D**

A common theme that describes adolescents' diabetes management behaviours (i.e. altering eating habits, incorporating physical activity, taking medications, monitoring blood glucose and achieving glycaemic control) is that responses vary on a continuum from "strict adherence to non-adherence". Along this same continuum, components of diabetes management that were strictly adhered to were described as being "easier" and components that were described as being "difficult" were equated to non-adherence.

Studies have shown conflicting results with respect to adherence to medication (Donnan et al., 2002; Grant et al., 2003). While it appears "easy" to take one's medication studies have found that adults taking more than one dose of medication are more likely to skip taking some medications at times. This finding was not found replicated by participants in my study. While they sometimes forgot to take their medication, participants in my study were more likely to follow through with it than to alter their eating habits or become active. Lifestyle habits such as altering eating behaviours and physical activity have consistently been shown to be the most difficult to

alter (Hentinen & K ngas, 1992; Glasgow, Hampson, Strycker, Ruggiero, 1997; Ruggiero et al., 1997). Thereby extensive research has examined the dietary challenges that both adolescents with T<sub>1</sub>D and adults with T<sub>2</sub>D have with making changes (Maclean, 1991; Schlundt et al., 1994; Schlundt et al., 1996; Tillotson et al., 1996; Sullivan et al., 1998).

Maclean (1991) characterized individual responses to dietary change along a similar continuum of adherence. Adults with T<sub>2</sub>D were classified into the following categories: strict diet, moderately flexible diet, very flexible diet and no diet (Maclean et al., 1991). Likewise, the findings in my study depicted a similar type of continuum for altering eating habits. However, rather than having distinct categories, participants in my study tried several strategies to change the quality of their diets and moved back and forth to either end of the continuum. These strategies were similar to the strategies used by the adults with T<sub>2</sub>D studied by Savoca and colleagues (2003). Strategies such as trying to eat more “healthier” foods and less of the “unhealthy” foods, eating regularly and eating less overall were similar. Furthermore, Savoca and colleagues found that adults with T<sub>2</sub>D attempted to follow a meal plan in order to change their dietary habits. However participants in that study did not describe any bingeing habits.

The factors that seem to influence the management practices of adolescents with T<sub>2</sub>D encompass many of those found in studies with T<sub>1</sub>D adolescents and T<sub>2</sub>D adults. These factors include personal characteristics, diabetes related factors (i.e. the disease itself) and contextual factors (i.e. family, peers, community members, and health professionals).

### **5.1.1. Personal Characteristics**

Every participant is an individual with his or her own personality, values, interests, lifestyle, coping styles and level of maturity. As other diabetes related literature has suggested, adolescent's management practices are influenced by psycho-social factors such as attitudes, beliefs, knowledge, self-efficacy, past lifestyle behaviours, coping style and life skills (Grey, Boland, Davidson, Tamborlane, 2000).

Previous studies have found that individuals' knowledge of diabetes and the management components do not necessarily change their behaviours (Savoca, 2001). In my study, participants were more likely to follow through with taking medication, as this action directly resulted in improved blood glucose control. In addition, in my study, recognizing the outcomes that result from alterations in eating habits and increasing physical activity into one's life being more long-term in nature and varying amongst individuals. Participants commented how it took time before they noticed a difference in either their weight or ability to move around more easily. Thus, the health professionals described focusing on the adolescents' blood sugars and trying to educate them on how the blood sugars are affected by their activity and eating habits and did not focus on weight concerns.

In my study, it was also found that participants who monitored their blood glucose levels were more likely to begin with altering their behaviours. Perhaps understanding the meaning behind the HbA<sub>1c</sub> value may also act as a motivator for individuals to make modifications in eating and lifestyle behaviours, as it is representative of long-term results. Furthermore, by understanding their long-term control value, participants may be

motivated to make changes and perhaps provide some comfort to participants who struggle with some of the irregular blood glucose readings they receive.

Similar to other studies, emotions such as stress were found to have a negative influence on eating and lifestyle behaviours of adolescents with T<sub>2</sub>D. Participants having difficulty with the emotional impact of diabetes and the components of management may benefit more require further therapeutic support to address their concerns. Grey and colleagues (2000) illustrated that incorporating a coping skills training course along with an education intervention assisted adolescents with T<sub>1</sub>D with maintaining their diabetes treatment and negotiating with family members. Teaching adolescents with T<sub>2</sub>D how to deal effectively with emotions may lead to improved diabetes care.

#### **5.1.2. The Diabetes Itself**

Previous researchers have described the experience of living with a chronic illness such as diabetes, as a phased process (Ellison & Rayman, 1998). Although it was not the explicit aim of this study to explore the phases of the illness experience, it was evident that the adolescent's experiences of implementing diabetes components varied from their initial diagnosis to the date of the interview. Due to the scope of the study and sample size, it was not possible to explore this issue to saturation. However, this study provides insights into how the disease itself shaped the management experiences of these adolescents with T<sub>2</sub>D. Certain aspects of the adolescents' experience were similar to the constructs documented in the Illness Constellation Model (ICM) (Morse & Johnson, 1991).

The first phase of their experience, labelled the “pre-diagnosis phase,” described the events that took place before the initial diagnosis. Similar to ICM, the first phase was characterized as a time of uncertainty, during which participants began to suspect they might be ill, either through body changes such as dizziness and excessive thirst, or “by accident” and consequently sought medical assistance. Initially, they knew very little about their health condition, and were referred for counselling to the diabetes and endocrinology clinic at B.C. Children’s Hospital, in Vancouver, B.C. Counselling attempted to support the participants as they moved into the second phase, during which time they implemented the changes required to manage their diabetes. The major changes involved medication, diet therapy and lifestyle modification. The considerable complexity underlying these behavioural changes disrupted both the participants’ confidence and their sense of self. This stage of their illness can be compared to the ICM’s time of disruption (Morse & Johnson, 1991). This was indicated through the negative feelings they had about their diagnosis as they tried to come to terms with their diagnosis. The ICM proposes that it is in this stage where family members become vigilant and accept responsibility over the individual that was sick (Morse & Johnson, 1991). Similarly, most participants in my study described their parents intervened and helped the adolescent incorporate the diabetes management components.

Gradually assisted by counselling, participants tried to regain some ‘balance or control’ in their lives. Illness theories suggest that there is a phase of adjustment that individuals go through to manage with their chronic illness (Johnson & Morse, 1991). In studies regarding heart attack victims, participants went through a time of coping with the impact that the heart attack would have in their life (Johnson, 1988). Similarly, the

participants in my study also went through a time of coping with the diagnosis.

Participants who were very confident in their abilities had a positive outlook towards the diabetes and they were able to incorporate different components of diabetes management.

In contrast, participants who had difficulty accepting the diagnosis and did not perceive it to be significant in their life did not respond with health promoting behaviours.

Subsequently, participants described times when family members intervened to assist with the transition. This type of action was found in other studies dealing with myocardial infarction victims (Johnson, 1988).

While the illness constellation model suggests that individuals go through a time of reassurance, the limited sample size and scope did not allow for exploration of this area in great detail (Morse & Johnson, 1991). Some participants in this study did seek reassurance and guidance from family members and this was described as being important to their continuing and sustaining new behaviours. Lastly, only a few participants described that they reached a time of balance when it came to their diabetes. The concept of "achieving a balance" has been explored by many researchers in the field of diabetes management (Morse & Johnson, 1991). Most importantly, participants in this study identified "balance" for certain diabetes management components within the context of their own lives. The process of coping with the diagnosis and incorporating the various components of diabetes management indicates that individuals' behaviours will vary throughout time. Thus health professionals need to recognize and support clients as they go through these various stages.

The phases adolescents with T<sub>2</sub>D may go through offer some guidance to their diabetes care. Firstly, it would be useful to assess the trajectory projection for the

adolescent with T<sub>2</sub>D. While concepts of the framework can be applied to practice, health professionals need resources such as guiding questions, to help them identify the specific phase the adolescent is in. Secondly, this model can be applied to adolescents with T<sub>2</sub>D over their life span and may potentially enhance the quality of care provided.

Developmentally, adolescence is one of the greatest periods of change throughout an individual's lifetime (Story, Neumark-Sztainer, French, 2002). During this time, body shapes change significantly, and independent and abstract cognitive processes begin, and the transition to acquiring the social values and roles of adulthood begin (Story et al., 2002). The participants' outlook towards the diabetes itself changed during the course of their illness and was shaped by their personal interpretations of the aetiology, time and mode of onset of illness. Medically accepted explanations for the causes of T<sub>2</sub>D included heredity and obesity. Hunt and colleagues (1998b) found that Mexican women living with T<sub>2</sub>D integrated the medical explanations along with personally relevant events and behaviours in their causal understandings of diabetes. Participants in my study who related their poor eating habits and lack of physical activity as reasons for their diabetes appearing were more likely to make alterations in eating habits and activity patterns. This behaviour was similar to findings in adults with T<sub>2</sub>D (Schoenberg et al., 1998). On the other hand, participants in my study who blamed the illness on genetic risk factors were less likely to alter their personal behaviours. The participants in this study tried to make sense of their illness and the treatment options. By understanding the complexity behind the diabetes itself, health professionals may be able to design strategies that will reach participants individually.

With regards to the relationships among beliefs and health behaviours, the findings of this study can be examined in relation to the expanded Health Belief Model. This theoretical model suggests that people need a reason to make changes: they need to believe that they are subject to serious consequences, that behaviour change can decrease the negative consequences, and that the benefits to making the change outweigh the costs of maintaining the status quo (Glanz, 2002). Other studies in people with diabetes have shown support for this model. In a sample of over 2000 adults with T<sub>2</sub>D, beliefs about treatment effectiveness and the perceived seriousness of diabetes were predictive of self-care. Furthermore, an individual's belief in treatment effectiveness was found to be a stronger predictor of behaviour change than barriers to adherence (Glasgow et al., 1997). In a prospective study of adolescents with T<sub>1</sub>D, beliefs in the effectiveness of the treatment regimen were predictive of better dietary self-care (Skinner et al., 2000; Skinner et al., 1998).

The findings of my study can also be seen as somewhat supportive of the Health Belief Model in that beliefs about the severity of consequences motivated at least some participants to change their behaviours. Participants taking anti-diabetic agents in this study shared similar thoughts towards insulin as the four adolescents with T<sub>2</sub>D in the pilot study conducted at B.C. Children's Hospital (Cairns, 2002). Participants in both studies believed that taking insulin was the "worst" thing that could happen to them. In addition, participants in this study were scared of needles and described being anxious about giving themselves insulin. Participants taking insulin believed their diabetes to be more serious than those not taking insulin, which supports findings that insulin is seen as an index of disease severity (Hampson, et al., 1990). While participants taking oral anti-



diabetic agents feared the thought of having to take insulin, participants taking insulin described being motivated to follow through with recommendations in order to not have to take insulin.

Similar to other studies, the health professionals in my study had different perspectives on the consequences of diabetes compared to the adolescents (Schoenberg et al., 1998; Anderson et al., 1995). In this study, the health professionals interviewed focused on the task of achieving glycaemic control in order to reduce the potential complications of T<sub>2</sub>D. While the risk of long-term physiological consequences motivated a few participants to incorporate diabetes management components, most participants were more concerned with the impact diabetes had on their relationships with friends and lifestyle. However, they did not follow many of the components of diabetes management because of the complexity of performing all these behaviours in their social life.

### **5.1.3. Family Members**

The family mediates the adolescent's dietary and lifestyle habits by procuring and providing food. The family also has influence over the adolescent's food attitudes, preferences and values (Story et al., 2000). In many cases, the mother took on an active role of gatekeeper regarding many aspects of the diabetes management. While it varied between participants in this study, parents were either watchful or inattentive when it came to incorporating recommendations. The participants, at varying times during their illness, perceived both parenting roles as being either supportive or unsupportive. It would have been beneficial to interview the parents to find out their perspective regarding their participation in the management.

Previous research suggests that greater family support is associated with better blood glucose monitoring and improved metabolic control for adolescents with T<sub>1</sub>D. Studies with adolescents with T<sub>1</sub>D have found that family support comes mainly in the form of tangible support such as meal planning, but emotional support is needed in forms of praise and validation of competence (Skinner et al., 1998; La Greca et al., 1998; Weinger et al., 2001). Likewise, in my study the participants acknowledged the need for assistance with meals and reminding to take oral anti-diabetic agents. However, they also found praise and encouragement, especially during the time of diagnosis, to be important. However, some participants mentioned the need for increasing independence from their families and did not want to always be watched over.

While family support can be helpful when one is initially diagnosed, the nature of the support changes throughout the course of illness. In my study, some participants reported their parents' involvement as supportive and caring, however at times it was annoying. Through their experience, some participants described their parent's watchful eye as frustrating. Increased autonomy is important for adolescents with T<sub>2</sub>D. Researchers have found that metabolic control and management deteriorates for adolescents when parents are not involved (Anderson et al., 1990; Ingersoll, 1986). In addition, studies with adolescents with T<sub>1</sub>D have shown that greater family support may result in conflict surrounding diabetes management behaviours (Anderson et al., 2002; Pendley et al., 2002; Skinner et al., 1998). Although I did not interview the parents, conflicts between the participants and the parents were observed during clinic sessions. These conflicts mainly related to monitoring blood glucose levels regularly, reporting of blood glucose values, and general adolescent habits surrounding performance. On occasion parents

commented on their frustration with their daughter or son not working “hard enough” to manage the diabetes. Lastly, some participants in my study described that they did not feel their parents understood how difficult it was to implement the diabetes management components, especially changing eating habits and becoming active.

Involving family members in the counselling process was found to be imperative in the implementation of the diabetes management components of adolescents with T<sub>2</sub>D. This aspect was also described as being the most challenging aspect for health professionals to address and manage. Unhealthy eating habits and lifestyles of family members were obstacles for many participants in my study. Researchers have repeatedly shown that altering eating habits and lifestyles are best achieved when family interventions are used (Sachiko, Perumean-Chaney, Sigman-Grant, 2002).

Taking into consideration the strong family history for T<sub>2</sub>D, including family members in the process of implementing health-promoting behaviours would be beneficial. Satin and colleagues (1989) used an intervention with adolescents with T<sub>1</sub>D. The intervention involved parental simulation of diabetes management. They found that this approach was more effective than the group without any simulation (Satin et al., 1989). This approach may assist adolescents with T<sub>2</sub>D in being more compliant. The challenge for health professionals is to develop interventions that address the lifestyle and health habits of the entire family.

#### **5.1.4. Close Friends and Peers**

An important aspect of an adolescent’s life is becoming part of a peer group. The peer group assumes that all of its members behave the same way (Hartup, French, Laursen,

Johnson, Ogawa, 1993). If the lifestyle of the adolescents with T<sub>2</sub>D does not fit with that of their peers, then there is a good chance that he/she will not follow through with the management of their diabetes (Pendley et al., 2002). The findings in my study were consistent with other adolescent health studies where friends were found to be both supportive and non-supportive in health promoting behaviours (Pendley et al., 2002).

La Greca et al. (1995) found that although family members provided support for some aspects of adolescents' treatment, friends provided more emotional and companionship support. While all participants let their friends know about the diagnosis, only a few discussed aspects surrounding their management practices with their close friends. Sharing their diagnosis with their friends may be part of trying to gain some independence from their parents. As suggested by Buhmester and Prager (1995) self-disclosure encourages individuals to develop close friendships and offers a mutual source of trust, intimacy and commitment. As these participants move forward through adolescence, they may disclose aspects surrounding the disease to their friends as a means of developing closer friendships and gaining independence.

While sharing their diagnosis with friends was a means of companionship, it was not consistently evident in this study that friends provided emotional support to all participants. Similar to other studies, participants were negatively influenced by "close friends" (Pendley et al., 2002; Thomas, Peterson, Goldstein, 1997). Young participants described being teased by friends for not being able to eat certain foods. Thomas and colleagues (1997) presented adolescents with T<sub>1</sub>D with hypothetical situations in which a choice was presented between completing diabetes management tasks or following peers. The majority of adolescents were more likely to not follow through with the diabetes

management tasks (Thomas et al., 1997). This lends support to integrating peer pressure management strategies into diabetes education.

In my study, all participants neglected to follow through with blood glucose monitoring in the presence of their friends. However, the older participants in this current study depicted stronger diabetes specific problem solving skills (i.e. finding alternatives or explaining their situation to their friends) than the youngest two participants. These older participants developed strategies to make “healthier” eating choices and test their blood glucose levels when they were out with friends.

While friends were found to be supportive with regards to some parts of their diabetes management, some participants reported the need to share their experience with adolescents living with diabetes. A study by Joseph and colleagues (2001) paired adolescents with T<sub>1</sub>D who were struggling with behaviour change. The participants reported that coaching was personal and helpful in managing their diabetes. Coaching differs from teaching in that the coach does not place emphasis on imparting new ideas, but rather focuses on supporting others in their efforts to reach a new goal (Joseph et al., 2001). While this strategy was shown to be beneficial, it was only tested on a small group of individuals who were in the contemplation stage of making lifestyle changes. Furthermore, it is unknown whether coaching would be effective in the long-term. Nonetheless, implementing this strategy may be beneficial to adolescents with T<sub>2</sub>D who are struggling with the diagnosis of the illness or its management. Furthermore, the concept of coaching may be important to the health professionals caring for adolescents with T<sub>2</sub>D. Learning to combine both teaching and coaching principles into one’s practice

may potentially enhance the quality of care provided. Future studies addressing the effectiveness of coaching for adolescents with T<sub>2</sub>D need to be done.

As shown in this study, peers can be supportive and non-supportive in the process of implementing diabetes management components for adolescent with T<sub>2</sub>D. Listening to the adolescents about their peer relationships may help health professionals adjust counselling strategies to include problem solving for adolescents with T<sub>2</sub>D. In light of this information, health professionals need to begin to develop support networks such as peer counselling.

#### **5.1.5. Social Context**

Events and special occasions influenced participants' management of diabetes that was similar to those identified by Remley and Cook-Newell (2001). They asked adolescents with T<sub>1</sub>D what situations were problematic for dietary adherence. They reported that holidays, friends and being upset were factors that made altering eating behaviours difficult. Similarly, participants in my study noted that these factors made it difficult for them to follow through with dietary recommendations. In addition, participants in my study noted that homework influenced their management practices specifically towards eating behaviours and becoming active.

Likewise, studies with adults with T<sub>2</sub>D have found that daily life schedules such as going to work influences one's ability to follow eating recommendations and incorporate physical activity (Anderson et al., 1995). Diabetes management components involve altering lifestyles and require life skills such as planning and time management. When things change in one's life, it is not uncommon that their diabetes practices may be

affected. Hence, while short-term goals may be initially required to initiate the process of incorporating new behaviours, participants may require long-term strategies so that they can identify how to cope with events that occur in their future for managing their diabetes.

#### **5.1.6. Community Members**

The role of social support has been examined at different levels within the literature. This study highlighted that community members such as teachers and resources such as diabetes workshops were positive facilitators in implementing lifestyle changes for the adolescent. Adolescence is a period of transition from dependence to independence, when adolescents begin to develop life skills (Kyngäs et al., 1998; Kyngäs & Rissanen, 2001). Depending on the adolescent and the school environment, teachers may assist by teaching adolescents with T<sub>2</sub>D skills such as time management. By taking time to understand the adolescents' interaction with teachers, health professionals could provide additional resources to help adolescents in developing life skills. Educational resources such as cooking classes offered by the Canadian Diabetes Association were items described as being helpful for some participants. Other researchers have shown that adolescents with T<sub>1</sub>D and adults with T<sub>2</sub>D who attained self-management skills and increased self-efficacy choose to invest in themselves by enhancing life skills and abilities. For participants who expressed interest in acquiring knowledge on their own and developing self-management skills health professionals should encourage the use of resources as mentioned and reinforce resources that may be beneficial to the entire family.

### **5.1.7. Health Professionals**

As reported in accounts of chronic illness experiences, health professionals play an important role in supporting disease management practices. Studies have examined the influence of health professionals on individuals with diabetes (Cohen et al., 1994; Hunt et al., 1998a; Pasquier-Fediaevsky et al., 1999). In studies where support from health professionals has been examined, the traditional role of information transmission has been repeatedly identified (Kyngäs et al., 1998). Likewise, in this study, the information provider role of the health professionals was indicated as being the most supportive when the participants were making changes and needed clarification or guidance.

Practical and instrumental support has traditionally consisted of access to resources and services (Skinner et al., 1998; Skinner et al., 2001; Kyngäs et al., 1998). However, in my study, support was found to expand beyond those two areas and involved setting goals and dealing with family conflicts. Health professionals can also influence care through emotional and expressive support (King, King, Rosenbaum, 1996). Most of the participants in my study revealed that they liked the health professionals at the clinic and over time, communicated some of the challenges they were facing with diabetes management to these health professionals. Building trusting relationships was illustrated in my study, as some participants described sharing family conflicts with the health professionals.

Studies have also shown that a collaborative relationship between a physician and a patient can positively influence an individual's health behaviour (Golin, DiMatteo, Gelberg, 1996; Lorenz et al., 1996). Differences between the perceptions of physicians and adolescents may constitute barriers to the relationship between a client and a health



professional. This was similar to findings in my study, as some participants believed that health professionals do not understand the difficulty behind incorporating the diabetes management components. The health professionals acknowledged that they have experienced instances where their counselling efforts have not always improved outcomes. However, as indicated by the health professionals, having the adolescents attend clinic sessions and attempting to include family members in the discussions was crucial in the management process.

Overall, relationships with health professionals need to be collaborative, take into consideration the adolescents' knowledge (Coates & Boore, 1996), and understand the adolescents' life. This is a challenge for health professionals as they attempt to assist the adolescents with T<sub>2</sub>D and family members to implement the diabetes management components. The development of a collaborative relationship between the health professional and the adolescent should be further explored.

## **5.2. Summary of Insights**

The insights into the management experiences of adolescents with T<sub>2</sub>D are summarized below:

- The findings emphasize the importance of recognizing individual variability with respect to what aspects of diabetes management adolescents with T<sub>2</sub>D are willing to incorporate into their lives.
- Incorporating new behaviours into ones' life involves managing emotions, thoughts and behavioural responses that change throughout time.

- Being cognizant of the individual responses an adolescent has towards diabetes is crucial to providing support.
- Implementing components of diabetes management is shaped by the experience of the diagnosis of the diabetes itself.
- The findings suggest that although participants attempt to exclude certain foods, they do not sustain such behaviours. Rather, trying to balance healthy foods with unhealthy foods is their goal.
- Participants are primarily concerned about the impact that these new behaviours are going to have in their life rather than the complications of diabetes.
- Counselling strategies incorporating ways to develop time management skills and problem solving skills may help the process of management.
- Innovative family based interventions are needed to address the impact that families have on the adolescents' behaviours.
- Peer support from other adolescents and adults with T<sub>2</sub>D who are successful self-managers would be beneficial to learning the management process.
- Resources from the Canadian Diabetes Association such as cooking classes may be beneficial for some participants and their families.
- A health professional's relationship with an adolescent with T<sub>2</sub>D is crucial to the adolescent's ability to implement the diabetes management components. Health professionals need to ask questions surrounding the adolescents' perceptions on their self-care behaviours and take into consideration the different life of these adolescents with diabetes.

In summary, the findings suggest that diabetes management is a complex phenomenon, encompassing several components, which have to be understood within the circumstances of the adolescent's life. Adolescents with T<sub>2</sub>D encounter various emotional, cognitive, and behavioural responses to the diagnosis of diabetes, as well as, to each of the diabetes management components. This study lends support to the perspectives for this particular group of adolescents with T<sub>2</sub>D and illustrates that the adoption of multiple strategies is needed. Perspective changes with time and reflects the needs of the individuals at a certain time and place in their life.

### **5.3. Study Limitations**

The results of this study must be interpreted in the light of certain limitations. The findings were generated from a sample size of 8 adolescents with T<sub>2</sub>D and 2 health professionals, and saturation of concepts was not reached. The participants were a heterogeneous group and thus, characteristics such as household composition and ethnicity were not replicated. These findings are only applicable to these specific adolescents in the B.C. Children's Hospital T<sub>2</sub>D clinic.

Another limitation of this study is sampling bias. Participants were recruited through their physician and during their counselling appointments. There is likely a difference in those who showed up regularly to the T<sub>2</sub>D clinic visits and were willing to be interviewed and those who did not attend. This limits the applicability of the findings to those willing to participate in a study. Adolescents with T<sub>2</sub>D who did not attend the clinic may be faced with other issues than those found in this study, or perhaps, they became self-managers and did not perceive themselves as requiring assistance.

Although key findings during the initial analysis were discussed with subsequent participants, complete findings were not sent to the participants for feedback. However, findings were discussed during follow-up visits and participants had the opportunity to add to their experiences that were documented in terms of field notes.

Furthermore, there is the possibility that participants provided socially desirable answers to questions. In order to reduce bias from reports, participants were asked to share their experiences surrounding their management experiences and were not criticized on whether they were “adhering” to the diabetes recommendations. Also, discrepancies during the interviews were clarified during the interview as member checks were conducted.

Lastly, an alternative theoretical perspective may have provided a different look at the management experience of adolescents with T<sub>2</sub>D. If I had taken a social constructivist perspective my interview questions would have been more open and the concepts emerging may have been different. For instance, perhaps the findings would have been more related to how their own identities (i.e. age, gender, socio-economic status) influenced their management experiences. Also, perhaps observing clinic counselling sessions along with multiple interviews may have provided further information on the nature of the relationships.

#### **5.4. Future Research Directions**

Despite these limitations, the findings provide interesting insight into the management experiences of adolescents with T<sub>2</sub>D. The findings bring forth the challenges perceived by the health professionals with regards to counselling and providing care. Additional

studies using more representative samples may also add to gaps in the current findings. Further studies should be undertaken to look at the transition stages that the adolescents with T<sub>2</sub>D undergo (i.e. from initial diagnosis through the adjustment process). Specific attention should be made to the emotional, cognitive and behavioural responses they experience as their illness progresses. Due to the limited sample size, concepts were not examined to saturation and thus it would be beneficial to further explore these concepts with a larger sample.

One of the most important finding of this study is that the role of the family needs to remain at the forefront of research for this population, as most diabetes management behaviour takes place within the household setting. The participants in this study come from a strong family history of T<sub>2</sub>D and as illustrated in many studies, behaviours such as dietary changes are more successfully implemented if family members take an active role in the process (Sachiko et al., 2002). Family members are intimately involved in the life of the adolescent with T<sub>2</sub>D. The way parents and siblings respond to the diabetes management components influenced the adolescent's behaviours towards the diabetes management components. Assessing parents' and siblings' behaviours will identify family barriers and benefits that they may have on the adolescents' management experiences. In addition, identifying perceptions from both parents and adolescents with regards to diabetes management responsibilities will provide guidance to health professionals with counselling. Lastly, future follow-up with these participants may be beneficial to identify needs of transition from an adolescent clinic to an adult clinic.

## **5.5. Clinical Implications**

The findings from this study highlight a number of clinical practice implications. Firstly, it seems evident that implementing diabetes management components involves emotional, cognitive and behavioural responses that evolve over time. In order for adolescents to learn to manage their diabetes, health professionals need to be aware of the emotional and cognitive responses they have to each of the diabetes management components. Asking key questions at different times of their diabetes experience may indicate what type of support may be beneficial for each individual at that time.

Another critical implication of this study is the challenge it poses to encouraging family members of adolescents with T<sub>2</sub>D to incorporate health-promoting behaviours along with the adolescents. Family members provide necessary physical and emotional support to each other due to their proximity and intimacy (Tillotson et al., 1996). This study highlighted the significance in having strong family support when altering eating habits and incorporating physical activity into one's life. Integrating a health professional with specialization in family counselling and therapy such as a psychologist may be beneficial to the adolescents with T<sub>2</sub>D. Issues relating to independence and parent-adolescent conflicts can be identified and strategies can be developed to assist the entire family network.

In addition to family support, peer coaching from other adolescents with T<sub>2</sub>D was found to be beneficial in the process of managing the diabetes. As friends were not always supportive, support groups that emphasize successful strategies for dietary and lifestyle changes should be part of the educational process. Adolescents who have been successful problem solvers can share their perspectives with the peer support groups.

Moreover, self-efficacy plays a central role in implementing behaviour and lifestyle changes. Peer support groups may provide adolescents with the opportunity to increase their belief that changes can be made. Furthermore, incorporating skill-building activities into education programs will also help to increase time management skills and practice problem solving techniques. While health professionals focused on blood glucose testing as being the main focus of diabetes management, the adolescents were more concerned with the psychosocial impact of the recommendations. Perhaps discussing the concerns adolescents have with each specific recommendation at varying times of their illness may assist with the management. However, health care professionals need to know as much about the social context of clients' goals, problems and aspirations, as well as their eating, exercising, medication and blood glucose monitoring practices.

Health professionals play an important role as they assist people with diabetes to identify and understand their perspective about their diabetes and management. In turn, health professionals need to listen to the adolescents to understand what is important to them. Furthermore, perspectives are not static and health professionals will need to tune their strategies according to the individual adolescents' needs.

These findings are useful in developing counselling strategies for each of the diabetes management components. Participants described the following strategies as being helpful: establishing goals, receiving positive feedback and balancing healthy eating. Allowing the adolescent living with T<sub>2</sub>D to choose a task that they believe they can incorporate into their life may help form the base of making changes.

This study adds to the importance of expanding resources to health professionals, adolescents and their families. Adolescents are going through a transition phase in their

life and require making many new lifestyle changes as they are attempting to develop life management skills of their own. Resources such as peer coaching, family and/or teenage cooking course, time management and emotional management workshops would be beneficial to everyone involved in this area.

Finally, incorporating health-promoting behaviours takes time and will vary according to the adolescents' personality, coping styles, outlook, understanding, family and social support networks. By understanding the daily challenges adolescents with T<sub>2</sub>D face and taking them into consideration, health professionals will be able to enhance management skills and improve the health status of adolescents with T<sub>2</sub>D.



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## **APPENDIX D: ADOLESCENTS' INTERVIEW GUIDE**

### **A. Opening**

Hello my name is Roula Tzianetas. I am a Master's Student in Human Nutrition at UBC. I am interested in learning more about your experiences with managing your diet with regards to your diabetes.

1. I would like to start off with getting to know you. Tell me a little bit about yourself.
  - age
  - diagnosis
  - family
  - parents occupations
  - cultural background
  - grade in school
  - lifestyle/interests
2. Take me through a typical day in your "shoes".
  - meals
  - snacks
  - school
  - friends
  - medication

### **B. Dietary Counselling Strategies**

1. Can you tell me about the time when you were first diagnosed with diabetes?
  - home
  - school
  - doctor's office
  - feelings
  - thoughts
2. Describe certain strategies you have learned to use to manage your diabetes.
  - eating
  - exercise
  - medication
  - blood glucose monitoring
3. How do you feel about using these techniques?
  - frustrated

- angry
  - stressful
4. Can you tell me a story of when your diabetes was difficult to manage?
    - check blood glucose
    - physician
  5. Can you tell me a story of when your diabetes was easy to manage?
    - check blood glucose
    - physician
  6. Where do you go to get advice to help manage your diabetes?
    - nutritionist/dietitian
    - doctor
    - family
    - friends
    - books
  7. What food or nutrition advice have you received?
    - prescribed diet plan
    - carbohydrate exchanges
  8. How do you feel about the advice?
    - frustrated
    - angry
    - indifferent
  9. Did you like the way the advice was discussed?
    - easy to follow
    - some difficulty
    - very difficult
  10. Can you explain to me how you think diabetes works for you?
    - insulin
    - food
    - sugar
  11. What do you think caused you to develop diabetes?
    - hereditary
    - dietary habits
    - exercise
  12. Why do you think it started when it did?
    - age
    - hereditary

### **C. Adherence Factors**

1. Can you tell me about a time when you didn't follow the recommendations?
  - happy
  - sad
  - frustrated
  - don't care
2. Do you get help from people to follow the recommendations?
  - friends
  - parents
  - family Members
3. Tell me what you think is happening with you and your diabetes.
  - blood sugars
  - hyperglycaemic/hypoglycaemic reactions
4. Can you tell me about some of the questions or concerns you may have with diabetes?
  - social life
  - health complications

### **D. Conclusion**

- End the interview by summarizing key points discussed.
- Ask participant for any feedback with regards to the interview.
- Thank you for your participation. Please be assured that the information from this interview will remain completely confidential.

## APPENDIX D: HEALTH PROFESSIONALS' INTERVIEW GUIDE

### A. Opening

Hello my name is Roula Tzianetas. I am a Master's Student in Human Nutrition at UBC. I am interested in learning more about the experiences of adolescents living with type 2 diabetes.

1. I would like to start off with getting to know you. Can you please tell me a little bit about yourself?  
(Probes)

- years working with adolescents with type 2 diabetes
- area of practice
- professional background

2. Thinking about a "typical" and "non-typical" type 2 adolescent with diabetes what is your approach in treating diabetes?

- diet/food –
- exercise –
- medications –
- blood glucose testing –
- psycho-social well-being

3. Describe some of the barriers and facilitators to 'good' self-care among the adolescents with type 2 diabetes?

- diet/food – eating patterns, food quantity; sugar/sweet foods
- exercise – getting started, knowing what to do
- medications – remembering
- blood glucose testing – remembering, fear of pokes, embarrassed in front of people/friends
- psycho-social well-being

4. As you've worked with these adolescents can you describe how these barriers and facilitators change over the course of their illness?

change

- Ex.: Family lifestyle → if family change's habits adolescents

4. Can you describe an example of when things are not going well with an adolescent and what approaches you use?

- Ex-- no shows

5. As a health care professional how/where would you like to see the adolescent's progress?
6. Can you describe what other services/resources would be useful for adolescents with type 2 diabetes?
  - internet chat line
  - family support centre
  - motivation exercises
  - group counselling
  - camp settings
7. With the experience that you have had in this are, describe how you think adolescents perceive the severity of their disease?  
(Probes)
  - consequences



**APPENDIX E: CODING SCHEME**  
**Pre-Diagnosis Phase**

<b>In vivo Codes</b>	<b>Refined Coding</b>	<b>Conceptual Code</b>	<b>Explanation for the Codes</b>
Drinking a lot  Going to the bathroom a lot more  Being tired all the time  Not able to sleep as much  Not being able to get up in the morning  Being dizzy  Drinking a lot  Getting thirsty Not feeling well  Not feeling right  Getting headaches Being shaky a lot	Having sign or symptom	Reading body	References participants make that caused them to take notice that something was different
Not feeling any symptoms	Not recognizing sign/clue	Reading their body	References participants make that explain why they did not think that anything was wrong with them.
Getting an infected toe  Seeing her blood glucose test	Visually seeing a sign/clue	Reading their body	References participants make that caused them to take notice that something was different
Being a fluke	Rationalizing the way of		References participants

<b>In vivo Codes</b>	<b>Refined Coding</b>	<b>Conceptual Code</b>	<b>Explanation for the Codes</b>
	finding out		made with regards to how they rationalized these sign/symptoms/clues.
Being at a first responders course	Contextual factor		The places where the participant was when they started to notice symptoms/clues/signs
Chalking up to stress	Rationalizing symptoms		References participants make with regards to how they rationalized these sign/symptoms/clues.
Getting formal test Going to the doctor	Getting medical expert opinion	Seeking advice	Specific accounts describing participants response to the sign/symptoms/clues
Didn't know what to think	Being confused/uncertain		Specific accounts describing participants cognitive responses to the sign/symptoms/clues
Not knowing what is wrong	Uncertainty		Specific accounts describing participants cognitive responses to the sign/symptoms/clues
Knowing mom is diabetic	Thinking about possible risk factor Being suspicious		References participants make that results in them being suspicious

## **APPENDIX F: MEMO**

### **Finding Out**

What is it about the events leading up to finding out that is so interesting? They are going through a process. They are trying to figure out what is causing them to have all these different feelings or how their bodies are working. I grouped all these in vivo codes under one code of "having a sign/symptom". These are all signs that made them listen to their bodies and seek medical help. I think the most interesting thing with regards to the initial diagnosis part is that some of the participants have suggested that they knew that they were "sort of at risk". Some knew that they were at risk because they tested their blood glucose with the use of a meter and/or the strong family risk. These participants described their initial diagnosis as either an "accident" or a "fluke".

Some participants suspected something was wrong and sought medical. These participants started to read their body for changes. For instance, these participants felt some of the common symptoms of diabetes such as: frequent urination, excessive thirst, extremely tired, nausea, headaches and blurred vision. Participants began to attribute these feelings to factors such as stress. Once they felt that they could not control these symptoms anymore they began to tell other individuals such as their parents who urged them to seek medical attention. They only wanted medical attention once these symptoms were not bearable.

## APPENDIX G: CONCEPTUAL DIAGRAM/MAP

