

A BITTERSWEET EXISTENCE: THE LIVED EXPERIENCES OF FOUR  
YOUNG WOMEN WITH DIABETES MELLITUS

by

KAITLYN TARA WALKER

A thesis submitted to the Faculty of Education  
in conformity with the requirements for  
the degree of Master of Education

Queen's University

Kingston, Ontario, Canada,

July, 2008

Copyright © Kaitlyn Tara Walker, 2008



Library and  
Archives Canada

Bibliothèque et  
Archives Canada

Published Heritage  
Branch

Direction du  
Patrimoine de l'édition

395 Wellington Street  
Ottawa ON K1A 0N4  
Canada

395, rue Wellington  
Ottawa ON K1A 0N4  
Canada

*Your file* *Votre référence*

ISBN

*Our file* *Notre référence*

**NOTICE:**

The author has granted a non-exclusive license allowing Library and Archives Canada to reproduce, publish, archive, preserve, conserve, communicate to the public by telecommunication or on the Internet, loan, distribute and sell theses worldwide, for commercial or non-commercial purposes, in microform, paper, electronic and/or any other formats.

The author retains copyright ownership and moral rights in this thesis. Neither the thesis nor substantial extracts from it may be printed or otherwise reproduced without the author's permission.

**AVIS:**

L'auteur a accordé une licence non exclusive permettant à la Bibliothèque et Archives Canada de reproduire, publier, archiver, sauvegarder, conserver, transmettre au public par télécommunication ou par l'Internet, prêter, distribuer et vendre des thèses partout dans le monde, à des fins commerciales ou autres, sur support microforme, papier, électronique et/ou autres formats.

L'auteur conserve la propriété du droit d'auteur et des droits moraux qui protègent cette thèse. Ni la thèse ni des extraits substantiels de celle-ci ne doivent être imprimés ou autrement reproduits sans son autorisation.

---

In compliance with the Canadian Privacy Act some supporting forms may have been removed from this thesis.

Conformément à la loi canadienne sur la protection de la vie privée, quelques formulaires secondaires ont été enlevés de cette thèse.

While these forms may be included in the document page count, their removal does not represent any loss of content from the thesis.

Bien que ces formulaires aient inclus dans la pagination, il n'y aura aucun contenu manquant.

  
**Canada**

## ABSTRACT

This study examined the lived experience of diabetes as told by four young women with type 1 and type 2 diabetes mellitus.

Assuming a qualitative approach, I asked participants to describe their medical, academic, social, and psychological experiences during a single, guided open-ended interview. Analysis of the data revealed the subjective and unique nature of the illness experience, and the variety of ways in which diabetes had influenced Abbey's, Olivia's, Hannah's, and Melinda's life choices and existence. Despite differing in the ways in which they experienced their illness, there were some similarities that existed across cases. These women all faced a variety of challenges throughout their lives, ranging from difficulties with the treatment regimen, with the lack of diabetes awareness in the school setting, and in coming to terms with their illness.

Applying the Shifting Perspectives Model of Illness (Paterson, 2001) to the stories told by these four women provided an in-depth view of how these four individuals with diabetes made meaning of their experiences. Because these women viewed their lives primarily from a wellness in the foreground perspective, they were able to identify the many positive ways in which diabetes had transformed their lives.

This study contributes to the understanding of the lived experience of diabetes in the literature, and is one of the few studies to explore the diabetes experience using a theoretical framework. Recommendations for teachers are made based on the participants' interpretations of the needs of diabetic students in the classroom, and based on suggestions offered by these four women.

## ACKNOWLEDGEMENTS

Throughout my journey as a graduate student, I have encountered several people who have helped me forge my path in the world. Although at times the bumpy road seemed as if it would never end, there were always people waiting at the path's edge, offering me a place of refuge when I needed it the most. Without these individuals in my life, my journey would have been incomplete. I would like to first extend my sincere thanks to the participants of this study. In sharing your stories with me, you have opened my eyes to the world of diabetes, and have provided valuable insight into how teachers can meet the needs of students with diabetes in the classroom.

To my supervisor, Dr. Nancy Hutchinson; thank you for being my mentor, my confidante, and most of all, my friend. You have been an immense help not only in writing this thesis, but have also provided invaluable guidance through the difficult and happy life events that have occurred over the past two years.

To my committee member, Dr. John Freeman; thank you for your helpful insight, last minute edits, and inspiring metaphors. You have made my three years at the Faculty of Education some of the most enjoyable and enlightening years of my entire university experience.

To my parents, thank you for accepting all long-distance charges incurred as I spoke with you for hours about my troubles and triumphs in the graduate program. You have always been my voice of reason, and I am eternally grateful.

To my three sisters, Robyn, Keirsty, and Jenn; thanks for your words of wisdom, encouragement, and coffee dates. Your insights into the writing process and the world of APA format have been very useful.

And finally a special thanks to Dan, for being a constant source of support in my life. You have got me through many stress-filled days and hypoglycemic rants. Thanks.

## TABLE OF CONTENTS

ABSTRACT .....	i
ACKNOWLEDGEMENTS .....	ii
CHAPTER 1: INTRODUCTION.....	1
Purpose .....	4
Rationale.....	5
Definition of Key Terms .....	7
Previous Classifications of Diabetes Mellitus .....	7
Type 1 Diabetes Mellitus.....	8
Type 2 Diabetes Mellitus.....	9
Insulin .....	10
Finding my Place in the Study.....	11
Overview of Thesis.....	12
CHAPTER 2: REVIEW OF LITERATURE .....	13
Medical Implications of Diabetes.....	14
Medical Complications of Diabetes Mellitus .....	14
Treatment of Diabetes in Children and Adolescents .....	16
Diabetes in the School .....	17
Canadian Laws and Recommendations of the CDA .....	18
The Teacher and Diabetes .....	21
The Student and Diabetes: Academic Abilities and Student Needs.....	24
Diabetes in the School Environment .....	28
Social Implications of Diabetes.....	31

Parental Support and the Adolescent Need for Autonomy.....	32
Relationships with Friends .....	34
Psychological Impact of Diabetes Mellitus .....	40
Depression and Diabetes Mellitus .....	40
Disturbed Eating Behaviour and Eating Disorders.....	43
Theories of Chronic Illness.....	48
Chronic Illness as a Biographical Disruption.....	48
The Shifting Perspectives Model of Illness .....	50
CHAPTER 3: METHODOLOGY .....	53
Recruitment of Participants .....	54
Description of the Participants .....	56
Abbey .....	56
Olivia .....	57
Hannah.....	58
Melinda.....	58
Data Collection.....	59
The Interview.....	59
Data Analysis.....	63
CHAPTER 4: DIAGNOSIS DURING ADOLESCENCE.....	67
Abbey’s Story: The Long and Bumpy Road .....	68
Medical Experience .....	68
School Experience .....	72
Diabetes in Secondary School. ....	72

Diabetes in University.....	74
Social Support .....	76
Family Support.....	76
Friend Support.....	77
Dealing with the Developmental Challenges of Diabetes .....	78
Summary of Abbey’s Experiences .....	82
Olivia’s Story: Learning to Live with the Terrible Roommate .....	83
Medical Experience .....	83
School Experience .....	87
Diabetes in Secondary School .....	87
Diabetes in College.....	89
Social Support .....	90
Family Support .....	90
Friend Support.....	91
Dealing with the Developmental Challenges of Diabetes .....	92
Summary of Olivia’s Experiences .....	98
CHAPTER 5: DIAGNOSIS DURING CHILDHOOD .....	99
Hannah’s Story: Not Just a Sick Person .....	99
Medical Experience .....	99
School Experience .....	103
Diabetes in Elementary School.....	103
Diabetes in Secondary School .....	107
Diabetes in University.....	110



Social Support .....	110
Family Support .....	110
Friend Support .....	112
Dealing with the Developmental Challenges of Diabetes .....	114
Summary of Hannah's Experiences .....	118
Melinda's Story: A Normal Life .....	119
Medical Experience .....	119
School Experience .....	122
Diabetes in Elementary School .....	122
Diabetes in Secondary School .....	125
Diabetes in University .....	127
Social Support .....	127
Family Support .....	127
Friend Support .....	128
Dealing with the Developmental Challenges of Diabetes .....	129
Summary of Melinda's Experiences .....	134
CHAPTER 6: DISCUSSION .....	135
Medical Experience .....	135
School Experience .....	140
Social Support .....	143
Family Support .....	143
Friend Support .....	144
Dealing with the Developmental Challenges of Diabetes .....	146

Revisiting Bury’s Theory of Biographical Disruption .....	151
The Shifting Perspectives Model of Illness .....	152
Illness in the Foreground .....	153
Shifting to a Wellness in the Foreground Perspective.....	154
Shifting to an Illness in the Foreground Perspective .....	155
Strategies to Maintain a Wellness in the Foreground Perspective .....	156
Paradoxes that Arise .....	157
Limitations.....	158
Suggestions for Teachers.....	160
Just do some Research! .....	161
Notice the Signs.....	161
Teach the Class about it.....	162
Keep the Child from Feeling Excluded .....	163
Future Directions for Diabetes Education .....	165
Suggestions for Further Research.....	166
The View from the Outside .....	167
REFERENCES .....	170
APPENDIX A: EMAIL LETTER OF RECRUITMENT .....	188
APPENDIX B: LETTER OF INFORMATION.....	189
APPENDIX C: CONSENT FORM.....	190
APPENDIX D: INTERVIEW GUIDE.....	191
APPENDIX E: CASE PROFILE STORIES .....	197
Abbey’s Story: The Long Bumpy Road.....	197

Olivia's Story: Learning to Live with the Terrible Roommate .....	203
Hannah's Story: Not Just a Sick Person .....	209
Melinda's Story: A Normal Life .....	216

## CHAPTER 1: INTRODUCTION

Imagine living in a world where you are constantly bombarded with commercials and advertisements of fast-food and sweets; where chips, candy, and pop are sold at every corner store; where donut shops and bakeries occupy countless city blocks. Imagine living in a place where holidays revolve around candy, where drinking alcohol or eating out is one of the main ways to socialize, where others can partake freely in these celebrations of food without immediate threats to their health. Now imagine knowing that a single miscalculated dosage of insulin, or a moment of weakness in the face of temptation could cause a dramatic downward spiral in your overall health, resulting in both short-term and long-term complications. For children and adolescents living with diabetes mellitus in Canada, this world is not fictional; this world is their reality.

Diabetes mellitus is a chronic medical condition that stems from the body's inability to sufficiently produce or properly use insulin, a hormone that is necessary for the appropriate use of glucose as an energy source in the body. Without insulin, glucose cannot enter cells in the peripheral tissue and becomes trapped in the blood stream, leading to elevated blood glucose levels, or hyperglycemia. Over time, chronic hyperglycemia can lead to life-threatening and debilitating complications such as heart disease, kidney failure, and blindness (Silverthorn, 2001). Despite international attempts at finding a cure for diabetes, the fourth leading-cause of death worldwide (International Diabetes Federation, 2007), no such remedy has yet been discovered. Individuals must instead rely upon a strict regimen of antidiabetic medication, daily insulin injections, controlled diet, exercise, and close monitoring of blood glucose levels in order to lead a relatively normal life.

According to the Canadian Diabetes Association (2007), more than 2 million Canadians are currently living with diabetes. By the year 2010, this number is expected to increase to 3 million, reaching epidemic proportions (Canadian Diabetes Association, 2007). Although the greatest increase in incidence has occurred in adult populations, the prevalence of type 1 and type 2 diabetes in children and adolescents has greatly increased over the past decade (Canadian Diabetes Association, 2007). Due to the rapidly rising incidence of diabetes in children, type 1 diabetes mellitus (T1DM) has become one of the most common chronic conditions among school-age children, affecting approximately 1 in 400 children under the age of 12 (Canadian Diabetes Association, 2007). Type 2 diabetes (T2DM), which had at one time been considered to occur only in adults, is currently on the rise in younger populations, affecting children as young as 5 to 8 years old in Ontario (Public Health Agency of Canada, 1999).

Despite the rapidly increasing prevalence of diabetes, many Canadians are unaware of the risks and complications associated with this disease, having never learned about diabetes (Canadian Diabetes Association, 2007). This lack of public awareness has added to the hardships faced by children and adolescents living with diabetes, denying them the care and support that they require, and placing them at risk for future diabetes-related complications (Canadian Diabetes Association, 2007).

Because children and adolescents spend the majority of their time at school, the lack of diabetes awareness that exists among educators and students is particularly concerning. Recent studies evaluating the level of diabetes knowledge possessed by school staff indicate that the majority of teachers are receiving inadequate or no training in the field of diabetes, and feel unprepared to deal with medical emergencies related to poor blood glucose control (Gormanous, Hunt, Pope, & Gerald, 2002; Hayes-Bohn,

Neumark-Sztainer, Mellin, & Patterson, 2004; Nabors, Lehmkuhl, Christos, & Andreone, 2003). This lack of awareness is reflected not only in the way teachers respond to medical emergencies, but also in the classroom rules they employ, the routines they follow, and the foods or treats they serve (Nabors et al., 2003). Peers frequently demonstrate a similar lack of awareness about diabetes, often rejecting chronically ill students for fear that the disease is contagious, or treating them differently because of the peculiar nature of the medical treatments involved (Cheung, Young, & Canham, 2006).

Recognizing the pervasive lack of diabetes knowledge that exists in schools, diabetes educators across Canada and the United States have attempted to increase the level of awareness through various instructional methods including in-class instruction, videos, pamphlets, and CD-ROMs. Although there have been numerous programs designed to educate school personnel on diabetes, program evaluations indicate that a purely medical approach to diabetes education is ineffective in increasing the overall level of understanding or care given to the student with diabetes in the classroom (e.g., Cunningham & Wodrich, 2006; Gesteland, Sims, & Lindsay, 1989; Husband, Pacaud, Grebenc, & McKiel, 2001). In focusing solely on the medical aspects of diabetes, these programs have disregarded many aspects of the overall illness experience, adding to the common misperception of diabetes as being an exclusively medical problem (Cunningham & Wodrich, 2006). In his 1987 book, *Awakenings*, Oliver Sacks warned that it is not possible to study the impact of a disease as a whole without considering the individual.

There is nothing alive which is not individual: our health is ours, our diseases are ours, our reactions are ours—no less than our minds or our faces. Our health, diseases, and reactions cannot be understood in vitro, in

themselves; they can only be understood with reference to us as expressions of our nature, our living, our being here...in the world. (p. 4)

If teachers and peers are to provide a source of positive support for the child or adolescent with diabetes, they must first understand the disease in its entirety in relation to the individual.

### Purpose

The purpose of this study is to learn about what it has been like for four young women to live with type 1 and type 2 diabetes. In listening to the women's personal accounts of life in the face of diabetes, I hope to understand their experiences living with this disease, and how it has shaped their lives, identities, and choices.

The specific research questions that guided the design and analysis of this qualitative study were:

1. How do these young women interpret their experiences with diabetes?
2. What do these women feel impeded or promoted adherence to the diabetic regimen?
3. How did diabetes affect the women's physical, social, emotional, and academic experiences?
4. What should teachers know about diabetes?

The results of this study provide the reader with a detailed account of what it has been like for four young women to live with diabetes during their elementary and secondary school years, and could serve to raise awareness among teachers and peers regarding the vast implications of diabetes mellitus.

## Rationale

According to the Canadian Diabetes Association (CDA), “school personnel should possess basic knowledge about diabetes and be able to recognize and respond to hypoglycemia and hyperglycemia” (CDA, 2008). To increase the understanding of diabetes among school staff, the CDA has provided principals and teachers alike with various informational pamphlets, instructional videos, and interactive CD-ROMs. Despite the abundance of diabetes education programs in both Canada and the United States, teachers have not learned significantly more about diabetes (e.g., Gesteland et al., 1989; Husband et al., 2001). In 1989, Gesteland and colleagues evaluated the effectiveness of two diabetes education programs frequently used to increase the level of diabetes awareness among teachers. A group of 156 teachers and school nurses participated in the study, and were divided into three groups, each of which received a different method of instruction. The first group, the program group, participated in a training session involving a 13-minute video, a group review of two handouts, and a question-answer period with a qualified diabetes educator. The second group, the self-taught group, had access to the video and handouts, and was instructed to look at them on their own time. Of the participants in the self-taught group, only 21% took the time to review the material. The final group, the control group, received no supplemental information on diabetes until after the post-test had been administered. Following the post-test, Gesteland and colleagues discovered that there was no significant increase in the teachers’ level of diabetes knowledge in any of the three groups.

In a more recent study, Cunningham and Wodrich (2006) received similarly discouraging results following their attempt at educating teachers on the medical and classroom implications of type 1 diabetes mellitus. The researchers split 90 teachers into



three groups. The first group received no disease information on type 1 diabetes, the second group received basic disease information, and the third group received basic disease information and a list of classroom implications. Each teacher was asked to create a list of accommodations that would be appropriate for a hypothetical student with type 1 diabetes. Although the teachers who had received disease information and classroom implications were better able to accommodate the hypothetical student, only 47% were able to link various classroom behaviours to the disease.

Recognizing the somewhat impersonal nature of previous diabetes education programs, Jarrett, Hillam, Bartsch, and Lindsay (1993) approached the problem from a different angle. These researchers recruited 49 parents of children with diabetes, and in a 2-hour session taught these parents how to educate teachers on diabetes. The presentation emphasized recognizing and responding to hypoglycemia and hyperglycemia, the importance of dietary management, and the unique diabetic characteristics of the child. Prior to meeting with the child's teacher, parents were given an additional handout to help them in their 20-30 minute presentation to the teacher. The 34 educators who participated in this study completed a pre-test and post-test following the presentation. Jarrett and colleagues found a significant improvement in the teachers' understanding of diabetes, and attributed this increase in knowledge to a better understanding of the child's individual needs.

While having parents educate the teacher regarding the needs of their child can increase the level of care given to diabetic students at school (Jarrett et al., 1993), parents may unintentionally provide the teacher with a disproportionate view of the seriousness of their child's diabetes (Urquhart Law, 2002). In his 2002 study, Urquhart Law found that mothers often reported worse diabetes consequences, greater emotional impact, and

greater variability in the course of diabetes than their diabetic sons or daughters. Since children and adolescents may have different perceptions of their condition and needs when compared to their parents, it might be helpful for diabetic students to speak with their teachers and peers about their personal experiences living with a chronic illness. Although children and adolescents are in the unique position to provide an accurate portrayal of life with diabetes, many choose to keep their diabetes hidden, and are unwilling to share it with others (e.g., Nabors et al., 2001). Should the student be reluctant to discuss his or her personal experience with the teacher or class, it would be helpful to have case studies readily available that illustrate the difficulties and benefits of life with diabetes. The personal narratives of the four young women living with diabetes that were collected in this thesis may provide teachers with a clear understanding of what it means for these individuals to live with diabetes, and may one day be used to augment the level of diabetes awareness among teachers and students in the schools.

### Definition of Key Terms

#### *Previous Classifications of Diabetes Mellitus*

From Arateus' description of diabetes as "the melting down of flesh and limbs into urine," to Thomas Willis' reference to the "pissing evil," diabetes mellitus has undergone numerous name changes throughout the years. Prior to 1979, diabetes mellitus was classified according to the age of onset of the disease. At that time, there were only two recognized forms of diabetes: childhood-onset diabetes, which occurred only in children and adolescents, and adult-onset diabetes, which affected people over the age of 18. When it became apparent that these two forms of diabetes differed not only in the age of onset but also in the means of insulin disruption, the National Diabetes Data group introduced a standardized nomenclature and system of classification that was endorsed by

the World Health Organization one year later. The new system of classification reflected advancements in the understanding of the mechanisms of insulin disruption, replacing the previously known childhood-onset diabetes mellitus with the name insulin-dependent diabetes mellitus (IDDM), and adult onset diabetes mellitus with the term non-insulin dependent diabetes mellitus (NIDDM). Once again, the subtypes of diabetes underwent a change in nomenclature when it became apparent that insulin could be used to treat individuals with NIDDM. The new classification system that is currently used in the medical profession identifies four types of diabetes mellitus: type 1, type 2, gestational diabetes, and “other specific types” (Feudtner, 2003). For the purpose of this thesis, the term diabetes mellitus is used to refer only to type 1 and type 2 diabetes; the two most common forms of the disease.

### *Type 1 Diabetes Mellitus*

Under the previous classification systems, type 1 diabetes was known as childhood-onset diabetes, juvenile diabetes, and insulin-dependent diabetes mellitus. Type 1 diabetes mellitus (T1DM) is characterized by the loss of insulin-producing beta cells of the pancreas, resulting in a deficiency of insulin. For reasons that as yet remain unclear, the body of an individual with type 1 diabetes launches an attack on its own cells, resulting in an autoimmune reaction, and the destruction of insulin-producing beta cells of the pancreas (Gould, 2002). As increasing numbers of beta cells are destroyed, insulin production ceases, and the body is no longer capable of processing glucose effectively. As a result, glucose levels in the blood increase, putting the individual at risk for several complications if not properly treated. Although it is not clear what triggers the autoimmune reaction in all cases, it is believed that in some individuals, the onset of diabetes may be triggered by some sort of infection, usually viral in nature, or in rare

cases by stress or environmental exposure to certain drugs or chemicals (Silverthorn, 2001). Although a genetic link has been found in some individuals, it is believed that an environmental trigger is still required to activate the inherited susceptibility to type 1 diabetes.

The onset of T1DM is usually acute, developing over a course of a few days or a few weeks. Type 1 diabetes usually develops before the age of 25; however, it can occur at any age, and affects both sexes equally (Silverthorn, 2001). Although there is currently no cure for type 1 diabetes, this chronic condition can be managed through a strict regimen of insulin injections, glucose testing of the blood, and adjusting insulin intake according to the amount of food eaten and exercise levels. If appropriate care is taken in adherence to the diabetic regimen, treatment should not impair normal activities.

### *Type 2 Diabetes Mellitus*

Type 2 diabetes mellitus (T2DM) is the most common form of diabetes, affecting 90% of all individuals diagnosed with diabetes (Canadian Diabetes Association, 2007). Previously known as adult-onset diabetes, obesity-related diabetes, and non-insulin dependent diabetes, type 2 is characterized by insulin resistance in peripheral tissue, and a reduction in the amount of insulin secreted by the beta cells of the pancreas. Type 2 occurs when insulin continues to be produced by the pancreas, but for a variety of reasons is not properly used in the body (Gould, 2002). In the early stages of this disease, the predominant abnormality is a reduced insulin sensitivity, and there are often elevated levels of insulin in the blood as the pancreas tries to compensate for the insulin insensitivity. At this stage, elevated levels of blood glucose can typically be reversed by medications that improve insulin sensitivity or reduce glucose production by the liver. As the disease progresses, the impairment of insulin secretion worsens, and therapeutic

replacement of insulin often becomes necessary. Although obesity is thought to predispose individuals to type 2 diabetes, other factors include aging and family history of diabetes (Silverthorn, 2001). Type 2 usually occurs later in life; however in recent years, more and more cases of T2DM are coming to light in young people (International Diabetes Federation, 2007). Type 2 is usually first treated by increasing physical activity, decreasing carbohydrate intake, and losing weight in a bid to restore insulin sensitivity. In certain cases it is possible to achieve long-term satisfactory glucose control with these measures alone. When these strategies are no longer effective, oral antidiabetic drugs are used to improve insulin production, to regulate inappropriate release of glucose by the liver, and to ease insulin resistance to a certain extent (Feudtner, 2003). As further impairment of beta cell insulin secretion ensues, insulin therapy is required to maintain normal or near normal glucose levels.

### *Insulin*

Insulin, or the “hormone of plenty” is a hormone that is found in humans and animals that is released by the pancreas after feeding. During digestion much of the food we eat is broken down into glucose, and the glucose enters the blood stream where it can be transported to various cells in the body that require this type of sugar for energy. In a healthy individual, the hormone insulin acts as a key, unlocking doorways into the cells and permitting glucose to pass through the cellular membrane where it can be converted to useable energy. In individuals who have diabetes, this key, insulin, is gone. Without insulin, there is no way for the glucose to travel from the bloodstream into individual cells. As a result, the cells begin to starve, and the level of glucose in the blood rises to unhealthy levels (Silverthorn, 2001).

### Finding my Place in the Study

Although I entered into the study of diabetes as an outsider, I was not approaching the topic uninformed. Having completed an honours degree in life sciences, I have a strong background knowledge of the medical particularities of both type 1 and type 2 diabetes. Before entering the Faculty of Education, I had intended to pursue a career in pediatrics. It was not until I recognized the extent to which medical practitioners often focus on the symptoms of illness rather than the illness experience that I realised I wanted something more in my chosen profession.

At the time that I began this thesis, I had been recently diagnosed with a condition known as reactive hypoglycemia. After five years and numerous medical tests, my doctor was finally able to find a medical diagnosis that explained all of the symptoms I was experiencing. While I was initially relieved to have an explanation for my frequent bouts of sickness, once reality set in and I discovered it meant I would have to change my way of life, the initial sense of relief was replaced with feelings of frustration and of loss of control. Although I had a strong background in medicine and knew how to properly manage the disease, adjusting to a new way of life has proven difficult.

Once I started researching the effects of hypoglycemia, I realised that there were physiological reasons for why I was feeling the way I was. Suddenly I was able to link headaches and nausea back to foods I had eaten, and discovered that if I had not eaten within the last few hours, I would have difficulties concentrating. I have noticed a deterioration in my memory which seems to worsen when my blood sugar is low. Upon reflecting on how reactive hypoglycemia has affected my life as an adult, I began wondering what life would be like for a child or adolescent with diabetes who had to deal

not only with the low blood sugar, but also with hyperglycemia. This question was the inspiration for what would be my 2-year journey into the world of diabetes.

### Overview of Thesis

This thesis is organized into six chapters. In the first chapter, I introduced the need for greater diabetes awareness in the schools, and provided a purpose for my study. In the second chapter, I review literature on how type 1 and type 2 diabetes affect the child's and the adolescent's medical, school, social, and psychological experiences. In the third chapter, I provide a detailed account of the methodology employed in this study. The fourth and fifth chapters present the cases of Abbey, Olivia, Hannah, and Melinda, separated into two chapters according to the age of diagnosis. In the final chapter, I discuss the results of these interviews, interpreting what life with diabetes meant to each participant, and linking the cases to theories in the literature. Suggestions for further research and suggestions for teachers are provided in this chapter.

## CHAPTER 2: REVIEW OF LITERATURE

When one thinks of diabetes, the thoughts that most often come to mind are those of the medical aspects of the disease: the hypoglycemic episodes, the insulin injections, and the testing of blood glucose. Because of the intense focus on health complications associated with diabetes that pervades the media and medical professions, many Canadians perceive diabetes as a purely physiological phenomenon, failing to recognize the extent to which diabetes affects the individual (International Diabetes Federation, 2007). The recent shift to a qualitative approach in medical research has led to a more holistic understanding of the effects of diabetes, illustrating how various aspects of a person's life might be influenced by a chronic illness. This chapter examines the experience of living with diabetes, focusing on how the medical, school, social, and psychological spheres of life are affected by type 1 and type 2 diabetes mellitus.

This review of literature is organized into five main sections. The first section discusses the medical aspects of type 1 and type 2 diabetes, and how the treatment of diabetes has changed over the past decade. The second section focuses on issues pertaining to diabetes in the schools, examining the current state of legislation in Ontario, the level of teacher knowledge regarding diabetes, and how diabetes can influence a child's or adolescent's school experience. In the third section, I review studies on the social impact of diabetes, discussing how the relationships of individuals with diabetes change over the course of their lives. In the fourth section, I review literature on the psychological impact of diabetes mellitus, focusing specifically on depression and eating disorders, both of which occur at higher rates in individuals with diabetes. In the final section, I examine theories of meaning in chronic illness.



## Medical Implications of Diabetes

### *Medical Complications of Diabetes Mellitus*

Throughout their lives, individuals with diabetes will experience numerous periods of poor metabolic control (Gould, 2002). From short-lived blood glucose fluctuations caused by imbalances among food intake, exercise, and insulin, to more long-term instabilities initiated by hormonal changes, numerous aspects of the individual's biology and environment influence his or her ability to maintain blood glucose levels within the desired range. While physicians suggest that people with diabetes should sustain blood glucose levels of between 4-6 mmol/L, many people may have blood sugars that lie outside of this range. When blood sugars stray out of the ideal range, a variety of acute and long-term complications may ensue. In the short-term, fluctuations may cause feelings of anxiety, aggression, or antisocial conduct. In the long-term, these fluctuations if left unresolved can lead to more serious complications such as kidney failure, blindness, stroke, and possibly death (Bryden et al., 2001).

In diabetes there are three types of metabolic crises: hyperglycemia, hypoglycemia, and diabetic ketoacidosis. All three of these conditions can be detrimental to the health and functioning of the individual with diabetes, and must be recognized and treated as soon as possible to prevent further complications from arising.

Hyperglycemia is a condition in which levels of glucose in the blood are elevated. Hyperglycemia occurs as a result of insufficient levels of insulin in the body, which may be caused by inadequate dosages of injected insulin, increased intake of food, or decreased levels of exercise. The symptoms of hyperglycemia develop slowly, and include feelings of malaise, fatigue, and excessive thirst. People who are in a hyperglycemic state may show signs of deep breathing, rapid heart rate, and, if the

symptoms remain untreated, may go into a coma (DePaepe, Garrison-Kane, & Doelling, 2002).

At the opposite end of the spectrum is the condition known as hypoglycemia, or low blood glucose. Unlike hyperglycemia, hypoglycemia or insulin shock develops rapidly in a person with diabetes who is treated with insulin. This glucose deficiency is caused by excessive insulin, strenuous energy output, insufficient food, or failing to eat after taking insulin. Individuals in a low may complain of headaches, nausea, and vomiting, restlessness, fatigue, excessive hunger, sudden changes in behaviour, and, under serious circumstances, may experience convulsions or coma (DePaepe et al., 2002). If a person presents with symptoms of hypoglycemia, he or she can prevent further deterioration by ingesting foods that are rich in sugar such as fruit juice or candy (Gould, 2002). When a person in a low slips into unconsciousness, he or she can be given a glucagon needle which increases the amount of glucose released by the liver. This needle is only a short-term solution, and the individual with diabetes must seek medical attention immediately to properly treat the hypoglycemia.

The final type of metabolic crisis that can occur in individuals with diabetes is diabetic ketoacidosis. This condition occurs when there is a build up of ketones in the body as a result of high levels of blood glucose, and insufficient supplies of insulin. A person who is experiencing ketoacidosis will exhibit a higher breathing rate, acidification of the urine, and high levels of potassium in the blood. If ketoacidosis goes untreated for a prolonged period of time, it can lead to circulatory collapse, and cause coma or even death (Touchette, 2000). A person experiencing ketoacidosis should be taken immediately to the hospital for insulin replacement, and fluid and electrolyte therapy (Gould, 2002).

### *Treatment of Diabetes in Children and Adolescents*

Prior to the discovery of insulin by Dr. Frederick Banting in 1921, individuals with diabetes were destined to a life of suffering, their bodies dying of starvation amidst a cornucopia of glucose in the blood (Gould, 2002). Today, through a strict regimen of daily insulin injections, regulated diet, and close monitoring of blood glucose levels, people diagnosed with diabetes are able to lead long and relatively healthy lives (Daley, Wodrich, & Hasan, 2006). The development of numerous varieties of insulin and insulin administration devices has facilitated the diabetic individual's ability to achieve and maintain glucose homeostasis. Hypodermic needles, insulin pens, and insulin pumps can be used by individuals with type 1 and type 2 diabetes, and each have their own assets and drawbacks.

Typically when individuals begin insulin therapy they are placed on a short-acting and a long-acting insulin that is most often administered using a hypodermic needle or insulin pen. The amount of insulin injected and the frequency of administration is highly individual, and depends on a variety of factors including the current level of insulin production by the pancreas, the person's weight, and his or her activity level (Canadian Diabetes Association, 2007). Based on these considerations, the physician or endocrinologist is able to calculate an insulin to carbohydrate ratio that is appropriate for that particular person.

Once the diabetic individual becomes accustomed to using hypodermic needles or the insulin pen to treat his or her diabetes, he or she may choose to switch to a more recent invention, the insulin pump. This device administers a constant flow of insulin to the body through an injection site that is embedded in the stomach, and functions in a similar manner to a healthy human pancreas. While the pump provides more freedom

from the strict diet and eating schedule that is imposed upon needle and insulin pen users, it requires more training and attention to ensure proper usage and prevention of infection (Canadian Diabetes Association, 2007).

Children and adolescents with diabetes will undergo several changes in diabetes regimens as their activity levels change, and as they grow and enter puberty. To increase the level of metabolic control and decrease the incidence of long-term complications, researchers from the Diabetes Control and Complications Trial (DCCT, 1993) suggest that physicians should prescribe a more intensive diabetic therapy of 3-4 injections a day. While a more intense insulin regimen may decrease the incidence of future diabetic complications, it places the individual at an increased risk of acute episodes of severe hypoglycemia, and may cause unwanted weight gain, making it more difficult for individuals to achieve glucose homeostasis (DCCT, 1993).

### Diabetes in the School

Because of the rapidly increasing prevalence of type 1 and type 2 diabetes among children and adolescents, all schools are likely to encounter a student with diabetes at some point (Nichols, 2002). Children spend on average 30 to 35 hours a week in the school setting, and often depend on the support of school staff to help them manage the medical, social, and emotional aspects of their diabetes (Lightfoot, Mukherjee, & Sloper, 2001). This section addresses some of the issues related to the academic experience of children and adolescents with diabetes, first examining Ontario law and the legal responsibilities of the school toward the diabetic student, then looking at the knowledge base of teachers pertaining to diabetes. The final sections examine research on the cognitive abilities and needs of individuals with type 1 diabetes, and discuss barriers in the school environment that may impede the full inclusion of students with diabetes.

*Canadian Laws and Recommendations of the CDA*

According to Canadian law, all students have the right to an education without discrimination on grounds of disability. The inclusion of diabetes mellitus in the definition of disability as laid out in section 10(1) of the Ontario Code of Human Rights ensures that individuals with diabetes are subject to laws under the Disability Policy of the Ontario Code of Human Rights (2005). In accordance with the Disability Policy, education providers must make efforts to accommodate all students with disabilities in a way that promotes their inclusion and full participation in the school to the point of undue hardship (Ontario Code of Human Rights, 2005). Educators must ensure that students with disabilities can participate in extra-curricular activities and in-class activities, accept students' rights to privacy and confidentiality, and educate all staff members and students about disability-related issues (Ontario Code of Human Rights, 2005).

When dealing with a medical condition in the school, it is often unclear whether or not a teacher has the legal responsibility to administer medication or provide medical assistance to a student with a chronic illness (Thomas, 2006). Under the Ontario Education Act, a principal has the duty to "give assiduous attention to the health and comfort of the students" (Ontario Education Act, 1990), and the Ontario Teachers' Federation (1996) requires that teachers provide a level of care for their students that could be reasonably expected of a prudent parent. While the Ontario Education Act and the Ontario Teachers' Federation suggest that school officials should provide a level of care and attention to the health of their students, the Ontario Code of Human Rights states that teachers need only accommodate students with disabilities to the point of undue hardship. The Code identifies three factors that may be considered in assessing whether an accommodation would cause undue hardship: cost; necessity of outside sources of

funding, if any; and health and safety requirements, if any. Since the treatment of diabetes mellitus most often involves injections and handling of blood, the student receiving the treatment and the teacher administering it may be placed at unnecessary risk for health issues including infection. Since maintaining a safe learning environment for students, school staff, and educators alike is an important objective, most school boards in Ontario do not require their staff to perform such medical treatments.

While teachers are typically not required to deal with medical issues in the classroom, the implementation of Sabrina's Law (2005) made it mandatory for every school in Ontario to establish and maintain a policy dealing with anaphylaxis in the schools. This law is the first of its kind, making it mandatory for schools to reduce exposure to allergens in classrooms and common school areas, to distribute information on life-threatening allergies to parents, students, and school employees, and to provide regular training for all employees who are in direct contact with pupils on a regular basis. In addition to a general policy for anaphylaxis, schools must also develop individual plans for each pupil with anaphylaxis, detailing the type of allergy, appropriate treatment, and procedure for the storage of epinephrine auto-injectors. In the case of an emergency, Sabrina's Law states that, if a school employee believes a student is experiencing an anaphylactic reaction, "the employee may administer an epinephrine auto-injector or other medication prescribed to the pupil for the treatment of an anaphylactic reaction, even if there is no preauthorization" (Sabrina's Law, 2005).

Despite the potentially fatal complications associated with type 1 and type 2 diabetes, there is currently no legislation in Canada requiring schools to have a diabetes policy similar to Sabrina's Law, or requiring that school employees be properly trained to deal with life-threatening hypoglycemia. Several Ontario school boards have recognized

the importance of creating such policies, and have formed handbooks which outline their procedures for managing diabetes in the classroom (e.g., Limestone District School Board, 2006; Ottawa-Carleton District School Board, 2002). These guidelines describe the responsibilities of school staff for monitoring the health and well-being of students with diabetes, and tend to follow the recommendations for diabetes management in the school as laid out by the Canadian Diabetes Association (2007).

According to the Canadian Diabetes Association (CDA, 2007), schools, parents, and students with diabetes all have specific roles and responsibilities to fulfill in the management of diabetes at school. Although the CDA does not recommend that teachers be involved in the medical aspects of diabetes management, it does recommend that they do all they can to ensure the safety and well-being of diabetic students in the classroom. Schools should be required to clearly identify the student with diabetes in a photograph that is accessible to all school personnel, and to ensure that all permanent and occasional staff members are aware of the student's condition and know how to handle a medical emergency (CDA, 2007). Since students with diabetes must continue to manage their condition while at school, the CDA cautions that school rules should remain flexible. Students must be allowed to monitor their blood glucose, go to the bathroom as needed, inject insulin, and eat and drink whenever required so that they are able to maintain good metabolic control. Designated areas for diabetes-related activities must be provided for the student, either within the classroom or in a different area of the school (CDA, 2007). To avoid hypoglycemic episodes, school staff should ensure that students eat all of their snacks and meals on time, and should notify the parents immediately when the child experiences moderate or severe hypoglycemia. In the case of hypoglycemia, members of the school staff are required to follow a pre-established protocol for treating the condition,

and must supervise students for at least half an hour after treatment has been administered (CDA, 1994).

The Canadian Diabetes Association asserts that students should be expected to perform all aspects of diabetes management at school of which they are capable. Should the student require insulin during school hours, the student and his or her parents are responsible for administering the injection. It is therefore the duty of the student or family to safely dispose of sharps and needles at school, or bring them home for disposal (CDA, 1994).

### *The Teacher and Diabetes*

The proper management of diabetes is a complex process that requires collaboration among the child with diabetes, parents, peers, school staff, and medical practitioners. While teachers are not responsible for providing medical treatments to the student with diabetes, they should be aware of the signs and symptoms of medical emergencies such as hypoglycemia and hyperglycemia. Failure to recognize the early signs of medical distress could result in the student losing consciousness, going into a diabetic coma, or, in extreme cases, death (Gould, 2002).

Unfortunately, many teachers do not have an adequate understanding of diabetes, and are unable to recognize the medical and educational needs of these students (Mukherjee, Lightfoot, & Sloper., 2000; Nabors et al., 2003; Wagner, Heapy, James, & Abbot, 2005). A survey of 463 elementary school teachers in Arkansas showed that 90% of the teachers had never received training on diabetes, and only a few could identify the symptoms or appropriate treatment of hypoglycemia (Gormanous et al., 2002). Since acute hypoglycemia can rapidly deteriorate into a life-threatening condition, these results are frightening.



The trend of inadequate diabetes knowledge among educators has been reported by both parents and students in numerous studies (e.g., Asprey & Nash, 2006; Lightfoot et al., 2001; Wagner et al., 2005). According to the 58 parents in Wagner and colleagues' study (2005), very few teachers who were responsible for assisting students in the management of their diabetes at school had actually received formal training from a medical professional. When asked what type of preparation the school personnel had received, most parents indicated that the training varied from informal conversations, to review of educational material, with very few actually receiving training directly from a healthcare provider. Parents often assumed the responsibility of educating staff members on their child's condition and on how to manage a medical crisis. Children whose parents reported having a trained professional on staff at the school had better levels of metabolic control when compared to students who did not have a trained individual at their educational institution. Because this study was cross-sectional in design, it was not possible for the researchers to determine the direction of association between training, glycemic levels, and quality of life. Measures of self-report data may have led to an inaccurate portrayal of the level of diabetes knowledge of school staff, since the parents and children may not have been aware of all forms of diabetes education received by school employees. Despite the limitations of Wagner and colleagues' study, Nabors and colleagues (2003) and Asprey and Nash (2006) received similar feedback during interviews with parents and students who had type 1 diabetes; that teachers often lacked a clear understanding of T1DM and thus were unable to provide adequate levels of support to diabetic students in the classroom.

Students with diabetes and their parents are not the only people to have questioned the ability of educators to manage diabetes in the school. Teachers often share this same

concern, indicating that they are not adequately trained to deal with medical emergencies should they arise. Mukherjee, Lightfoot, and Sloper (2000) interviewed 34 teachers who had experience working with chronically ill children. The researchers conducted focus group sessions with these educators which examined the teachers' perceptions of their abilities to handle students with chronic illnesses in the school. Many educators felt that they were uninformed about a wide range of illnesses including diabetes, cancer, leukemia, epilepsy, and asthma, and often worried that they would not respond appropriately during medical emergencies. Other worries that were mentioned during focus group sessions included the possibility of pushing chronically ill children too hard to keep up with schoolwork, dealing with the reactions of other students in the class, and being unable to provide chronically ill children with the academic and emotional support they required. Teachers reported a sincere desire to learn more about type 1 diabetes; however, they would rather that the information came from a healthcare professional than a parent. Since communication with healthcare providers often involved a significant time delay, many teachers were unable to obtain the medical and academic information they required in a timely fashion. Many educators were reluctant to seek out medical information from parents, since they did not want to overburden parents, did not want parents to think of them as incapable of caring for their child, and believed that healthcare providers were better able to give medical advice. Of the teachers who reported approaching parents for medical advice, some described the parents as being either unwilling or unable to pass on valuable medical and academic information to the teacher. Participants in this study were also concerned about a general lack of medical knowledge among all staff members, stating that if only one individual on staff was trained to deal with medical emergencies, children would be unnecessarily placed at risk should that

staff member be absent. These teachers also noted the importance of informing all occasional staff of the child's medical conditions and of any symptoms or signs of medical problems for which they should be looking.

If teachers are to exert a positive influence over the outcome of a student's diabetes, they must first have a well-developed understanding of the condition. By recognizing the diverse needs of diabetic students, making appropriate accommodations, and providing medical and emotional support, teachers can help make the student's school experiences more positive, rewarding, and safe (Hayes-Bohn et al., 2004).

*The Student and Diabetes: Academic Abilities and Student Needs*

Although the impact of diabetes on the body is well known, the impact it has on the brain and cognitive functioning has only been recognized recently (Rovet & Alvarez, 1997). When researchers initially began examining the effects of diabetes on neurocognitive functioning in children and adolescents, they consistently reported satisfactory levels of intelligence and academic achievement among this small group of individuals. These findings produced a false sense of hope, and further studies in the area were abandoned (Rovet, Ehrlich, Czuchta, & Akler, 1993). It was not until several years later when new methods for measuring metabolic control were developed that researchers began to revisit the possibility of neurocognitive impairment in children with diabetes. As more studies were conducted, it became apparent that, although children with diabetes tended to be of average intelligence as measured by IQ tests, they often suffered from deficits in verbal intelligence, visual spatial abilities, and attention.

Kovacs, Goldston, and Iyengar (1992) were among the first researchers to demonstrate long-term deficits in academic and neurocognitive ability in children and adolescents with T1DM. Following 87 children between the ages of 8-13 years from the

initial time of diagnosis for a total of 6 years, these researchers found that the participants' academic abilities, as determined by grade point averages and marks on report cards, decreased significantly over time. Upon examining annual scores achieved by individuals on the Vocabulary and Block Design subtests of the WISC-R, Kovacs and colleagues noticed that children with T1DM had lower verbal intelligence than a control group of healthy individuals who were matched on the basis of age, socioeconomic status, and ethnicity. Although the homogeneity of the sample limited the generalizability of this study (all participants were white, middle to upper class, with good metabolic control), Kovacs and colleagues' longitudinal study played a pivotal role in demonstrating the potential long-term effects of diabetes on the intellectual functioning of children and adolescents.

As many researchers continued to investigate the notion of intelligence and diabetes, some began searching for other areas that could potentially be affected by instabilities in glycemic levels. One area of functioning that was of particular interest to Rovet and Alvarez (1997) was attention. To examine how various aspects of attention were affected in children and adolescents with T1DM, the researchers recruited 103 individuals between the ages of 9-18 years who had type 1 diabetes, and 100 healthy individuals. Upon administering several tests of attention, including the WISC-R, Modified Matching Familiar Figures Test, and Stroop Colour-Word Test, the researchers discovered that children and adolescents with type 1 diabetes experienced significantly more difficulties with the focus, select, and inhibit aspects of attention when compared to the healthy control group. While Rovet and Alvarez demonstrated that diabetes could potentially affect numerous aspects of attention, they only administered each test to the participants once, and all tests were completed on the same day. At the time of the

experiment, most participants had blood glucose levels within the normal range. Because the researchers did not test the participants when their blood sugar was higher or lower than normal, they did not show how fluctuations in glycemic levels might influence a person's attention. Further studies examining attention in individuals over a prolonged period of time would be useful in determining what types of accommodations should be provided to students with type 1 diabetes in the classroom.

In a study assessing the effects of mild hypoglycemia on cognitive functioning in diabetic children, Ryan and colleagues (1990) discovered that when they induced a hypoglycemic state in 11 participants, a significant decline in mental efficiency occurred. These researchers assessed the participants' mental efficiency using three measures: the simple choice visual reaction time test, the trail making test, and the Stroop Colour-Word Test. The participants completed each measure prior to receiving the insulin glucose clamp at a euglycemic state, once they started showing symptoms of hypoglycemia, and once their blood glucose levels had returned to normal. At the hypoglycemic state, participants showed significantly slower reaction times, a decrement in functioning on the trail making test, and poorer word-reading scores on the Stroop Colour-Word test. These cognitive changes appeared shortly after the initiation of hypoglycemia, indicating that even a moderate state of hypoglycemia could significantly affect a child's ability to perform in the classroom. Even following a return to a euglycemic state, the participants showed some difficulties on the tests when compared to the initial euglycemic measurements.

In a similar study, Sommerfield, Deary, McAulay, and Frier (2003) induced hypoglycemic states in 16 healthy adults using a hyperinsulinemic glucose clamp. Employing tests of immediate and delayed verbal memory, immediate and delayed visual

memory, and working memory, the researchers discovered that all memory systems were impaired during acute hypoglycemia, with working memory and delayed memory being particularly affected. These two studies suggest that the detrimental effects of acute hypoglycemia on memory and mental efficiency could impair a student's ability to learn while in a state of low blood sugar, and immediately following the return to normal glyceic levels.

Not only can fluctuations in blood glucose levels affect cognitive functioning, but they can also cause changes in behaviour. Both hyperglycemia and hypoglycemia have been found to initiate changes in moods, at times resulting in problem behaviour (e.g., Valdovinos & Weyand, 2006; Warren, Deary, & Frier, 2003). Individuals experiencing hyperglycemia are prone to feelings of irritability, restlessness, and agitation (Warren, Deary, & Frier, 2003). Similarly, individuals in a hypoglycemic state show evidence of impaired judgment, emotional lability, moodiness, irritability, belligerence, and fatigue (Gould, 2002). Since diabetes can influence the cognitive functioning, behaviour, and attention of children and adolescents, it is important that teachers are aware of these effects, and properly attribute them to fluctuations in blood glucose instead of attributing them to the students' willingness to cooperate and learn.

Children and adolescents with diabetes have a diverse range of needs, and may require differing levels of support and accommodations while in the school setting (Mukherjee et al., 2000; Nabors et al., 2003). Studies that rely on qualitative methods such as interviews and focus group sessions with diabetic youth and their parents have identified some areas in which individuals may need support from teachers and other school officials (e.g., Mukherjee et al., 2000; Nabors et al., 2003). Although some participants in these studies reported receiving adequate support from teachers, most

individuals suggested that teachers and other school employees needed to make more of an effort to satisfy the medical and academic requirements of people with diabetes. In a study by Nabors and colleagues (2003), the researchers interviewed 105 children (60 boys, 45 girls) in a group setting during diabetes summer camp sessions. Children completed the 'how is school scale' which addressed their perceptions about the amount of support they needed from teachers, nurses, and friends while at school for monitoring their blood glucose, administering insulin, and following their meal plan. Several of the participants described ways in which teachers could help them to deal with their condition in the classroom. These suggestions included allowing students to check blood glucose whenever they felt that their levels were high or low, having their test kits in an accessible area, ensuring that there were snacks in the classroom in case the children experienced hypoglycemia, and allowing the students to take breaks when they felt low, even if the teacher was in the middle of a lesson or test. These students wanted their teachers to understand their condition, and to refrain from drawing too much attention to them when they were not feeling well. Younger children wanted reminders to test their blood sugars and to snack; however, teachers had to be careful not to overstep the line between reminding and nagging. Despite variations in the requirements for medical assistance, all participants reported needing a certain level of emotional support from teachers or peers in order to adhere to the diabetic regimen at school.

#### *Diabetes in the School Environment*

Although the low level of diabetes awareness that exists among teachers and students in the classroom places the student at risk for poor diabetes management, there are several other barriers in the general school environment that may further threaten the student's overall metabolic control. The scarcity of healthy food in the cafeteria, stringent

school rules, and difficulties associated with participating in extra-curricular activities may influence the overall school experiences of students with diabetes.

Hayes-Bohn and colleagues (2004) conducted a study with 30 adolescent females 13-20 years old who had T1DM. Through semi-structured interviews, the researchers learned about the girls' perceptions of the barriers and resources for diabetes management that existed in their schools. One of the issues brought up by several participants was the lack of healthy food choices available in the cafeteria. According to the girls, there was a high prevalence of junk food in the cafeteria and in the vending machines. Cafeterias often did not provide the nutritional information about the food they prepared, which made it more difficult for participants to accurately monitor their carbohydrate intake. Other studies that have examined meals offered in cafeterias throughout the United States have called similar attention to the fact that very few cafeterias provide healthy food options (e.g., Shannon, Story, Fulkerson, & French, 2002; Wechsler, Brener, Kuester, & Miller, 2001).

Although the participants were mainly concerned with the lack of healthy food choices offered by the cafeteria, several girls also commented on the difficulty of adhering to the diabetic regimen when friends or teachers offered them treats (Hayes-Bohn et al., 2004). According to several of these individuals, teachers often brought in candy or other sweets as a reward for their class. This practice made the girls feel excluded and singled out, as their classmates noticed when the girls refused to eat the treats. For participants who preferred to keep their diabetes a secret, the teacher's act of generosity resulted in feelings of discomfort and humiliation.

When schools are inflexible with their rules, students with diabetes may be placed at a disadvantage. Rules that prohibit the presence of syringes at school mean that



students with diabetes must go to the nurse's office where they can be supervised administering their insulin. For individuals who prefer to keep their condition hidden from their peers, this process of leaving the classroom so that they can be supervised by an adult is embarrassing. Studies by Hayes-Bohn and colleagues (2004), and Wagner and colleagues (2005) indicate that many students are required to leave the classroom before checking their blood glucose levels or administering doses of insulin. According to Wagner and colleagues (2005), 56% of children who participated in their study had to go to the nurse's office, main office, or their locker when giving an injection during school hours. These children who were required to leave the classroom had poorer metabolic control than those who were allowed to monitor their condition in the classroom. Leaving the room to manage their diabetes meant that the students would miss class time, a fact which many students described to be an inconvenience (Hayes-Bohn et al., 2004). Some teachers also refused to allow students to eat or drink in the class, or to go to the bathroom as needed, because they did not believe it was fair to the other students in the class who had to follow rules established by the school. As such, many individuals with type 1 diabetes experienced difficulties maintaining a consistent level of metabolic control while at school (Hayes-Bohn et al., 2004; Nabors et al., 2003). By refusing the students their rights to fulfill diabetes-related needs, schools were unnecessarily placing students with diabetes at risk.

Because of the general lack of diabetes knowledge among school staff, children with diabetes are often unnecessarily denied the opportunity to participate in extra-curricular activities (Mukherjee et al., 2000; Nabors et al., 2003; Wagner et al., 2005). Many people believe that individuals with diabetes are unable to partake in excessive physical activity, since it would undoubtedly result in hypoglycemia (e.g., Raile et al.,

1999). These beliefs, however, are flawed. With proper monitoring of blood glucose, altering of insulin dosage, and snacking when blood glucose levels drop, students with diabetes are able to participate fully in a wide variety of extracurricular activities (Hopkins, 2004). Exercise can even reduce the risk of future diabetes complications by increasing the level of cardiovascular fitness (Raile et al., 1999). Despite the ability of children and adolescents with diabetes to participate in extracurricular activities, many barriers exist that discourage them from joining after-school programs. Participants in Nabors' (2003) study told of instances where there was no longer an individual on staff after school hours that could help them manage their disease. They complained that coaches often did not understand their condition, and refused to let them participate in different sports even though they were capable of playing. Other participants noted that their diabetes supplies were often locked in the nurse's office after school, and could not be accessed easily in the case of an emergency. All of these factors impeded the child's ability to participate in extracurricular activities, and may have deprived the student of feelings of support, belonging, and connectedness to the school.

#### Social Implications of Diabetes

The relationships that children and adolescents with diabetes have with their parents and friends can have a large influence over their psychological and physical well-being. These relationships can either provide a source of support to the diabetic individual, increasing the likelihood that they will be able to deal with the stresses of diabetes management, or can act as a negative enforcement, influencing the individual to abandon his or her regimen. This section examines relationships between the diabetic individual and his or her parents, as well as the relationships with friends.

### *Parental Support and the Adolescent Need for Autonomy*

As a child enters the world of adolescence, the role of the family in diabetes management changes (Seiffge-Krenke, 1998). During early childhood, parents frequently take on the daunting task of monitoring blood glucose, exercise, and diet (Schroff-Pendley et al., 2002). However, as the child becomes older and enters the school system, he or she begins to accept more responsibility for the management of diabetes (Wiebe et al., 2005). In some cases, parents are reluctant to relinquish control, and as a result, are perceived by their children as being overbearing (Wiebe et al., 2005). Constant scrutiny and concern from parents diminishes opportunities for adolescents with diabetes to participate in normal teenage activities, since doing so might lead to conflict with parents or would require that the youth check in with family members on a regular basis (Schroff-Pendley et al., 2002).

Upon entering adolescence, support from parents is typically viewed as less positive (Furman & Buhrmester, 1992). At this time in their lives, adolescents are striving for a sense of autonomy, a goal which is often difficult for youths living with chronic illnesses to achieve. Attempting to meet the expectations of society, many parents allow their children full control of diabetes management at an early age (Palmer et al., 2004). Although children are typically able to participate in most aspects of diabetes management by the age of 13, Wysocki (1993) suggests that many parents are transferring the responsibility of diabetes management to their child too early. According to Schroff-Pendley et al. (2002), parents who surrender complete control of diabetes management to their teenager and no longer offer assistance to their son or daughter are unintentionally placing their loved one at risk for poor diabetes compliance and increased hospital admittance.

In their 2001 study, Wiebe and colleagues examined how adolescents' appraisals of maternal involvement in coping with diabetes were associated with metabolic control and quality of life. The researchers administered a series of questionnaires to 127 adolescents ages 10-15 years and their mothers to obtain measures of regimen adherence, parental support, appraisal of parental involvement, and quality of life. Wiebe and colleagues found that mothers of children who had been diagnosed at an earlier age were frequently less involved in the management of their child's diabetes, and that the lack of parental involvement was associated with poorer metabolic control and lower life satisfaction. Maternal collaboration was seen most often with parents of teenagers who had more recently been diagnosed with diabetes, and who were on more intense interventions. Parental collaboration was associated with better adherence and metabolic control, yet was still associated with lower life satisfaction among the youths. The researchers concluded that optimal diabetes care is more likely to occur when children view their mothers as collaboratively involved in dealing with issues surrounding disease management. Wiebe and colleagues' finding that having a controlling parent leads to poorer life satisfaction is consistent with the findings of other researchers (Ott, Greening, Palardy, Holdreby, & DeBell, 2000; Williams, Freedman, & Deci, 1998; Wysocki, 1993). Having a controlling parent may lead adolescents to believe that their parents do not trust them to manage their own condition, resulting in decreased levels of self-efficacy (Carroll & Marrero, 2006; Seiffge-Krenke, 1998). In an attempt to exercise their autonomy, teenagers may revolt against the desire of the parents, and refuse to follow the diabetes treatment (Carroll & Marrero, 2006). To reduce levels of parental anxiety and to avoid conflict, other adolescents may refrain from diabetes management tasks such as testing

their blood glucose, especially when they believe it is low or high (Carroll & Marrero, 2006).

### *Relationships with Friends*

While struggling to cope with normal issues that confront others their age, children and adolescents with type 1 diabetes are faced with the additional stress of managing a chronic illness. Although individuals with T1DM and T2DM would benefit from increased levels of peer support during these tumultuous times, many do not receive the assistance they require. This lack of peer support has been attributed to a variety of factors, including the diabetic person's self-consciousness, the strict requirements of the diabetes medical regimen, and the lack of diabetes knowledge among peers (Boice, 1998; Schroff-Pendley et al., 2002).

During the childhood years, peers play a significant role in the individual's adherence to the diabetic regimen. The influence of friends and classmates continues to increase throughout childhood, reaching a peak during adolescence. Adolescents begin to spend more time in the presence of their peers as they seek to gain insight into the normal rules of behaviour, and the process for identity formation (Cheung et al., 2006). The guidance, emotional support, and understanding that were once bestowed upon the individual by parents are now sought out from peers (Cheung et al., 2006). Although social relationships are important in determining the quality of life of most individuals, these relationships with friends are particularly influential for adolescents with diabetes, affecting not only their quality of life, but also their overall state of health (Faro, 1999). Studies examining the role of social influences and peers on diabetes adherence have consistently shown that peers can exert a great amount of influence over the individual

with diabetes, whether the influence be positive or negative (e.g., Cheung et al., 2006; Faro, 1999; Hains, Berlin, Davies, Parton, & Alemzadeh, 2006).

In a qualitative interview study conducted by Bearman and La Greca (2002), participants with type 1 diabetes reported that friends were the main source of emotional support during adolescence, and that they provided companionship when the adolescent was experiencing difficulty adhering to the diabetic regimen. Greco, Pendley, McDonnell, and Reeves (2001) echoed this concept of emotional support, finding that peers were more likely than family members to provide adolescents with the emotional support that they required over the course of their disease.

Seeking to gain a better understanding of peer support during adolescence, Cheung and colleagues (2006) examined adolescent perceptions of the quality of support obtained from peers. The researchers selected 29 participants between the ages of 13-17 who had attended at least one diabetes camp, and 10 participants who had never attended camp. The adolescents completed a series of questionnaires that included a quality of life survey, and a survey to assess the nature of their friendships with others. Over half of the participants in the study felt that diabetes limited their social relationships and friendships. Those who reported having several close friends also obtained higher scores on the Quality of Life survey. The benefits of friendship were amplified when adolescents with T1DM were granted the opportunity to interact with other people suffering from diabetes in the camp setting, since it provided them with mutual and sincere support as they struggled to manage their disease. Because of the nature of the study, it is not possible to determine the direction of the relationship between number of friends and level of metabolic control. While it is possible that having more close friends would increase adherence to the diabetic regimen, it is also possible that people had more

positive relationships because of better moods associated with good glycemic control. Because of the small sample size, Cheung and colleagues' findings may be limited in generalizability.

Despite an increased need for support among adolescents with chronic illness, several researchers have found that chronically ill adolescents spend more time in isolation, and have fewer friendships than healthy individuals (e.g., Boice, 1998). Fears of appearing different from peers and feelings of self-consciousness often overwhelm the chronically ill individual, leading to decreased efforts and motivation to initiate friendships with healthy individuals (Cheung et al., 2006). Social interactions may be further limited by the unwillingness of the adolescent to test blood glucose in a public setting for fear of blood-borne disease, and the possibility of contracting an illness (Cheung et al., 2006). When adolescents do choose to engage in social activities, they often decide not to check blood glucose levels, administer insulin, or eat foods that are different than their peers in an attempt to appear normal (Falsetti et al., 2003; Hains et al., 2006). The restrictive nature of the diabetes regimen might also interfere with the teenager's participation in a variety of social activities, including sports, driving, and dining out with friends (Carroll & Marrero, 2006).

Although adolescents with diabetes may actively choose not to engage in many social activities, the reactions of their peers may also dictate whether or not they will participate. Most healthy adolescents lack knowledge on the subject of diabetes (Canadian Diabetes Association, 2007; Seiffge-Krenke, 1998). This lack of knowledge can be problematic, since it may cause them to view the diabetic individual as being different or even scary. According to a study by Faro (1999), many adolescents with diabetes felt that their peers behaved differently towards them, and one third of the

participants stated that they frequently needed to explain to non-diabetic peers that diabetes was not contagious. Many participants chose to keep their diabetes a secret, since they feared that this knowledge might lead their friends to abandon or disown them.

Even though many adolescents with diabetes report having positive relationships with non-diabetic peers, their friends often negatively influence the teenagers' diabetic regimen adherence. Engaging in activities that are appropriate for their developmental level often conflicts with good diabetes management practices (Frey, Guthrie, Loveland-Cherry, Park, & Foster, 1997). Schroff-Pendley and colleagues illustrated this issue in their 2002 study. Attempting to examine the level of social support offered by peers to adolescents with chronic illnesses, Schroff-Pendley and colleagues recruited 68 children ages 8-17 that had been diagnosed with T1DM. The participants selected a minimum of 3 people from their extended family, peer-group, or school to act as a support team over the course of the study. As part of the study, the researchers presented diabetic individuals with a series of hypothetical social situations in which they had to decide between diabetes adherence and peer desires. The researchers discovered that most individuals when presented with such a problem were more likely to comply to peer desires than to maintain their diabetes regimen. Schroff-Pendley and colleagues also discovered that although peers may treat the individual with diabetes like everyone else, the peers were actually encouraging non-adherent behaviour.

While the reactions of friends may directly influence the diabetic individual's desire to adhere to a specific regimen, Hains and colleagues (2006) argue that it may instead be the diabetic person's appraisal of peer beliefs that exerts the greatest amount of control over his or her decision to abandon the treatment regimen. Adolescents often choose to filter out certain aspects of a particular situation, and may view a friend's



reaction as being negative when it is actually not (Hains et al., 2006). In an attempt to avoid such negative reactions, people with diabetes may decide to avoid aspects of their diabetes management. These false attributions are not only concerning due to their negative health implications, but also because the adolescent may be missing out on opportunities for valuable friend support (Hains et al., 2006). In their 2006 study, Hains and colleagues examined the relationships among negative attributions of friend reactions, anticipated adherence difficulties, diabetic stress, and metabolic control. In all, 104 participants with T1DM between the ages of 11-18 took part in this study. The researchers gave each individual a package of questionnaires which assessed friend attributions and diabetic stress. The researchers discovered that individuals who showed greater levels of negative friend attributions also demonstrated higher levels of diabetic stress, lower metabolic control, and anticipated more adherence difficulties. Although Hains and colleagues have shown that negative friend attributions are associated with decreased metabolic control and adherence, it is not possible to determine whether or not it is a causal relationship. Hains and colleagues employed vignettes that were similar to those used by Schroff-Pendley and colleagues (2002) in which the adolescents were presented with a social situation which required them to decide between peers or adherence to the diabetic regimen. The problem with using an instrument such as this is that it may not be an accurate reflection of how the adolescent would act if placed in the situation. The use of alternative instruments in future studies is important to see if these trends are indeed observable in everyday life.

In recent studies, high levels of social support have been linked to greater regimental adherence, fewer diabetes-related complications, and greater quality of life in children and adolescents living with diabetes (e.g., Cheung et al., 2006; Mayou, Bryant,

& Turner, 1990). Because an increased level of social support has been linked to better health and psychological outcomes among diabetic individuals, it is important that children and adolescents with diabetes have ample opportunities to form friendships within the school setting. Recognizing the benefits of social support in the school, Wagner and colleagues (2006) have suggested that schools implement a “diabetes buddy” program. This program would permit one or a few classmates to accompany the student with diabetes over the course of the day as he or she goes about managing his or her condition in the school. Not only would this “diabetes buddy” program be a cost-effective intervention for promoting diabetes care in the school, but could also increase the level of peer awareness surrounding diabetes, and promote the formation of friendships between the diabetic student and his or her peers (e.g., Greco, Schroff Pendley, McDonnell, & Reeves, 2001; Wagner et al., 2006).

In addition to encouraging the formation of friendships between diabetic students and their classmates, LaRusso, Romer, and Selman (2007) believe that teachers can reduce the occurrence of risky health-related behaviours in students by creating a positive and respectful school environment. In providing support when students need it, and valuing the students’ perspectives and decision-making capabilities, teachers can establish a respectful class environment that increases students’ feelings of social belonging.

While several suggestions have been made as to how diabetes educators can increase the level of social support given to the individual with diabetes, very few of these suggestions have been tested in the school setting. Future research in the area of social support and diabetes should include program evaluations of “diabetes buddy” programs and other peer interventions to determine the effectiveness of increased social support on the diabetic student’s adherence, academic performance, and overall quality of life.

## Psychological Impact of Diabetes Mellitus

Being diagnosed with a chronic condition such as type 1 or type 2 diabetes can be life-altering at any age. For children and adolescents in particular, this metabolic illness can have resounding effects on their psychological well-being (Hood et al., 2006). From the time they are diagnosed, individuals with diabetes must assume numerous roles, bouncing among the roles of nurse, physician, mathematician, and dietician. They must take over the responsibilities of the pancreas, performing tasks that in a healthy human being occur subconsciously; balancing the level of insulin to carbohydrate in an attempt to achieve glucose homeostasis. At first, these individuals may receive support from parents and medical teams in managing the complex everyday tasks of the diabetes regimen; however, as they become more familiar with treatment demands, the responsibility of maintaining their health falls completely on their own shoulders (Seiffge-Krenke, 1998).

As these children and adolescents struggle to deal with the lifelong demands of self-care, they must also face the same challenges that plague others their age as they mature and find their place in the world (Dovey-Pearce, Doherty, & May, 2007). From changes in their social lives, to changes in their knowledge levels, to physical changes, adolescents often must relearn how to manage their diabetes upon entering puberty. This sudden loss of control over their health can bring about various psychological repercussions such as stress and anxiety, depression, and eating disorders. This section examines a few of the psychological complications that are associated with diabetes.

### *Depression and Diabetes Mellitus*

Diabetes is considered to be one of the most psychologically and behaviourally demanding of the chronic illnesses (Cox & Gonder-Frederick, 1992). The stress

associated with managing a chronic illness, the restrictions imposed by the diabetic regimen, as well as bodily changes resulting from the disease all play a role in determining how an individual responds to his or her condition. Although many children and adolescents who have been diagnosed with type 1 and type 2 diabetes are able to adjust well to life with a chronic illness, others may experience greater difficulty adjusting to this new way of living. A perceived loss of control, low self-esteem, and disease complications may lead to feelings of negative affect in the child or adolescent with diabetes, and in some cases may manifest as full-blown depression.

Although there have been several studies examining the co-occurrence of depression and diabetes, the majority have focused on depression in adults. Studies of adults with type 1 and type 2 diabetes have shown an increased risk of associated depression, with 20%-30% of participants with diabetes meeting the criteria for major depression (e.g., Anderson, Freedland, Clouse, & Lustman, 2001; De Groot, Anderson, Freedland, Clouse, & Lustman, 2001). Although estimates of depression in youths with diabetes are thought to be lower than those seen in adults, they are believed to be higher than the depression rates seen in the general population (Lustman & Clouse, 2005).

In one of the few studies examining the prevalence of depressive symptoms in youths with diabetes, Hood and colleagues (2006) administered a series of questionnaires to 145 participants. Using the Children's Depression Inventory to assess depression, the researchers found that 15.2% of the participants scored at or above the clinical cut-off for depression. The number of individuals with depression in this study was nearly double that of the highest estimate of depression in youth in general (Anderson & McGee, 1994; Lewinsohn, Clarke, Seeley, & Rohde, 1994). Other studies that used different tools to measure depression in diabetes obtained mixed results; showing both higher and lower

incidences of depression (e.g., Egede & Zheng, 2003). Reasons for the mixed results include differences in methodologies used to assess depression, small sample sizes, and unrepresentative groups of participants (Ciechanowski, Katon, & Russo, 2000; Korbel, Wiebe, Berg, & Palmer, 2007).

Similar to trends seen in healthy adolescent populations, females with diabetes appear to be at a higher risk of developing depression than their male counterparts (Korbel et al., 2007). This gender difference is thought to emerge between the ages of 10-15 years, when the prevalence of depression among girls increases to twice that of boys (Nolen-Hoeksema, 2001).

Although studies have differed on estimates of the prevalence of depression in diabetes, one thing remains certain; that the co-occurrence of these diseases is particularly dangerous for children and adolescents. In youths with diabetes, depression is associated with a 10-fold increase in suicide and suicidal ideation (Goldston et al., 1997; Goldston, Kovacs, Ho, Parrone, & Stiffler, 1994). Children and adolescents who take insulin have a ready method of performing suicide, since an overdose of this hormone will inevitably lead to severe hypoglycemia and probable death if left untreated. Depression in children and adolescents with diabetes is also associated with negative diabetes-related health control outcomes such as poorer glycemic control (Kovacs, Iyengar, et al., 1990; La Greca, Swales, Klemp, Madigan, & Skyler, 1995), and recurrent diabetic ketoacidosis (Stewart, Rao, Emslie, Klein, & White, 2005), both of which increase the likelihood of future diabetes-related complications.

Several researchers have noticed a link between depression and hyperglycemia in both adults and youths with diabetes (e.g., Engum, Mykletun, Midthjell, Holen, & Dahi, 2005; La Greca et al., 1995). Because of the cross-sectional designs of these studies, it

has not been possible to determine the direction or cause of this relationship. While some suggest that the resultant high blood glucose levels might be a manifestation of poor diabetic regimen adherence, others suggest that it may be the physiology of depression that is to blame. Because 95% of diabetes management is conducted by the patient, comorbid depression in diabetes may lead to poorer outcomes and increased risks of complications by lowering adherence to glucose monitoring, exercise, diet, and medication regimens (Ciechanowski et al., 2000). In a study by Hood and colleagues (2006) of 145 youths with diabetes, the researchers found that the individuals who scored higher on the Children's Depression Inventory reported checking their blood glucose levels less frequently, had higher HbA1c levels, and a higher level of diabetes-related stress. Another proposed mechanism for the hyperglycemia that is seen in depressed diabetic individuals is that cortisol abnormalities that are associated with depression may have hyperglycemic effects, as might the insulin resistance that accompanies depression (Lustman & Clouse, 2005).

#### *Disturbed Eating Behaviour and Eating Disorders*

Adolescence has been found to be one of the most critical times in a diabetic individual's life. According to the Diabetes Control and Complications Trial (1994), adherence to intensive diabetes therapy during the adolescent years can lower blood glucose levels, and reduce the risk of long-term diabetic complications significantly. Although the period of adolescence is one of great promise for the successful treatment of diabetes, many adolescents experience extreme difficulty adhering to the diabetes regimen (Du Pasquier-Fediaevsky, Chwalow, & Tubiana-Rufi, 2005; Madsen, Roisman, & Collins, 2002). This deterioration of self-care behaviours and glycaemic control can have lasting effects on the individual, resulting in the development of long-term diabetes-

related complications such as retinopathy, nephropathy, and neuropathy (White et al., 2001).

One of the developmental tasks that all adolescents face is to accept one's body and the changes that have occurred as a result of puberty (Seiffge-Krenke, 1998). For individuals living with diabetes, this task can be particularly troublesome (Carroll & Marrero, 2006; Dabadghao, Vidmar, & Cameron, 2001). During puberty, boys and girls experience major hormonal changes, often resulting in weight gain particularly among females. The increases in body fat that occur during puberty come at a particularly critical point in the female's life when she is becoming increasingly concerned about her body shape and appearance. The resultant weight gain and changes in body size may result in a heightened level of body dissatisfaction, and place young females at an increased risk of developing disturbed eating behaviours and eating disorders (Jack, 2003).

Females who have diabetes are at an even higher risk of developing disturbed eating behaviours due to several interacting factors related to diabetes and its treatment (Rodin et al., 2002). Prior to beginning insulin therapy, many males and females with undiagnosed diabetes experience a period of rapid weight loss as a result of chronic hyperglycemia and glucosuria (Kelly, Howe, Hendler, & Lipman, 2005). Upon commencing insulin therapy, these individuals will gain weight as their body begins to effectively use the glucose that is ingested through dietary means (Kaufman, 2006). Through the combination of pubertal weight gain and insulin-mediated weight gain, females with diabetes have been typically found to have a higher Body Mass Index (BMI) than their healthy peers (e.g., Bryden et al., 1999; Rodin et al., 2002). According to Rodin and colleagues (2002), this increased BMI may heighten body dissatisfaction in the female with diabetes, triggering a cycle of dieting and subsequent bingeing and purging.

In recent years there has been a heightened interest in the comorbidity of diabetes and eating disorders. Some studies have found an increased incidence of anorexia nervosa, bulimia nervosa, binge-eating, purging, excessive exercising, and food deprivation in female adolescents with type 1 diabetes (e.g., Bryden et al., 1999; Rodin et al., 2002) while others have found no such relationship (e.g., Meltzer et al., 2001). Researchers who have examined studies which show no increase in incidence have pointed to several flaws in the studies that may be responsible for the conflicting results. Studies such as that conducted by Meltzer and colleagues (2001) typically employed small sample sizes of females who are in the age of highest risk for eating disturbances (i.e., older adolescence and young adulthood), did not use age-matched control groups, had low statistical power, and lacked structured diagnostic interviews for the assessment of eating disorders (Rodin et al., 2002).

Recognizing the importance of examining small age groups separately, Colton and colleagues (2004) conducted a cross-sectional, case-controlled study of 101 girls with type 1 diabetes between the ages of 9-14 years, and 303 age-matched female non-diabetic control subjects. The researchers collected information on the participants' height, weight, BMI, and level of glycemic control. Participants completed a private semi-structured standardized interview, the Children's Eating Disorder Examination interview. Upon analysis the researchers found that the same percentage of diabetic and non-diabetic girls reported at least one disturbed eating behaviour in the previous month; however, significantly more diabetic girls reported currently engaging in two or more disturbed eating behaviours. The most common behavioural combination reported by females in this age group was strict dieting with intense, excessive exercise for weight control. Binge-eating was also more common in diabetic than in non-diabetic girls. The



researchers concluded that although disturbed eating behaviour was moderately common in preteen and early teenage girls, the severity was most often mild. Only 2% of the diabetic females in this study employed insulin omission as a weight-loss tool.

Colton and colleagues (2007) later extended their study to a 5-year prevalence study. A total of 98 females with type 1 diabetes completed the 5-year follow up. At the end of the 5-year period, 49% of the females reported current disturbed eating behaviour, 43.9% actively restrained their diet, 6.1% engaged in binge-eating episodes, 3.1% reported self-induced vomiting, 3.1% omitted insulin, and 25.5% employed excessive exercise for weight control. Of the women who participated in this study, 13.3% met the diagnostic criteria for an eating disorder.

Despite variations in the estimated comorbidity of diabetes and eating disorders, researchers agree that these patterns of disturbed eating are particularly hazardous to the health of individuals with diabetes. Disordered eating behaviour has been associated with recurring hypoglycemic episodes, more frequent episodes of diabetic ketoacidosis, poor metabolic control, and higher incidence of diabetes related complications including retinopathy and nephropathy (Jones, Lawson, Daneman, Olmsted, & Rodin, 2000; Rydall, Rodin, Olmstead, Devenyi, & Daneman, 1997).

In young women with body dissatisfaction, diabetes provides a unique but dangerous opportunity to control weight by deliberate insulin omission. By reducing or omitting doses of insulin, individuals with diabetes can induce hyperglycemia and glucosuria, effectively starving their body of the food they ingest. This dangerous method of purging, referred to as diabulimia, is reported by 1% of girls in preteens, rising to 11-14% by the mid-teens, and 34% by older adolescence and adulthood (Kelly, Howe, Hendler, & Lipman, 2005; Rodin et al., 2002). According to Rydall et al. (1997), between

1/3 and 1/2 of all young women with type 1 diabetes frequently take less insulin than they need for good glycemic control in order to control their weight. Bryden and colleagues (1999) found similar incidences of diabulimia, with 30% of the 76 women admitting to intentionally reducing or omitting insulin to control their weight during the adolescent years. The duration of insulin purging by the women in this study ranged from 3 months to an average duration of 2 years.

Often eating disorders in people with diabetes go unrecognized and untreated. Because the treatment of diabetes requires individuals to focus a great amount of attention on proper diet, it is often difficult to differentiate between the normal concerns with food and body image and pathological ones (Adili et al., 2006). Frequent episodes of diabetic ketoacidosis, suboptimal or erratic blood glucose control, significant weight loss without illness, and frequent and severe episodes of hypoglycemia are all warning signs that an individual may be suffering from an eating disorder. In order to prevent life-threatening complications, it is important that parents, teachers, friends, or healthcare professionals recognize the presence of disturbed eating behaviours in individuals with diabetes, and seek proper medical attention.

Despite recognizing an association between diabetes, depression, and eating disorders, very little is known about the actual prevalence of these psychological conditions in children and adolescents with diabetes (e.g. Bryden et al., 1999; Hood et al., 2006). While the actual comorbidity of these conditions is unknown, one thing remains certain; the co-occurrence of diabetes, depression, and eating disorders can have resounding effects over the diabetic individual's health, social experiences, and academic performance (e.g., Hilsman & Garber, 1995). Because children and adolescents spend on average 30 hours a week in school, it has been suggested that schools might be the

primary setting for the identification of depression and eating disorders in children and adolescents (Moor et al., 2007). While teachers are considered to be one of the primary agents in the detection of depression and disordered eating in schools, many teachers are unable to accurately identify students exhibiting signs of these psychological conditions (e.g., Verhulst, Koot, & Van Der Ende, 1994). Moor and colleagues (2007) suggest that even following training sessions involving videos, case vignettes, and general management strategies, teachers are not able to effectively identify depressed students. The design and implementation of more effective depression and eating disorder identification tools in schools may help teachers and school personnel to catch early signs of eating disorders and depression, reducing the risk of future health complications, and increasing the diabetic individual's quality of life (Van Tilburg et al., 2001).

### Theories of Chronic Illness

The lived experience of chronic illness is one that has long fascinated researchers. Over the past 50 years, several theories of chronic illness have been proposed. From the Health Belief Model (Kirscht, Haefner, Kegeles, & Rosenstock, 1966), to various adaptations of the trajectory model, to the Shifting Perspectives model (Paterson, 2001), the experience of life with a chronic illness has undergone intense examination. During the early years of these theories, chronic illness was often depicted as a negative experience wherein lives were ruined and the sick individual was destined to an existence of pain and suffering. More recent theories of chronic illness have focused on the processes of transformation and adaptation in individuals living with a variety of diseases.

#### *Chronic Illness as a Biographical Disruption*

One of the most highly regarded theories of chronic illness is Bury's (1982) notion of chronic illness as a biographical disruption (De-Graft Aikens, 2003). According

to Bury, chronic illness can be viewed as a critical situation causing disruption in three distinct areas of the ill persons' life; their taken-for-granted assumptions, their biography, and the persons' mobilization of resources. How the person experiences his or her illness and makes meaning of it will depend on the resulting levels of disruption to each of these three areas. As the affected person's symptoms become more prevalent, the disease begins to structure his or her everyday life, and the very foundations of the individual's pre-illness conceptions and beliefs are toppled. The loss of taken-for-granted assumptions can in turn alter the individual's biography. A new understanding of the illness, the consequences it has on the person, as well as the effect it has on loved ones are all incorporated into chronically ill persons' life stories, changing how they view themselves as individuals. While struggling to deal with the emotional and psychological implications of their disease, the affected individuals may simultaneously experience a disruption in the mobilization of resources (Bury, 1982). The type of support received by the affected person, his or her social interactions with others, as well as the cultural, medical, and financial resources that are available to the chronically ill individual all play a role in shaping the affected person's new sense of identity (Bury, 1982).

Although many researchers have embraced Bury's portrayal of illness as a biographical disruption, others have argued that it is limited in its ability to portray the true experiences of individuals living with chronic illness (Williams, 2000). While Bury focuses on the disruptions caused by the onset of illness, others believe that chronic illness can be a positive experience of transformation. Studies of a wide range of illnesses including diabetes, asthma, arthritis, lupus, and cancer have shown that chronically ill individuals may actually perceive their disease as being a gift, or something that enhances their quality and meaning of life (e.g., Paterson, Thorne, Crawford, & Tarko, 1999). In

light of these studies, researchers have called for a more recent and extensive theory on the experience of living with chronic illness.

*The Shifting Perspectives Model of Illness*

Following a metasynthesis of 292 qualitative studies of chronic illness, Paterson (2001) developed the Shifting Perspectives Model of Illness. Unlike previous models which depicted the adaptation to life with an incurable disease as being a phased process in which a person follows a predictable path, the shifting perspectives model assumes that the experience of living with a chronic illness is an ever-changing process. According to this model, a person with a chronic illness can assume one of two perspectives; the illness in the foreground perspective, or the wellness in the foreground perspective. Although individuals may have a preferred outlook, they are likely to shift between the two several times over the course of their illness experience.

While assuming an illness in the foreground perspective, the individual focuses on his or her sickness, and the burdens, suffering, and loss associated with it. The chronic illness is viewed as destructive to the self, and to others in their lives. People assuming this perspective become absorbed in their illness experience, and may have difficulties attending to the needs of significant others. While this perspective is typically assumed by individuals who have been newly diagnosed, individuals who had previously assumed a wellness in the foreground perspective can assume an illness perspective when there is a threat to control such as signs of disease progression, an inability to manage the disease, or interactions with others that emphasize dependence and hopelessness (Paterson, 2003). While it would appear that illness in the foreground is the least desirable of the two perspectives, this is not the case. In focusing on their illness, individuals are able to learn about and reflect on their disease in an attempt to come to terms with their new way of

life. For a disease such as diabetes where many of the underlying symptoms and pathologies are invisible to the untrained eye, a focus on the illness and symptoms may allow the individual with diabetes to provide evidence to others that the illness is real. Focusing on the illness may also help the chronically ill individual seek required attention from family members, healthcare professionals, and school officials (Paterson, 2001).

The second perspective that individuals may assume is the wellness in the foreground perspective. In this perspective, chronically ill people view their illness as being meaningful, and as serving a purpose in changing their relationship with the environment and with others. To achieve this perspective, individuals must create consonance between their self-identity and who they have become as a result of their disease. In doing so, individuals are able to accept the limitations that may exist, and view themselves as healthy beings (Paterson, 2001). While some researchers suggest that viewing themselves as healthy may be considered denial, Paterson and colleagues do not agree. They believe that in viewing themselves as healthy, chronically ill individuals are not distorting reality, but re-examining what is possible and normal. At this point the self, and not the diseased body, becomes the source of identity. By objectifying the body and placing it at a distance, chronically ill individuals are able to perceive their body as something to which things are done instead of something that controls the person. Individuals can assume a wellness in the foreground perspective by learning as much as possible about the illness, identifying the body's unique patterns of responses, and sharing their knowledge with others. The initial change in perspective from illness in the foreground to wellness in the foreground can occur either gradually, or as a result of a sudden awareness. Individuals who have assumed an illness in the foreground perspective as the result of a particular occurrence can resume a wellness in the foreground

perspective by reframing the situation to appear less daunting. In returning to a focus on wellness over illness, the individual may have a renewed sense of appreciation for life.

While Bury's notion of chronic illness as a biographical disruption has been used as a theoretical framework in studies of other chronic illnesses (e.g., Buki, Kogan, Keen, & Uman, 2005; Faircloth, Boylstein, Rittman, Young, & Gubrium, 2004), very few studies examining diabetes have used this framework or any other theoretical framework to guide their research. De-Graft Aikens (2003) is one researcher who employed Bury's notion of biographical disruption in the study of adults living with diabetes in rural and urban Ghana. This researcher used Bury's theory of meaning in chronic illness to guide the interview process, as well as the data analysis portions of her study to discover how diabetes disrupted the body-self, social identity, family and social relationships, and economic circumstances of her participants. Similar to De-Graft Aiken's study, I used Bury's (1982) view of chronic illness as a biographical disruption along with Paterson's (2001) shifting perspectives model of chronic illness as the theoretical frameworks for my study. These theories loosely informed the design of my interview questions, and served as a starting point for thematic development in the data analysis.

### CHAPTER 3: METHODOLOGY

When I began this research I had one purpose in mind; to understand what it is like to live with diabetes. Having never been diagnosed with this chronic condition, I was asking the question as an outsider peering into a world in which I had never set foot. Knowing that I wanted to obtain a clear and information-rich understanding of this particular phenomenon, I chose to approach the issue from a qualitative perspective. This research paradigm would allow me to develop information-rich cases that would help me to better understand the experiences of four young women living with type 1 and type 2 diabetes (McMillan & Schumacher, 2006). One of the first challenges I faced with this thesis was choosing a method of data collection. While as a researcher I value the utility of observation and researcher participation, these methods were neither appropriate nor feasible methods for answering the research questions I had in mind. Instead, to experience life with diabetes, I would have to observe this phenomenon through the eyes of the participants under study during an interview.

While initially I believed that in taking a qualitative approach to health research I would be treading on new territory, after delving into the recent research in qualitative health studies, I realised that I was not among the first to assume this perspective in studying chronic illness. A recent wave of interest in the subjective phenomenon of illness has swept through health research, inspiring several studies into the lived experiences of various diseases such as rheumatoid arthritis, cardiovascular disease, and cancer (e.g., Collie & Long, 2005; Hwang, Kim, & Jun, 2003). While health professionals are moving towards an understanding of the subjective nature of chronic illness, this notion of illness as being a highly individualized phenomenon has not yet entered programs designed at increasing diabetes awareness in the schools (e.g., Cunningham &



Wodrich, 2006; Jarrett et al., 1993). For friends and educators to play a positive role in the diabetic individual's life, it is important that they are able to appreciate the many ways that diabetes may influence the individual's existence. In developing four case studies, I hoped to illustrate the subjective nature of the diabetes experience, while looking for similarities that existed across cases.

### Recruitment of Participants

Prior to commencing the research process, I was granted the opportunity to attend the Canadian Diabetes Youth Advocacy workshop that was held in Toronto in February of 2007. Having noticed an advertisement for the workshop on the Canadian Diabetes Association website, I eagerly contacted the organizer to inquire about attending the workshop as an observer. The Canadian Diabetes Association granted me permission to attend, and two months later I was on my way to learning about pertinent issues for youths with diabetes. Canadians ranging in age from 16-30 years old gathered in Toronto, united by a common interest: the shared needs of individuals with diabetes. During this conference, the participants were taught how to effectively advocate for individuals with diabetes, and how to unite as a group to lobby the government for additional support.

Following the conference, I maintained contact with the youth advocates via a Facebook page that was designed to bring together diabetes advocates across Canada. Individuals who wished to stay in contact with other panellists voluntarily joined this group, making their email addresses available to the entire diabetes advocacy community. In total, there were 11 individuals from Ontario who joined this site, excluding myself.

Because of the nature of my study, the participants I selected needed to be articulate individuals who were willing to share their personal experiences with diabetes. Having previously spoken with many young people at the diabetes advocacy workshop, I

realised that these individuals would be ideal candidates for my research. Not only had they demonstrated their willingness to speak publicly about their personal experiences with diabetes, but they had also demonstrated a sincere desire to make a difference in the lives of children and adolescents living with diabetes across Canada. I thus opted for a sampling procedure that could be considered purposeful sampling. According to Patton, purposeful sampling is “selecting information-rich cases for study in-depth” (Patton, 2002, p. 242), and can be used when the researcher wants to understand something about a particular case without expecting to generalize to all such cases (McMillan & Schumacher, 2006). Because I wanted to study information-rich cases, I needed participants who were both articulate and willing to share their experiences. In choosing individuals who had attended the diabetes advocacy workshop, I was ensuring that my participants met both of these criteria.

Before commencing the recruitment process, I set a list of criteria to be met by participants for inclusion in the study. Participants had to be between the ages of 18-30, had to reside in Ontario, and had to have received a diagnosis of diabetes prior to completing high school. Using the Facebook contact list that was available to all individuals who attended the Canadian Diabetes Youth Advocacy workshop, I randomly selected 4 of the 11 young adults residing in Southern Ontario within a 450 km radius of Kingston to inquire about their willingness to participate in my study. Initially I sent out a recruitment email (see Appendix A) to four individuals explaining the criteria for involvement in this study, the purpose of the study, and asking for each individual’s participation. Each person was given one week to respond to the email. The first two individuals I contacted agreed to take part in the study, and satisfied the criteria for participation. The other two young adults who were contacted were not eligible for

participation in the study, since they were diagnosed with diabetes during university. The next two emails I sent out never received a reply. I continued emailing letters of recruitment to individuals on the contact list until I had received a total of four confirmations. Despite my attempt to randomize the gender of participants, all of the individuals who chose to participate in this study were female. I had contacted all of the males on the list; however, none of them responded to my emails. Also, one of the four willing participants had been diagnosed with diabetes later than the period set in my criteria. Deciding that it was more important to ensure that my case studies were information-rich than equally representative of the genders or identified early in life, I made the decision to continue with the research process using the four female participants who had volunteered.

After I had received confirmation from the individuals that they were interested in participating in my study, I sent them the letter of information (see Appendix B) as well as a copy of the consent form (see Appendix C) to read prior to our meeting. I asked each person for her preferred method of communication, and each woman chose to converse via email. Over the weeks leading up to our interview, I frequently emailed each participant, organizing a time and place to meet, and answering any questions she had regarding my study. Upon meeting with the four women, I asked them for a brief description of themselves. Their individual descriptions are summarized in the following section: Abbey, Olivia, Hannah, and Melinda.

#### Description of the Participants

##### *Abbey*

Abbey is a 20-year-old woman who was diagnosed with type 2 diabetes at the age of 17. Initially diagnosed with reactive hypoglycemia by her doctor, Abbey continued to

push her doctor for further tests until she was eventually diagnosed with type 2 diabetes. Abbey is the first person in her family of five to have received a diagnosis of diabetes. Immediately following diagnosis, Abbey began an insulin therapy regimen whereby she gave herself injections 2 to 4 times a day. Because of her intense phobia of needles, this treatment regimen was difficult for Abbey to grow accustomed to. At the time of data collection, Abbey was using the insulin pen, but hopes some day to purchase an insulin pump. At the time of diagnosis, Abbey was enrolled in a small private school in her hometown.

Abbey began her university career in the sciences; however, when it became apparent that the symptoms of diabetes were impeding her performance, she switched her majors to English and Religion. During her first year of university, Abbey became sick and had to return home. For this reason, she is currently repeating first year. Due to her illness, Abbey was unable to attend the Diabetes Advocacy workshop in 2007, but hopes to attend in 2008. She has been, however, participating in the Facebook site.

### *Olivia*

Olivia is a 25-year-old woman who was diagnosed with type 1 diabetes at the age of 18. While she was not diagnosed until the end of secondary school, Olivia presented with symptoms of the disease long before her diagnosis. Olivia struggled with her diagnosis for many years, failing to adhere to the diabetic regimen and becoming more depressed. She had never heard of diabetes prior to her diagnosis, and was not sure what the future held for her. It was not until the age of 22 that Olivia realised life with diabetes did not have to be the end of the world. Olivia began insulin therapy using hypodermic needles, and at the age of 23 switched to the insulin pump. She completed her degree in nutrition, and is currently seeking employment as a diabetes educator. Olivia has attended

several diabetes advocacy conferences across Canada, and participated in a rally on Parliament Hill. She has been all over Canada in conjunction with the Canadian Diabetes Association, sharing her story with those who will listen.

### *Hannah*

Hannah is a 26-year-old PhD student at an Ontario university. Having lived with type 1 diabetes since the age of 5, Hannah has devoted her life studies to discovering ways to transplant islet cells in the hopes of someday finding a cure for type 1 diabetes. Hannah is the only person in her immediate family of six who has diabetes, so she recalls it being a learning experience for everyone. During her elementary school years, Hannah was enrolled in a local Catholic school. Upon entering high school, she switched to the public school system. When Hannah was first diagnosed with diabetes, she began insulin therapy using hypodermic needles, and performed 2 injections a day. Her treatment later changed to a 3 needle a day regimen, at which point she began using the insulin pen. During her university years, Hannah switched from the insulin pen to the insulin pump, and continues to use a pump for insulin therapy. Hannah has been actively involved with the Canadian Diabetes Association, acting as a youth advocate both in Toronto, and on Parliament Hill.

### *Melinda*

Melinda is 21 years old and has type 1 diabetes. Diagnosed at the young age of 2, Melinda cannot remember life without diabetes. Because of her young age of diagnosis, diabetes has been a natural part of Melinda's life, and has not restricted or held her back in any way. Melinda attended a small French elementary school and French high school. During elementary school, Melinda was very active with gymnastics. In high school she continued in gymnastics, and also enrolled in swimming and band. While Melinda began

insulin therapy using hypodermic needles, in Grade 8 she switched to the insulin pump. She is currently enrolled in a 4-year Bachelor of Chemistry program, and hopes to one day become a doctor. Melinda is an avid diabetes advocate, having participated in the Canadian Diabetes Youth Advocacy workshop, the International Youth Advocacy Conference, and many other political advocacy meetings.

### Data Collection

Case studies are used in many areas of research because of their power to portray vividly an individual life or phenomenon (Buki et al., 2005). In my research, I selected a case study design involving four cases as a means to convey what it is has been like for four young women to live with diabetes.

#### *The Interview*

Prior to commencing the interview process, I created an interview guide of open-ended questions to use with each participant (see Appendix D). The design of the questions was influenced by many sources, particularly Seidman's phenomenological interview (1991), Atkinson's life story interview (1998), and the McGill Illness Narrative Interview (Groleau, Young, & Kirmayer, 2006). According to Seidman (1991), phenomenological interviewing normally features three interviews, each of which has a specific purpose. The initial interview focuses on the individual's life history and the context of the participant's experience. During the second interview, the participant provides as much detail as possible about his or her experience with the phenomenon in question; in this case, diabetes. In the final interview, the participant is asked to reflect on the meaning of his or her experience, and whether or not it has had an impact on his or her life. Although my interview questions incorporated all of the aspects of Seidman's phenomenological interview, I condensed the interview into a single session intended to

last 90 minutes. The reasoning for this was that my participants were all university students enrolled in highly demanding programs, and might well not have had the time to commit to a series of three interviews. The cost of conducting three interviews with each participant would have also exceeded the budget I set aside for this research, since I would have had to stay in hotels in the city of the four participants' residence on three occasions.

With Seidman's three purposes of phenomenological interviewing in mind, I turned to Atkinson's writings on the life story interview for further inspiration. The life story interview is a qualitative research method for gathering information on the subjective essence of one person's entire life (Atkinson, 1998). It begins with a recorded interview, is transcribed by the researcher, and ends up as a flowing narrative that is completely in the words of the person telling the story. What attracted me to this method was Atkinson's view that the only way to truly understand another's position in life is to tell that individual's story in his or her own words, allowing his or her voice to be heard first and foremost. One way that I could assure that the stories of Abbey, Olivia, Hannah, and Melinda were indeed their own stories was to adopt Atkinson's method of case presentation, presenting the stories of these four women in their own words. According to Atkinson, the life story interview can be used to provide new insights, to entice compassionate judgment, to create shared knowledge and meaning that can inform professional practice, and to illustrate possibilities for human action and feeling (Atkinson, 1998; Witherell & Noddings, 1991). Atkinson suggests that a life story interview can last anywhere from under an hour to several interviews lasting three hours each.

Initially I began writing my interview questions using only Seidman's phenomenological interview and Atkinson's life story interview. Upon further reflection, however, I came to realise that the questions I had designed were too broad, and would not provide me with information specifically related to the illness experience. Thus, I had to find a way to refine my questions. The final qualitative interview method that influenced the development of my interview guide was the McGill Illness Narrative Interview, or the MINI (Groleau et al., 2006). This theoretically driven, semi-structured, qualitative interview protocol was designed specifically to elicit illness narratives in health research. The MINI consists of questions arranged into five sections: initial illness narrative, prototype narrative, explanatory model narrative, services and responses to treatment, and impact on life. Questions in section 1 of the MINI are intentionally unstructured, and invite participants to tell their story in their own way. Section 2 aims to elicit narratives which reveal prototypes relating to self, family, society, and media, and how the narrator uses these prototypes to reason about her or his health problem. Questions in section 3 are designed to elicit explanatory model narratives, looking specifically for bodily, social, and cultural explanatory models that are used by the narrator to make sense of his or her health problem. Section 4 examines the narrator's experiences with the health care system. Groleau and colleagues (2006) state that this section of the MINI is optional, and should be used only if relevant to the research questions. Questions in section 5 explore the impact of the health problem on the narrator's life in general, and examine if and how the illness has led to changes in identity, roles, and functioning. This section also examines methods of coping and social supports available. Since I was interested in learning about the illness experience in the school and not in the hospital or medical setting, I had to adjust the questions contained in



the MINI to meet the needs of data collection for this particular study. Combining the interview techniques of Seidman, Atkinson, and Groleau with the theoretical frameworks put forth by Bury (1982) and Paterson (2001), I developed an open-ended interview guide that was used with each of my four participants.

Before conducting the interviews with the four women under study, I tested the questions in a pilot interview with an individual diagnosed with epilepsy. The selection of a participant with a diagnosis other than diabetes was made so that his responses to the questions would in no way influence my views on the experience of living with diabetes. The pilot interview was audio-recorded, transcribed, and then reviewed by myself and my supervisor to ensure that the questions I had designed elicited relevant responses. This interview showed me that some of my questions were too general, and did not encourage the interviewee to focus on the illness experience. I made the required modifications to the interview guide prior to meeting with the study participants.

Since I would be conducting interviews in the participants' cities of residence, I allowed the women to select a time and location for the interview. In allowing the participants to select the location of the interview, I hoped to increase the level of comfort they felt so that they would feel free to tell their stories (Patton, 2002). All of the women except for one chose to meet me at their homes. The fourth woman arranged to meet me at a local coffee shop. However, when we realised there was no place to sit, she opted to complete the interview at the hotel where I was staying.

Prior to commencing the interview, each participant was asked to read the letter of information and to sign the consent form. I provided a brief summary of the purposes of my study and of the role they played in the research. They were reminded that their names would be changed to assure anonymity, and that they were free to withdraw from

the study at any time without consequence. When they were satisfied with the information, I began the interview process.

Each interview was audio-recorded using a digital wave voice recorder. Although the interviews were expected to last a total of 90 minutes, three of the interviews lasted close to two hours. At the 90-minute mark, each woman was given the opportunity to either continue with the interview, or to schedule a time for a second interview. All three of the women chose to continue with the interview until it was complete. The fourth interview lasted 90 minutes, and was complete at that time. Throughout the interviews, I referred frequently to the interview guide to ensure that topics to be discussed were touched upon. Probes were used to elicit further discussion from the interviewees, and new topics were explored as they arose.

During and immediately following the interviews, I recorded in my reflective journal my initial thoughts and feelings about what had occurred and about what each woman told me. This process allowed me to separate my own thoughts from those of my participants, and also to record initial thoughts on possible emerging themes or categories (Patton, 2002). Following completion of the interviews, I transcribed the interviews verbatim.

### Data Analysis

Since it is the ultimate goal of the phenomenologist to uncover the meaning or experience of a particular phenomenon as is held by the individual, I turned to the works of Patton (2002), Moustakas (1994), and van Manen (1990) for guidance on analyzing qualitative data. Following Patton's writings on phenomenological analysis, I analyzed my data in four phases. During the first phase, *epoche*, I looked inward and identified any preconceived ideas or notions I had about the experience of living with diabetes. During

this phase, I kept a journal consisting of thoughts on what I expected to hear from the participants based on personal experiences and the findings in the literature, beliefs I held regarding diabetes, and beliefs I held about my own struggle with hypoglycemia. During this phase of reflection, I realised that I had expected to hear stories of how diabetes was difficult to manage, and psychologically overwhelming. In acknowledging my personal biases, I was able to separate them from the data, thus allowing me to look at the data with naïve eyes. Throughout the data analysis process, I continued to refer back to my journal, asking whether the findings were the result of my personal biases, or whether they were supported by the data. In doing so, I was able to shift from my initial focus on diabetes as an illness, to the participants' focus on diabetes as a transformational or purposeful experience. After reading through each interview transcript several times and looking for any holes or inconsistencies in the data, I contacted the participants via email for clarification. This was the preferred method of contact for all participants.

In the second phase, phenomenological reduction, I first removed all of the researcher's questions from the transcripts and looked at the transcripts as a whole without interruptions. At this point, I began identifying key phrases and statements that related to the participants' medical, school, social, and psychological experiences. During the third phase, horizontalization of the data, I organized the key statements and phrases into meaningful clusters of similar themes. In a process that Douglass (2000) refers to as "moving around the statue," I attempted to organize the data into a variety of different themes and categories. In my initial attempt, I organized the data according to three themes: learning to live with diabetes, a changing life, and acceptance. My second attempt entailed arranging the data into chronological order, moving from the pre-diagnosis experience, to the diagnosis experience, to struggling with diabetes, and finally

accepting diabetes as a new way of life. In my third attempt, I organized the narratives into categories based on the Shifting Perspectives Model of Illness (2001). Upon reflection, I realised that none of these thematic organizations would provide an accurate depiction of the experiences of the four young women living with diabetes, and might have unintentionally implied that the process of adjusting to life with diabetes followed a linear trajectory. Returning to the thematic organization I assumed in Chapter 2, I organized the findings under four main headings: medical experience, school experience, social support, and dealing with the developmental challenges of diabetes. Because the stories told by the four young women were not purely psychological in nature, I changed the previous category of “psychological experience” to “dealing with the developmental challenges of diabetes” in an attempt to encompass the more holistic experience of the participants.

The final stage of data analysis involved synthesizing the data into text form. Following the works of Flaton (2006) and Atkinson (1998), I initially chose to present each case profile first in the words of the woman living with diabetes, followed by the researcher’s interpretations so that the reader could feel, empathize, and experience life with diabetes through the eyes of the person living with it (Atkinson, 1998). As I set about creating the case profiles, I began by organizing the data in chronological order so that the story would lead the reader from the initial phase of diagnosis through to the current day. Based on the analysis, I wove relevant quotations from the data into a coherent story, bracketing any words that were added by the researcher. This case profile was then returned to each participant so she could verify the contents for accuracy. All four of the participants approved the case profiles, and did not propose any changes. Although my initial intent was to include the case profiles in the findings section, I

ultimately decided to move the profiles into the appendix (see Appendix E). While these stories proved useful in allowing me to view the experience of life with diabetes through the eyes of the participants, they were not reader-friendly. As such, I chose to take a more narrative approach in reporting the findings, weaving the women's own words into a more coherent case study. Throughout Chapters 4, 5, and 6, italics are used to denote quotations taken directly from the four women under study. Shorter quotations remain embedded in the text without quotation marks, while longer quotations are written in block style. Because these case studies retain many original quotations from the interview transcripts, they fulfill the desired purpose of allowing readers to experience life with diabetes through the eyes of the individuals living with this chronic condition.

#### CHAPTER 4: DIAGNOSIS DURING ADOLESCENCE

You can know the name of a bird in all the languages of the world, but when you're finished, you'll know absolutely nothing whatever about the bird...so let's look at the bird and see what it's doing—that's what counts. (Richard Feynman, as cited in *The Quotations Page*, 2007)

Chapter 2 reviewed the literature on the lived experience of diabetes mellitus.

While it provided a starting point or context for this thesis, it has merely translated Feynman's bird into many different languages. The following two chapters are dedicated to presenting the findings of this thesis. Chapter 4 and Chapter 5 provide a glimpse into the lives and personal experiences of Abbey, Olivia, Hannah, and Melinda from the time of diagnosis to the present day. Since previous studies suggest that the experiences of individuals diagnosed with a chronic illness vary according to the age at which they were diagnosed (e.g., Lavigne & Faier-Routman, 2002) I have separated the four women's stories into two chapters. Chapter 4 examines the experiences of Abbey and Olivia who were diagnosed during adolescence, and Chapter 5 focuses on Hannah and Melinda who were diagnosed during childhood. Themes are organized under the general headings of medical experience, school experience, social support, and dealing with the developmental challenges of diabetes. Although I have chosen to separate the findings under these general headings, these experiences are by no means separate entities. The women's medical, school, social, and developmental experiences are all intertwined into one greater experience; their life experience.

## Abbey's Story: The Long and Bumpy Road

### *Medical Experience*

*I was diagnosed with reactive hypoglycemia on my 16<sup>th</sup> birthday. I was in Driver's Ed, and I had a candy necklace. I felt really low and shaky, and had heart palpitations after eating it. I went straight to my doctor and explained that I just ate candy and felt like I was going to pass out. The doctor didn't do any blood work on me or anything to find out what was going on. He just suspected that it was reactive hypoglycemia, so I just stopped eating candy and simple sugars, and it was fine after that. When I was in Grade 12 biology we had to do an independent study on a disease of our choice, so I picked reactive hypoglycemia. As I was researching it, I found out that I had all of the symptoms for diabetes. I called my doctor and told him that I wanted a blood test for diabetes. After my mom yelling at him and me getting on his case about it, I finally got a blood test, and I have it. I was diagnosed with type 2 diabetes at a really weird time of my life, around February of 2006. I was 17 years old at the time. I am insulin resistant, and I don't produce enough insulin. It is really rare in my age group.*

Long before Abbey was officially diagnosed with type 2 diabetes, she experienced subtle signs of illness. In elementary school, Abbey was constantly sick. While at the time she considered these frequent bouts of illness to be a normal part of childhood, Abbey now believes that they may have been early signs of blood glucose fluctuations, foreshadowing the events to come. Despite subtle hints of illness, Abbey did not recognize that there was something physically wrong until the age of 16. Cutting out simple sugars and carbohydrates from her diet seemed to alleviate the appearance of

symptoms for a brief period of time; however, Abbey was once again affected by the undiagnosed diabetes upon writing her Grade 11 chemistry exam.

*I normally did really well in school. I was a high 80s and 90s student, and I received highest honours four years in a row. I was experiencing really bad symptoms in January and February, right when they do the exams in high school. I failed my chemistry exam because I couldn't concentrate.*

While many individuals might have blamed their doctor for missing such an important diagnosis, Abbey willingly accepts the blame.

*As a kid I had a little bit of a hypochondriac tendency. I think maybe that is what he thought it was. Because, you know, I was studying diabetes at the time, so he thought that maybe I was just paranoid. I wouldn't make that up. It is kind of a serious thing to make up. I don't blame him, or whatever, because in Grade 1 I was sick with every disease in the world. I think I just wanted to get out of school.*

Abbey can recall vividly the events that took place over the next few days.

*The doctor called me at school and told me I had diabetes. When I went to the hospital, it took two and a half hours just to poke my finger [with a lancet]. I wouldn't do it. I was needle phobic. When they told me that I had to start injecting myself with insulin, they actually had to put me in the hospital for four days. I refused to give myself insulin, and I refused to let anyone that was living in my house give me insulin except a trained and certified nurse. The nurses tried to get me to leave the hospital and come back during the day, but I told them that I needed to stay there. I just couldn't deal with it at home, or I would go crazy. I finally did manage to give myself some insulin, and that was probably the hardest thing I have ever had to do in my life.*



Although Abbey's parents tried to do everything they could for Abbey while she was in the hospital, Abbey wanted to deal with her diagnosis independently.

*It was new territory, and I didn't need my parents there worrying about me. My mom was at the hospital with me most of the time, but it was nice to be able to get away from her and kind of breathe, because it was a lot to take in, especially at 17.*

When Abbey was first hospitalized, the doctors placed her on insulin injections to try and lower her blood glucose levels with the idea that it would only be a temporary solution.

*The doctors thought that after six weeks they would put me on pills, but it has been a year and a half, and I am still on insulin. I tend to give myself an injection about three to four times a day. I normally test my blood sugar two to three times a day.*

While Abbey's diabetes was the first case in her family, she was no stranger to the world of diabetes.

*I have had a very long affair with diabetes before I was diagnosed with it. When I was 10, my best friend was diagnosed with type 1 diabetes, so that opened my eyes to the world of diabetes. I didn't believe the diagnosis at first, to be honest with you. I was home sick the day she was put in the hospital, and my brother came home and told me that Cindy was diagnosed with type 1 diabetes. I was only 10 years old; I didn't know what diabetes was. I had so many questions. Is she dying? Is she contagious? Can I have it? I went to visit her in the hospital. It was different, but I learned a lot about diabetes, and I learned a lot more about health*

*care. She actually kind of introduced me to the carb to insulin ratio. She would explain, "If I give myself this much insulin, I can eat this much ice cream."*

Even though Cindy had introduced Abbey to aspects of life with diabetes, there was much left for Abbey to learn. Like most newly diagnosed diabetics, Abbey began diabetic classes at the hospital where she learned how to administer insulin, test her blood sugars, and calculate her insulin to carb ratios. Because Abbey is *a big fan about knowing everything about anything that is affecting me*, she took it upon herself to learn as much as possible about diabetes through various websites, books, and medical journals.

Dealing with diabetes on a daily basis, Abbey learned through experience how to handle the specifics of her treatment regimen. *The first little while I kind of went into a really strict diet; I was almost obsessive compulsive about it. And with time, I became more relaxed.* As Abbey learned to read the subtle body signals that prior to her diagnosis she had ignored, Abbey quickly discovered what it felt like to be high, and what it felt like to be low. For Abbey, being high brings a feeling of warmth and confusion. *When I am hyper, I am a little more aware of what is going on around me. I still get shaky, but I can still focus and concentrate when I am high.* Although the lows feel similar to the highs, Abbey is able to identify a few subtle differences. *When I am low, I get shaky and confused and a little discombobulated. It is more difficult to concentrate, and everything is a little more blurred.*

Being able to recognize the signs of high and low blood sugar has helped Abbey to reduce the number of times she must test her blood sugars during the day from five times to two to three times a day. This ability to detect highs and lows has also allowed her to adjust insulin doses to match her food intake, granting her more freedom from the

strict diabetic regimen. Carrying snacks and diabetic supplies with her at all times has also helped Abbey to maintain her blood glucose at constant levels.

For the most part, Abbey adheres to the diabetic regimen fairly well. At first she went into a very strict diet, counting every carb and matching it with insulin. However, as the permanency of diabetes set in, she began to ease up on the treatment regimen and allowed herself certain indulgences.

*If I am craving [a certain food], I don't stop myself from having it. I will indulge a little bit if I need to, because if you don't give yourself what you need or want sometimes or are restricting yourself too much, you get a little emotional about it. It is like being on a permanent diet. You know, you have to have that pizza sometimes, and you need to go out with your friends and go to the bar, you just have to be careful about how much you drink and that you eat something with it. But you can go out. You can't restrict yourself from everything, because then you are just going to get emotional about it and hate yourself.*

Although at times Abbey strayed from the recommended diet, she always did so in a very controlled manner, keeping track of what she was eating and drinking, and compensating with the appropriate level of insulin or exercise.

#### *School Experience*

*Diabetes in secondary school.* Abbey describes herself as being a good student in high school. *I was a high 90s student. High 80s and 90s.* Because Abbey was accustomed to achieving high marks, when she failed her Grade 11 chemistry exam because of an inability to concentrate, she knew something was wrong. Recognizing uncharacteristic behaviours in Abbey such as a glazed-over look and inability to focus, her chemistry teacher granted her a 70% in the course because she had done well in the class leading up

to the exam. Once she was properly diagnosed with type 2 diabetes and began managing the disease, Abbey found it much easier to remain focused on her work.

Prior to being diagnosed, Abbey was actively involved in extra-curricular activities both inside and outside of the school.

*I was involved in a lot of things. I used to volunteer. I was the counsellor for our church group; it was for little girls. And I did a lot of organizing and stuff for banquets and things for the school. When I found out I had diabetes, I just didn't get involved with them as much anymore. I was just going through some stuff. It was kind of hard to just keep doing it all.*

Although Abbey initially did not have to give herself insulin injections at school, when the doctor increased her regimen to three needles a day, she had to start administering insulin at lunch. By this time, many of her friends and peers had already seen her give herself injections. *They were okay with it. I would give myself injections in the cafeteria under the table. Most people can't even see what was going on.*

Despite having received previous diabetes training because of another student who had type 1 diabetes, the teachers at Abbey's private high school underwent a second session of training when Abbey returned to school. For the most part, Abbey's teachers were very accommodating.

*During exams and stuff they would let me go to the bathroom, because you have to urinate every 15 minutes, and you are drinking gallons of water a day. So the teachers were pretty understanding when it came down to that. They would let me leave during the exams. But yeah, everyone was pretty understanding.*

While Abbey considered them to be helpful, she did not believe that her teachers truly understood the complexities of diabetes.

*My Society, Challenge, and Change teacher came up to me one day and was talking to me about diabetes. He told me his aunt died of diabetes when she was 4, so he was staying off the sugars so that he wouldn't get it. I think a lot of people have a misconceived notion about it.*

Instead of being disheartened by their blatant lack of understanding, Abbey would often explain different aspects of diabetes and its management to her teachers.

Because Abbey was enrolled in a small private school, when she was diagnosed with type 2 diabetes, all of her classmates knew. *My Grade 12 graduating class was really close, so everyone knows what is going on. So it wasn't a big deal for them.*

Although some of her peers were a little oversensitive about her diabetes, others downplayed the seriousness of her condition.

*Some of them are a little over sensitive, some of them are a little, you know, under sensitive about it, and are totally in your face, like "Abbey, there is nothing wrong with you. You can eat that. You can go get wasted with everyone else." And so I have to tell them "Maybe not tonight, guys."*

Although it was frustrating when her classmates dismissed the seriousness of her condition, Abbey was not overly concerned with their reactions. *With friends like that, it doesn't bother me. I am okay with that. Especially since the people who do that I am normally not too close with.*

*Diabetes in university.* Because Abbey was diagnosed with diabetes during the final year of high school, she found the transition from high school to university to be a difficult one.

*I was debating about taking a year off and maybe staying at home and dealing with things. I decided at the last minute that I was going to go to school, because*

*who wants to be a year behind all of their friends? But I ended up being a year behind all of my friends anyways.*

During her first year at university, Abbey was enrolled in a biochemistry program in the hopes of becoming a doctor. When her blood sugars raged out of control, Abbey made the decision to switch programs.

*In my first year of university I really wanted to be a biochemist. I had a hard time in the labs with my low blood sugar and high blood sugar affecting the stability of my hands. Working with DNA and genes, it is way too difficult to control a science experiment when you can't control your own body. I had to go home from university that year because I was sick. My blood sugar was high, and I couldn't get it under control. I had become resistant to the insulin I was on.*

Searching for a program that would allow her to ask questions about the bigger picture, Abbey returned to university the following year and enrolled in a Religion and English program.

When Abbey was accepted to university, she was granted a scholarship that would carry over the four years she was at school provided she maintained a certain average. Abbey lost this scholarship when she had to return home due to her illness. Upon appealing her scholarship the following year, the university dismissed her appeal.

*They didn't think it was a valid excuse or reason even though I had a note from my endocrinologist. I was like "No, you are going to give me this money. If a kid came to you and said I have to quit school because I am dying of cancer, and they went into remission and came back, you would probably give them the scholarship money back. I mean, what am I supposed to do about that?"*

After pointing out the double standard the university held for medical leave, her scholarship was reinstated.

Because Abbey is currently enrolled in classes with hundreds of students, she does not know her professors on a personal basis. As such, none of her professors are aware of the fact that Abbey has type 2 diabetes. None of her teaching assistants are aware of her condition either. Abbey is not worried about this lack of awareness since she has friends in every class who know of her medical condition.

### *Social Support*

*Family support.* Although Abbey has tried to limit her family's involvement in many aspects of her diabetes management, they have remained a constant source of support throughout the years. From her sister asking Abbey to test her sugars, to her mother cooking meals for the whole family using Splenda, her relatives do whatever they can to make Abbey feel like a valued member of the family.

While Abbey's parents are now able to handle their daughter's diagnosis, when Abbey was first diagnosed, it was overwhelming.

*[My diagnosis] was hard on my parents. I think it was the first thing that my parents couldn't teach me. For them, they were always like "I've been through it, don't worry." This was the first time they were like "I haven't been through it. There is nothing I can do." So, it was hard for them.*

As is the case with many parents, Abbey's parents spend a lot of time worrying about her. *My parents worry about me when I am away from home like any parent, but it is 10 times worse, because I am sick and I am dealing with it myself. It is just me.* In an attempt to alleviate some of their worries, and out of respect for her parents, Abbey calls

*home all of the time to make sure my parents know and update them, because it is not just about you. Everyone else is worried too.*

*Friend support.* Like many individuals progressing from childhood to adolescence, Abbey's friends played a large role in her life at this point.

*My friends in particular made it easier for me. When I needed to talk about [my diabetes], they just listened. They ate the same types of food [as me]. We wouldn't go out for dinner or lunch. Instead we would eat in or have potluck dinners because I couldn't really go out. It wasn't good for me.*

Prior to Abbey's diagnosis, her friends did not truly understand the disease. Through watching Abbey and asking questions, they learned a great deal about diabetes. They became so knowledgeable that eventually they were able to detect the early signs of hypoglycemia, and would suggest to Abbey that she should test her sugars. Abbey's friends also helped her to become more comfortable giving injections in public.

*At first I did not want to give an insulin injection in front of people. But my friends made it easier. They were like "You can just do it at the table, it's okay. You don't have to go to the bathroom." Which was a big thing, because when you have to go to the bathroom and give yourself an injection all of the time, it is kind of a pain. To leave the table and come back is a 10-minute ordeal. And trying to find a bathroom, especially if you are in a public place is always fun.*

While having diabetes did not prevent Abbey from going out with friends, it did influence who she chose to become friends with, particularly during university.

*You are always wondering are they prepared to deal with me? You are afraid to let people in sometimes because are they going to be able to handle you? Are they going to be able to take care of you? You start to pick your friends around how*



*stable they are, and you start to choose people who are like you; who are really vulnerable. When it comes to being the friend of a diabetic, it is a lot more take on our side. I know I take a lot more than I give, because I feel like I go through things more often. Especially with the hormones going everywhere, and the highs and lows and stuff. And then you are sick more often. It is nice to just have someone there.*

Abbey believes it is important to have friends who have diabetes; however, she does not know many individuals her own age who share this disease. While working at Tim Horton's, Abbey had the opportunity to meet several older people with type 2 diabetes, and would often engage in conversations with them. Abbey believed it was helpful to talk about living with the disease, but found that she had very little in common with these older individuals. She is currently trying to set up a diabetes support group on campus at her university so that she can talk to others who are living with diabetes.

#### *Dealing with the Developmental Challenges of Diabetes*

For Abbey, life with diabetes has been *psychologically overwhelming*. Since being diagnosed with type 2, Abbey has fluctuated between periods in which she is comfortable and accepting of the disease, and periods in which she wishes she had never been diagnosed with diabetes. Abbey finds it hard to come to terms with her disease because *it is not something that is going to go away. You have to live with this for the rest of your life, and it's horrible*. Although Abbey speaks of friends and family as being supportive, she often stresses the fact that *I am sick and I am dealing with it myself and it is just me*. Abbey is considering seeking the attention of a psychologist because *sometimes you just want help getting through that or dealing with it all*.

While accepting the chronic nature of diabetes presents Abbey with a challenge, some of the side effects of the diabetic treatment also pose psychological threats to her wellbeing. Abbey describes how injecting herself with hormones makes her feel like a different person.

*That kind of messes with your head sometimes. Sometimes I feel like I go nuts, I just go crazy. You know, high blood sugar, low blood sugar, it makes you feel different. You feel like a different person. You are kind of outside of your body. It is kind of like being bipolar, but it is because of your meds.*

Being diabetic, Abbey has to worry about a lot of things that other people her age don't have to think about. She must always plan ahead when going out to ensure that she has all of the necessary supplies with her, and must worry about issues that are beyond her years.

*[Having diabetes], you stress about the future a lot; about life, about moving on, about being able to afford this for the rest of your life. I need a job that either has really good health benefits or makes enough money that I can afford to stay alive, because you can't mooch off your parents or friends [forever]. I think that is one of the most stressful parts about it. Even in university, I really should be studying science because I know I will probably get a better job with more health benefits, but I don't want to study it anymore. I can't be unhappy for the rest of my life just because I need to be able to afford to stay alive.*

She is currently in the process of trying to solve some of these worries as she strives to find a balance in her life.

Since Abbey was 17 years old at the time of diagnosis, the sudden onset of diabetes posed a threat to her sense of autonomy. Struggling between her desire for help

and the teenage need for independence, Abbey frequently closed her parents out of her treatment, opting to stay in the hospital rather than returning home following her initial diagnosis. *It [was] new territory. I really didn't want [my parents] there. I kept thinking I am glad I am not at home right now, because you need to relax and sometimes home isn't the most relaxing place.*

Unlike children who are diagnosed at a younger age, Abbey was expected to assume full responsibility for her health from the moment she was released from the hospital. Although her mother helped by cooking her meals, Abbey took on the daunting tasks of managing her blood glucose levels. Abbey's parents frequently worried about her while she was away at university, and often suggested that she should return home or seek help from others. Abbey quickly learned that in order for her parents to allow her to maintain her independence, she would have to cease telling them certain things that might cause them to worry.

For Abbey, being diagnosed with type 2 meant that her life would have to change. The frequent testing, injections, and monitoring of her diet often made it more difficult for Abbey to blend in with the crowd. While others might have been tempted to hide their diabetes in an effort to *appear normal*, Abbey was very open about her illness, teaching friends and acquaintances about the disease and answering any questions they had. Although Abbey is very open about having diabetes, establishing herself as different during the teenage years posed a dilemma for Abbey.

*I think normality is something everyone wants. You are in your teen years and you are already having problems, and you kind of wind up getting out of control because you want to be like everyone else. Or you want to be one step above everyone else because you don't want people to think that you are lagging behind.*

This need to be seen as one step ahead of everyone else placed an immense amount of pressure on Abbey to achieve good grades, and to participate in activities that others her age were engaging in such as drinking and smoking.

Because diabetes changed many aspects of Abbey's life, following diagnosis she was forced to assimilate her new sense of self as a person with diabetes with her previous identity. For Abbey, having diabetes has changed a lot about how she views herself, and what she expects for the future. Before she discovered she had diabetes, Abbey saw herself as an intelligent and capable student. However, when Abbey was affected by blood glucose fluctuations, her views on her own abilities changed.

*At graduation when I won a lot of academic awards I felt like no matter how sick I am I still have my brains. Now that feeling is all gone because I am kind of foggy still, and I think that my brain chemistry is a little different now than when I was 16 and super intelligent.*

Not only has having diabetes affected Abbey's perception of her own intelligence, but it has also changed her self-concept.

*Living with diabetes has definitely changed me. I became more self-conscious and worried about letting people into my life. I have learned that I am probably not as strong a person as I used to think I was. I used to think that I would be able to take anything; that you could throw anything at me and I could handle it. I don't think that anymore. I am not the same person that I used to be.*

Having diabetes has also interrupted Abbey's hopes for the future and life goals.

*I used to want children. I used to want to travel the world. I used to want to do everything. I have the desire, I just know I can't necessarily do it as easily. I can't*

*just take off for a year and expect it to all be okay. It is not always going to work out.*

When asked what an individual newly diagnosed with type 2 diabetes could expect, Abbey summarized her own experiences in the following statement.

*I would say to expect a long bumpy ride. You are going to have to work. You are going to cry. You are going to get frustrated. You are going to change your plans. You are going to hate it. You are going to hate yourself. But you are going to get through it, because there is no point in just killing yourself. You have got to live for something. Take care of yourself. It is not a day thing; it is not something you come to grips with in a day. It is definitely a process.*

While the diagnosis of type 2 diabetes has brought several negative repercussions for Abbey, she is able to identify certain positive aspects of living with this chronic condition.

*I have had quite the experience the past year and a half. I think in more ways it has shaped me for the better. I definitely feel like I have something to work towards. I can help people in different ways. I feel lucky that I can open people's eyes to different things and make them more compassionate. I feel like I have more of a voice. Maybe people would listen to me better because you can learn so much more from someone that is living with diabetes. My diabetes gives me purpose, because what is the point of getting something like this if you are just going to let it sit and not do anything with it?*

#### *Summary of Abbey's Experiences*

For Abbey, being diagnosed with diabetes was a life-altering event. All of her hopes and dreams for the future were tossed aside to make room for her new reality.

Abbey still considers diabetes to be a huge burden, and is struggling to find a balance between her desires and her diabetic needs. Abbey states that she is perfectly capable of dealing with the physical requirements of diabetes, but finds the psychological aspects to be overwhelming still. The constancy of the disease and the requirement for planning are some of the biggest inconveniences of diabetes for Abbey.

#### Olivia's Story: Learning to Live with the Terrible Roommate

##### *Medical Experience*

*I was diagnosed with type 1 diabetes in the summer of my final year of high school when I was 18 years old. I was working two different waitressing jobs in two different cities to earn money for school in the fall, so I was constantly busy. I was really tired, and could not get out of bed in the morning. By the end of the year in June, I no longer made it to my morning classes. Besides being tired, I was really skinny. My average weight was around 120 pounds; when I was diagnosed I weighed only 92 pounds. When my uniform at work didn't fit me anymore, I went to see my doctor.*

For Olivia, the diagnosis of diabetes came as a surprise. While doctors suggested that it was a stomach virus Olivia acquired on a trip to the Dominican Republic that may have been responsible for the rapid onset of full-blown diabetes, Olivia recalled experiencing subtle hints of illness long before she had been diagnosed. Throughout high school, Olivia was frequently sick with everything from bladder infections to strep throat. She was constantly exhausted, and by halfway through high school was missing morning classes on a regular basis. Although severe exhaustion, a sudden change in vision, and rapid weight loss may have compelled others to seek medical attention, Olivia did not visit her doctor until her clothes hung loosely from her skeleton-like frame. Upon seeking

medical attention, the seriousness of her condition was not immediately recognized by the optometrist, or her family doctor.

*At first my doctor didn't know what it was. I told her that I had lost weight, I was tired, and that all of a sudden I needed glasses. That triggered something in her head, because she turned around and asked if I was really thirsty all of the time. The doctor tested my sugar, and it was 36.6 which is near comatose levels. The doctor grabbed my hands and she sat down and told me that I had diabetes. I remember asking if that was good. I didn't know what diabetes was. I had heard of it, but no one in my family and none of my friends had it. So it was psychologically overwhelming, I guess you could say. I fell apart. I didn't know that diabetes could be controlled; I didn't know that if you take care of it you can be healthy. I didn't know how I would feel or what it would mean for other things in my life. All I knew was that I was going to die. At the time of diagnosis my doctor told me that I would probably have to take some pills. She never said anything about needles, or where I would have to go or that I would have to see a dietician and an endocrinologist. She was very brief about all of the things that were going to happen over the next few weeks. Initially I received no training whatsoever; I was only sent home with medication.*

For Olivia, the period immediately following diagnosis was one of *severe learning and training*. Because Olivia was initially placed on anti-diabetic pills, she did not receive the intense training through the hospital that others receive upon diagnosis. At the request of her mother, Olivia attended a couple of free seminars offered through the diabetes center in her hometown. It was not until Olivia was re-hospitalized after an allergic

reaction to the pills that she received a proper education from a dietician at the hospital. It would be another month before Olivia would get in to see an endocrinologist.

Because of Olivia's intense fear of needles, she remained at the hospital for a total of three weeks until she was able to give herself an insulin injection.

*Every time I would try to take the needle myself, I just couldn't, so the nurse would do it for me. I wasn't motivated to conquer the disease; I was just motivated to get out of the hospital. I didn't want to be there anymore, and I was getting more and more depressed. So I tried it, and my first needle hurt like hell because I hit a nerve. It took me another two days before I would even try again. The next needle I didn't even feel. It was kind of like when you just start to drive a car. You don't know what you are doing; you are really scared. But the more you do it, the more you get used to it. So the more I gave myself injections, the more I found out which spots hurt, and I would stay away from them.*

While Olivia learned how to properly administer insulin and how to follow the diabetic regimen, she did not always adhere to the treatment protocol prescribed by her doctor. In an attempt to maintain a semblance of the normal life she had previously led, Olivia frequently refused to take her needles in social situations, and engaged in social eating habits that were detrimental to her overall health.

*Until I was 22 years old, I was terrible with the diabetes management. I would eat whatever I wanted, because if you count the sugar on the back of the [nutrition] label, you can match it with the insulin. So I would eat chocolate bars and French fries and all of that, and I was very skinny because I wasn't taking enough insulin. My body was trying to find energy somewhere, so it was breaking down body fat just like before I was diagnosed. I didn't really understand the consequences of*



*what I was doing to my body. I didn't understand that it was very hard on my kidneys, very hard on my heart and arteries running my sugar that high.*

It was not until Olivia began gaining a lot of weight that she decided to take charge of her diabetes.

*The whole weight thing bothered me, and that is what got me to take care of myself, not the fact that I have diabetes and should take care of myself. It was because I had gained a lot of weight. So I just ate well, and I felt really good. I felt like I didn't have diabetes anymore. It was at that time that I fell out of the whole depression and denial phase and thought that if I just eat well and take care of myself, I will feel a lot better. It just might take awhile.*

Through experience, Olivia has learned what it feels like to be high, and what it feels like to be low. She describes the highs as feeling

*Kind of like what you feel like when you open your eyes first thing in the morning, or in the middle of the night when something wakes you up and you open your eyes. Just so tired, or as if you haven't slept for about three or four days. Your eyes actually physically become too hard to hold open. And if you can keep them open, everything you see is blurry. I also get really sluggish and lazy. I don't even want to get up or move around.*

She describes the lows as being the exact opposite.

*I feel really jittery, really sweaty, and kind of like your adrenaline is rushing. You know, like when something scares you and your heart is beating really fast, you can literally feel your heart beat really hard. I feel very nervous, very scared, and very panicky because you know it is low.*

Being able to distinguish between highs and lows has helped Olivia to manage her diabetes, allowing her to lead a relatively healthy life.

As Olivia's diabetes has changed over the years, so too did her treatment regimen. After her initial allergic reaction to the anti-diabetic pills, Olivia was placed on a two-needle-a-day regimen which consisted of a short-acting and a long-acting insulin.

*I would inject at 8:30 in the morning, and within half an hour it would kick in and I would start to feel shaky and weak so I would have to eat. And then the long-acting part would kick in on its own without another injection at 12:30. So no matter where you are, what you are doing, or what is going on, you had to eat at 12:30. And then I would take another needle at around 4:30 which would work for supper within half an hour and would get me through the night without eating until the morning needle.*

Olivia remained on the two-needle-a-day regimen until she began experiencing numerous highs and lows at college. *My lunch was different every day. And I was having a lot of lows and highs in class, and missing class, so the doctors put me on a four times a day regimen.* At this point, Olivia took a short-acting insulin at breakfast, lunch, and dinner, then would take her long-lasting insulin before bed. After a couple of years on the four-times a day schedule, Olivia went on the insulin pump at the age of 23. At first, Olivia was reluctant to go on the pump because she preferred wearing tight clothes and did not want the device to stand out. But once she tried it, she *felt like I don't have diabetes anymore.*

### *School Experience*

*Diabetes in secondary school.* Despite showing early signs of diabetes throughout high school, Olivia was not officially diagnosed with type 1 diabetes until July after she

had graduated. When Olivia thinks back on her years as a high school student, she remembers having been an inattentive student.

*I couldn't pay attention in class, and I wasn't studying either. When I would try to read the required books for class, it didn't really work, because I would fall asleep. I didn't have the motivation to go to school, and when I was in school, I was literally sleeping on the desks. If I was sleeping and woke up, I would ask somebody what was going on, and I would get in trouble for talking. I had a lot of detentions, and I accepted it, because you are not supposed to sleep in class. I just thought, okay, I will take detention and then get in trouble again. It was just a normal thing.*

Even though Olivia was feeling sick and had missed the final three weeks of the term, she chose to write her final exams and did very poorly on them. At the time, Olivia did not understand how sick she truly was. *I just thought that I was overworking myself and it was my own fault for not going to class and not studying. I passed; I got into college, so I didn't really care. But maybe I should have.*

Although Olivia was exhibiting overt signs of illness throughout her final years of high school, her teachers remained oblivious to the early signs of Olivia's deteriorating health. It was not unusual for Olivia to miss assignments and tests, so when she reverted to her old habits after a brief period of academic improvement during her OAC year, her teachers were not overly alarmed. Instead of recognizing Olivia's overwhelming exhaustion and sudden drop in weight as symptoms of an underlying medical problem, her teachers assumed that Olivia was lazy, and continued to hand out detentions. Even if her teachers had asked her why she was so tired, Olivia believes she would have mistakenly assumed it was because she was overworking herself at her two waitressing

jobs. It was not until Olivia was hospitalized for diabetes that her OAC biology teacher realised she had been showing early signs of diabetes all along.

*When he came to see me in the hospital he said “It all makes sense now. You were so skinny, you were always leaving the class to go get something to drink, and you were always sleeping. I should have noticed. I can’t believe I didn’t notice.”*

Unlike the teachers at her school, Olivia’s friends and classmates noticed subtle differences in her health and behaviour. *A lot of people said to me “You work a lot. You are always tired, and you are getting skinny.”* Although Olivia’s close friends pointed out some of these physical and behavioural changes to her, no one ever suggested that she seek medical attention. Olivia recalls how *people in high school used to whisper and gossip all the time that I was anorexic, because I was so skinny. But nobody said, “Hey, maybe you should go see a doctor.” Nobody would talk to me about it.* While Olivia recognizes how difficult it would have been for her friends to confront her, she believes that if they had suggested she seek help, that she might have been diagnosed sooner.

*Diabetes in college.* Despite having been recently diagnosed with diabetes, Olivia enrolled in a college program immediately following graduation. The first year away from home was a particularly troublesome time for Olivia.

*Every first year post secondary school is a learning experience. You live on your own most of the time while going through those life changes. Plus, I was learning the whole diabetes thing. I would miss classes steadily. My attendance in the first year was about 60%. [Being in college], my lunch was different every day. I was having lows and highs in class, missing class, and panicking and not knowing what to do, so they put me on a four times a day needle regimen instead of the previous two times a day regimen.*

Even being on the four needles a day regimen, Olivia continued to experience several lows.

*One time I didn't have my Medic Alert bracelet on and I got very mouthy with one of my professors. After telling him to F-off, I got sent to the Dean's office. As I was waiting to go into the Dean's office my roommate walked by and saw that I was really pale, that I was sweating, and that it was 2:00 in the afternoon. She came over and asked if I was alright, but at that point I couldn't even talk. She ran to get me a bottle of pop and then tested my sugar and I was very low. I don't even know how I made it that far without passing out. The Dean and professor both thought that I was intoxicated because my breath smelled like booze. That is what happens when your blood sugar goes really low; your breath smells like alcohol. My roommate went into the Dean's office and explained everything, and then she went back to the professor. He was very educated about diabetes, but he didn't know that I had it because I didn't tell anybody.*

Once her professors were aware of her diabetes, they were very accommodating. Olivia recalls being allowed to eat in class whenever she needed to, and how her professors made special arrangements and exceptions for her. The support she received from the university made it easier for her to maintain a firm grasp over her diabetes management.

### *Social Support*

*Family support.* The teenage years are typically viewed as being a time in which individuals pull away from their parents and become independent. For Olivia, being diagnosed with type 1 diabetes impeded her independence, making Olivia cling tighter to her mother and father. *I became totally dependent. I turned into an 8-year-old child. I*

*didn't do anything for myself. My mom did everything for me again; my laundry, my cooking, making me take my needles. She even tested my sugar for me.*

While Olivia's mother eagerly resumed her role as caregiver, Olivia's father assumed the role of provider and chauffeur.

*My dad had a hard time with it. It made him depressed because he didn't know what to do. He didn't know how he could help, because I wasn't a little kid anymore; I was 18. It broke his heart that I had diabetes because there was nothing he could do to help. If I needed to go somewhere, my dad would drive. Or if I needed money for something he would give me money. But he was really quiet for a couple of years.*

Although Olivia's parents were supportive in helping her manage the disease, they were unable to provide her with the psychological support that she yearned for. *Even today [my mom] is still a nervous wreck, wondering if I am alive, if I am okay, if I have taken my needle. My mom was no help. She needed help, actually.* Olivia feels that her whole family should have received psychological counselling. Like Olivia's mom, Olivia's dad found it difficult to come to terms with her diagnosis. Over the years Olivia's dad has become more knowledgeable about diabetes, and is more involved in Olivia's life.

*Friend support.* Before she was diagnosed, Olivia and her friends participated in the usual teenage activities: going to the movies, throwing parties, going shopping, and hanging out at the beach. When she discovered she had type 1 diabetes, Olivia started avoiding her friends and social situations.

*That summer I didn't go out; didn't go to the beach, didn't do any of that. Because wherever I went, I had to have these stupid needles, so I basically became a*

*hermit. If I did go out, I didn't take my needles. I would leave them at home; I didn't even bring them in my purse. I didn't want anyone to see me take it, because I had lived 18 years not having to do that. I was ashamed of having [diabetes], so I never hung out with my friends. I didn't want to have to answer any questions because I didn't really know anything about it. And I was still mad that I had it.*

Ignoring Olivia's attempts to sever the ties she had with her friends, Olivia's friends continued to push their way back into her life. Olivia's best friend was particularly supportive throughout the whole ordeal. She encouraged Olivia to take her needles, and frequently asked Olivia questions about the management so that she could learn more. Because of her best friend's interest and support, Olivia eventually became comfortable giving herself injections in public. *If I had to take a needle somewhere, she would pull out all of my stuff. She would pretty much make me feel like it was okay to do it.*

When the summer was over and Olivia went to college, she spent the majority of her time hanging out with her roommates. She never really saw her high school friends much after graduation.

### *Dealing with the Developmental Challenges of Diabetes*

Coming to terms with her diagnosis of type 1 diabetes was a difficult task for Olivia.

*For four years I was in denial about having diabetes and I was depressed. I didn't agree with my diagnosis. I didn't want it because I didn't understand how manageable it is. I was 18 going on 19; I was getting ready to graduate high school and go off to college to be with my friends. I just didn't want anything to do with not being normal. Some days I wouldn't get out of bed; I would just stay in*

*bed all day. Some days I wouldn't even brush my hair. I would just throw on a hat, or pull it back in a ponytail. I didn't wash my face, and I never wore makeup. I just didn't care anymore.*

To help herself forget about having a chronic illness, Olivia would avoid people and situations that reminded her of the fact that she had diabetes. Olivia believes that her pervasive lack of knowledge regarding diabetes may have perpetuated her state of depression. It was not until Olivia discovered that she could lead a relatively normal life if she ate properly and took her injections on time that she fell out of her state of depression.

*I just ate well, as if someone were normal and trying to lose weight. That is what I did. And I felt really good. I felt like I didn't have diabetes anymore.*

Having hidden her diabetes from friends and peers for so long, Olivia discovered that through talking to others about her personal experiences, she was actually helping herself to come to terms with the illness.

*Until about two years ago I wouldn't tell anybody [about my diabetes]. Now I am completely open about it. Now I would talk to anybody about anything. And the more people I meet, it is usually one of the first things that comes up. I wear my insulin pump where it is visible. I wear a Medic Alert bracelet now. I test my sugars in public. I do everything in front of people, because if someone would have done that around me, maybe I would have known more about diabetes. Maybe I would have been interested. Maybe I would have seen it and thought I need to know more about this. Having diabetes is like having a terrible roommate; you have got to live with them, so you may as well just get along with them. I think that teaching people about it and talking to people about it makes me feel better. Hiding it from people was making me feel alone and depressed.*



Throughout the teenage years, Olivia struggled with several developmental challenges. One of the challenges she faced was to maintain the sense of independence she had previously held. Prior to being diagnosed with diabetes, Olivia led a very independent life. She worked two jobs throughout high school to pay for college, and had her own car by the age of 18. She *didn't really need help from anyone for anything*. When diabetes struck, Olivia was forced to quit her jobs, and reverted to an earlier stage of dependency. Her mother did everything for her, from chores, to cooking, to testing her sugars. For the first year, Olivia thrived on her mother's attention, but after a while became frustrated with her lack of independence.

*At first I would just snap at her and get mad. Now I just let her do what she wants and I ignore it because she is the way she is, and she is going to keep being the way she is; that is what makes her feel comfortable.*

Olivia satisfies her mother's need for involvement to a certain extent, calling her as often as her mom requests. However, in an attempt to sever some of the threads that bind her to her mother's care, Olivia now refrains from telling her mother certain things about her illness. As Olivia sees it, *what she doesn't know won't hurt her. It is on a need to know basis when it comes to negative things, because it just makes her worry more*. Having her own bank account and income once again has helped Olivia to reassert some of her lost independence. *I have my own vehicle, I have my own job, I have my own bank account. I am buying my own food, so it is my decision of what is going into my body.*

Not only does Olivia struggle with her sense of independence, but also struggles with her weight. When Olivia was first diagnosed with diabetes, she had dropped from 120 pounds to a mere 92 pounds. While for some people, this rapid loss of body fat would be cause for alarm, it did not bother Olivia. Usually when individuals with diabetes begin

administering insulin, they experience weight gain. Olivia, however, did not experience this side effect immediately. Because she was not giving herself enough insulin for the amount of carbohydrates she was consuming, Olivia continued to lose weight. Eventually Olivia's strategy of matching insulin to food caught up with her, and she began gaining weight. Motivated to lose the additional weight she had put on, Olivia began following the treatment regimen as laid out by her doctors. *The whole weight thing bothered me, and that is what got me to take care of myself, not the fact that I have diabetes and should therefore take care of myself.*

Having diabetes has changed a lot of things in Olivia's life. Before diabetes, Olivia was an avid figure skater, competing in the Canadians on several occasions. When the effects of diabetes reduced the circulation in her feet, Olivia had to abandon the activity that had once occupied her time. Not only did she quit figure skating, but other athletic activities as well. *I became totally lazy because I told myself I couldn't go to the gym or I can't do this because I have diabetes. I just didn't know how to [compensate for exercise] and I didn't care to learn.* Olivia has noticed a change in her physical abilities since the onset of diabetes. *I have no stamina now. If I needed to run up a flight of stairs, I would be very tired after and I would get a low sugar.*

Not only did diabetes affect her activity level, but also played a role in determining her future career goals. At the age of 14, Olivia dreamed of becoming a pilot. When her vision deteriorated as a result of the undiagnosed illness, this dream was set aside. In her final year of high school, Olivia decided to pursue a career as a dental hygienist. Once again, the side effects of diabetes took their toll, and Olivia no longer believed herself capable of completing such a difficult college program. Instead, she enrolled in a nutrition program, and began learning more about the relationships among

insulin, diabetes, and food. Olivia now wishes to become a diabetes educator, and is pursuing an internship in the hopes of completing the diabetes educator program.

Olivia has also decided not to have children. Although this decision was reinforced by her unwillingness to pass the disease along to her unborn children, she had decided prior to being diagnosed that she would never bear children. If she chooses to have a family, she will adopt.

Olivia considers diabetes to be *an annoying disease*. One of the main inconveniences of diabetes for Olivia is the constancy of the disease.

*Diabetes is a 24 hours a day, 7 days a week job. Diabetes is a habit, it is my life now. It is not something I have, it is my life. Everything I do in my life has to do with diabetes. I can't do anything without worrying what my sugar is going to do. Breathing, taking a shower, sleeping, everything I put in my mouth, everywhere I go, what kind of purses I buy, what kind of shoes I wear, how tight my belt is, everything! There is nothing I can do besides eat celery, cucumbers, or green peppers without worrying about my sugars.*

The inflexible nature of the diabetes treatment regimen has meant a loss of spontaneity for Olivia.

*I did more stuff spontaneously [before]. You know, Canada's Wonderland, water parks, going to the beach, stuff like that. Now I don't do it, because it is a big planning ordeal. I have got to make sure that I have all of my medications. Or if I do plan something, it has got to be well in advance, and I have got to be well-organized. I always have a bag of stuff ready, but it has to stay at a certain temperature. It can't freeze, it can't get hot. It is just a little more planning, because if I forget that, I won't make it through the day.*

Eating out is another inconvenience for Olivia. Although she has become accustomed to guessing how much insulin to give herself, the fact that different restaurants use different ingredients or preservatives in the same dish sometimes makes it more difficult to calculate. The insulin pump has made eating out much easier for Olivia, since there is a feature on the pump that helps the wearer estimate how much insulin to give.

As she is becoming more independent, the financial burden of diabetes is beginning to overwhelm Olivia. When she was a student, most of her supplies and appointments were covered under her healthcare plan. However, now that she is 25 and no longer a student, the burden of paying for the insulin, lancets, pump, and appointments now falls on her shoulders. Olivia is worried that this will become even more complicated when she begins her unpaid internship.

Although Olivia finds many aspects of diabetes to be inconvenient, she now believes that diabetes is the best disease to have.

*When everything is going right and I am doing things properly, I am not in pain. It does not hurt to test your sugars. It is just a little prick on the finger. Yes you do it six or seven times a day, but honestly compared to other diseases, it is not painful. If I had to have one disease in the world, I would choose diabetes. I wouldn't even choose lactose intolerance over this. All this disease does is teach you how to live a healthy life. Now that I know eating right is best for me, I am one of the healthiest people in my family. At least in the way I eat. Maybe not my organs and immune system and everything. But my diet is the healthiest diet out of my entire family and friends. It is controllable. I may still live a shorter life, but I can still do everything a normal person does.*

Having diabetes has given Olivia a new outlook on life and her personal health.

*I eat really well because I know what will happen if I don't. I drink a lot more water. I force myself to exercise even though I may not want to. I do a lot of things that are really good for me that I probably wouldn't have before.*

Even though Olivia acknowledges the benefits of the disease, she warns about how serious a condition it actually is. *Despite everything positive I have said about it, it is a long-term disease. It is a chronic illness, and it is severe. You can die within 15 minutes of having something go wrong.*

#### *Summary of Olivia's Experiences*

Being diagnosed with diabetes was a life-altering event for Olivia. Initially she fell into a state of denial and depression. She did not want to have diabetes, and did not want others to know about her diabetes, so she frequently abandoned the diabetic regimen for the normal life she had previously held. An improper schedule of insulin injections and improper diet led to several complications for Olivia, including episodes of severe lows and weight gain. Motivated by a desire to lose the weight she had put on, Olivia began following the diabetic diet, and immediately felt better. Once she realised that she could be healthy despite living with a chronic illness, Olivia fell out of her state of depression and began taking care of herself once more. Now Olivia is comfortable with her condition, and is embracing a career as a diabetic educator.

## CHAPTER 5: DIAGNOSIS DURING CHILDHOOD

This chapter reports the stories told by Hannah and Melinda, both of whom were diagnosed with diabetes during their childhood years.

### Hannah's Story: Not Just a Sick Person

#### *Medical Experience*

*I was diagnosed with type 1 diabetes at the age of 5. It was really bad timing, because my family had just moved here. My youngest brother had just been in the hospital for a month with whooping cough and he was only a month old, and my dad had just gotten a new job. I started dropping weight and falling asleep in kindergarten, and I drank liquids like I couldn't drink enough. I couldn't go anywhere without drinking. My mom took me to the doctor, and he said not to worry about it, that I was just going through a phase. When I was admitted to the hospital, my blood sugar was 56. The doctor looked at me and said he had never seen a kid walk in on her own two feet with sugars that high. I was scared, but at that point I knew I was sick. I knew something was not right and I was feeling so awful that I would do anything to make it feel better. I was terrified, because [the nurses and doctors] started running around and yelling while attaching heart monitors. They were worried that I was going to have seizures when my sugars finally came down. The whole week that I was in the hospital, the nurses would come in and hold me down to give me my injections. At that point I definitely thought that I was being ambushed. The next day my mom sat down with me and said "Okay honey, you have diabetes." I had heard the word before; I had seen it on Sesame Street. I remember thinking I do not want that. That means needles every day. And I thought "No. Not me."*

Hannah recalls the diagnosis period as being a frightening time in her life. While she was willing to let the doctors and nurses do anything they could to make her feel better, she was aware of what the future held in store for her; needles. In the hospital, Hannah willingly accepted the treatment provided to her by the nurses; however, as soon as she left the hospital she was not so accepting of her illness.

*At times I got very angry, and extremely frustrated. I would just scream "I didn't ask for this! Why do I have to deal with this?" I used to ask on my Christmas list not to have diabetes anymore. Unfortunately having diabetes is not like having cancer where you either live or you die and then it is done. It is every day. [When] you are having a really crappy day, or you get the flu and you are vomiting, you still have to take your shots and you still have to eat something. And then you vomit it up again. You feel completely powerless.*

Hannah's early introduction to diabetes by Sesame Street had taught her a bit about the treatment regimen she would have to follow; however, there was much left for her and her parents to learn. Since Hannah was not capable of managing her own diabetes at the age of 5, her parents underwent intensive diabetes training at the hospital. Hannah's parents attempted to include their daughter in the treatment as much as possible from day one. When Hannah would finish throwing her temper tantrums, her parents would ask Hannah how much insulin she needed. As she became accustomed to calculating the dosage, her parents allowed her to mix the insulin. The next step was to encourage Hannah to push down the plunger on the needle, and finally to self-inject. Hannah felt that her inclusion in the treatment at an early age was a critical step in helping her learn to handle diabetes independently. By the age of 7, she was completing her injections independently with minimal supervision from her parents.

While she had a basic understanding of what foods to avoid, Hannah did not fully comprehend the extensiveness of the treatment regimen.

*When I was first diagnosed, I didn't understand it at all. I guess I had the information; I have to eat this at this time, and I can't have regular coke anymore, but it didn't really go in. I remember feeling hungry once and going down to the kitchen and getting a bowl of cereal at eight o'clock at night. I knew I wasn't supposed to eat sugar, so I was eating bran flakes. My mom came down and screamed "Hannah! What are you doing?" and pulled the bowl away from me and dumped it down the sink. I started crying and said "Mommy what is wrong? I don't understand. I am eating healthy. I am hungry." And she said "Okay well we need to sit down and talk about this." I have always had a good appetite, so I learned that I could have either extra green vegetables or extra meat if I was still hungry. I learned that having a glass of milk is different than having a cookie, is different than having a banana. Different foods have different effects, and you have to have all of the food groups in the same meal.*

With time and experience, Hannah learned what it felt like to be high and low.

*When Hannah is low, she feels dizzy, sweaty...kind of like an adrenaline rush. You can feel the firing of axons...I will shake, my lips will get tingly, and I just won't think. When she is high I just feel really tired. I am draggy, I have a very hard time concentrating. Very thirsty. I feel really nauseated and I will vomit.* This ability to predict blood glucose levels has allowed Hannah to treat highs and lows quickly, thus avoiding critical medical situations. Listening to her body has also helped Hannah develop the ability to predict illness or infections at the first signs, and seek medical attention *before it is raging out of control.*



When she was younger, Hannah frequently experienced episodes of hypoglycemia.

*I used to go low a lot when I was younger. Like if I was excited for my birthday party, I would drop like crazy. If I didn't eat on time, I would definitely go low. I used to have really bad lows in the night. I would wake up, and I wouldn't be able to move half of my body. Or I would know that I was low, but I couldn't actually make the process of getting to the fridge, opening the door, and getting the juice. I remember once I woke up and I wanted to go get juice, but I ended up falling and my bookshelf fell on top of me. My parents woke up when they heard this thundering crash. Eventually I kept a little box under my bed that had juice and granola bars and stuff. So if I could think it through, I would definitely treat the lows myself. If not, I had to go get my sister or yell for my parents.*

Over the course of her lifetime, Hannah's diabetes treatment regimen changed frequently. When she was initially released from the hospital, Hannah was placed on a two-needle-a-day regimen of a short-acting insulin and MPH. *For a while after that first year I went down to just one needle a day. And then I went back to 2.* Hannah's treatment regimen stayed steady at two needles a day until she reached Grade 8, at which point she went on the insulin pens and began injecting 3 to 4 times a day. For the first time in her life, Hannah was required to give herself an injection at lunch.

When Hannah was in her first year of university, she switched from the insulin pens to the insulin pump. At first Hannah was reluctant to get a pump because *I didn't want to be attached to a machine. I didn't want people to know, or physically see something different about me.* After switching to the pump, Hannah's treatment regimen became more flexible.

Throughout the majority of her elementary and secondary school years, Hannah adhered strictly to the diabetic regimen. With the help of her mother, Hannah ate proper foods at set times, tested on a regular basis, and gave injections on a strict schedule. It was not until Hannah started gaining weight in high school that she began to ignore the treatment requirements set by her doctor. *I knew that if you take more insulin, you feel hungrier. So I tried to cut back on the insulin so that I wouldn't eat as much.* Once her parents recognized the problem and threatened to put Hannah in a rehabilitation center for eating disorders, Hannah became more compliant to the requirements of her diabetic regimen.

#### *School Experience*

*Diabetes in elementary school.* Despite excelling in academics, elementary school was not always easy for Hannah. From inflexible class rules, to field trips, to a lack of teacher awareness, Hannah often felt singled out from her classmates.

*Having access to food at all times was a big struggle for me. A lot of teachers had a no gum-chewing, no snacking, and no drinking in class rule. I always knew that I could supersede that rule, but I always felt like I had to hide it or I had to sneak it in. I never wanted to get up in the middle of class and walk over to my backpack. I wanted to be part of the group; I didn't want to draw any attention to something that is not cool. If you have the attention because you have a new jacket, that is cool. If you are the kid who is always singled out because you need to drink your juice, no. You are just the kid who eats all of the time.*

Bake sales, class parties, and field trips seemed only to reinforce the fact that Hannah was different from her classmates.

*Sometimes I felt left out. Like at parties when I was really young, like 5, 6, and 7, I didn't really eat anything. When you are 5 and you are at the Valentine's Day bake sale and you are going to buy the granola bar, it is not the same as getting that double fudge chocolate cupcake. Sometimes I would eat some of it, or eat the cake part and leave the icing. I guess I did feel left out sometimes, but what can you do about it, right? There is not much I could have done. Field trips were always sort of a landmine, because the teachers would say they were going to give you lunch, and sometimes they wouldn't. Or sometimes they would change the program around and you would eat at 2:00 instead of noon. And that was just treacherous. I remember once we went to the sugar bush for the pancake breakfast at 10:00 in the morning. I can't eat a pancake that has maple syrup on it at 10 in the morning, so it was a feeling that this place is really neat with the huge Clydesdale horses and the log cabin, but now everyone is eating their pancake breakfast and I am not. And then you would feel totally left out of the group.*

Although Hannah's mom talked to her teachers at the beginning of each school year in an attempt to avoid such situations, Hannah does not believe her teachers truly understood.

*My mom would go over everything with them; she needs to eat at noon no matter what; she has to have her snacks or she goes low. I think people are just head nodders. They say they understand, but they really don't. Or they take in parts of the information, but they don't really get it. I think some of my teachers were terrified by it. They definitely saw it as another burden; another special needs student in the classroom. So I always felt like I had a strike against me when teachers found out I was diabetic; because I thought that they would think that I was just going to be some hassle. Some of my teachers were fine, but most of them*

*as long as I said I knew what I was doing, they were like “Whew! Better you than me.” But I also knew that I really couldn’t rely on them. If I had said “I need your help” they would have helped me, but I would have had to walk them through it.*

Because of the teachers’ demonstrated lack of diabetes awareness, Hannah knew that she could never rely on them for assistance. One instance which illustrated to Hannah that she could not rely on her teachers occurred in Grade 6.

*I was in art class, and I knew I was low. I said “Mr. Foster, I am low. I need to go get something to eat.” And he said okay. So I went and I drank some juice and I had a cookie, but I still wasn’t feeling good. My teacher came in and asked if I was feeling better, and I said “No. I am still low.” One of the other teachers came in and they had this 10- minute debate over how to treat me. I said I was going to go buy a coke, and the other teacher said “You can’t have coke. You need to have orange juice.” Mr. Foster told her it didn’t really matter what the sugar source was, but she kept saying “No. I know diabetics should not have coke. She should have orange juice!” At this point I always feel like it is not going well.*

In Grade 8, Hannah was once again reminded of how limited her teachers’ knowledge was on diabetes. Her class was on a religious retreat, and the school was to be providing lunch to the students. Instead of providing the nutritional lunch that was originally planned, the school served a late lunch of pizza and regular pop.

*I was carrying my insulin pen case with me. It was grey, and it was about the size of a glasses case. I was looking for a bathroom, and I couldn’t find anything, so I had to deak into one of the side rooms of an old house. I came back and was carrying the case in my hand, and one of the teachers said “Where were you? What is that, a remote control in your hand? What were you doing watching TV?”*

*Get back with the rest of the group!” I went home that night feeling awful. I mean, you are in Grade 8, you are totally wanting to be cool.*

Not all of Hannah’s teachers in elementary school showed such an extreme lack of understanding. Some of her teachers were very accommodating, and tried to give Hannah’s mother plenty of warning before class parties so that she could provide food for the class or discuss with Hannah what she was allowed to eat. In these particular instances, Hannah felt like an active member of the classroom.

Upon switching to the insulin pens in Grade 8, Hannah began giving herself insulin injections at lunch. This new treatment requirement posed some difficulties for Hannah at school.

*The teachers would ask if I wanted to go to the nurse’s office, but having somebody who doesn’t really know what is going on have more control than the person who does is scary. I hated feeling that I had to go and sit in front of the nurse’s office like I was in trouble, to give an injection in front of somebody who didn’t even know what was going on. So I chose to do it in the bathroom instead. Maybe it was just that I am weird, but I just didn’t see the need to involve people in [the treatment], because I knew that they would resent it after a while. I knew what I was doing. Because I was so young when I was diagnosed, it was something that I just did. I didn’t think about it all that much.*

In elementary school, all of Hannah’s classmates knew she had diabetes. Even though she had taught most of her friends and classmates about diabetes, she spent a lot of time re-educating them.

*You know, I am not allergic to sugar; I don’t have to take needles because I am bad. I can’t swallow a pill because it won’t work. I think a lot of people just didn’t*

*get it though. Even my friends that I had had for years, they just didn't get it. If I said I was low, they would ask me if I needed my insulin.*

While the majority of her classmates were accepting of her diabetes, Hannah vividly recalls one experience in which one of her friends reacted strongly to her diabetes.

*I was in Brownies, and we went camping. I had left my kitbag full of syringes, insulin bottles, and testing supplies open on my bed. One of the girls walked in and she saw the needles, and she freaked out. She started vomiting and crying. To me, I was wondering "What the heck is the problem? What is the issue? Why are you freaking out?" But to her it was terrifying, and I shouldn't have left it out, I guess. I learned really quickly that people have different responses to seeing needles. Some people have extremely visceral reactions to a syringe, and not everybody is as cool or nonchalant about it.*

*Diabetes in secondary school.* Hannah recalls her secondary school experience as being more pleasant than elementary school.

*I felt that there was a lot more freedom in high school than elementary. You are more of your own person by high school. You have your own agenda. You are not being herded from class to class with the same people all of the time.*

Hannah continued to excel in academics, enrolling in English, science, and music courses.

Unlike elementary school, Hannah had to give insulin injections at lunch for the entire five years she spent in high school. Because the *cafeteria was cleaner than the bathrooms half of the time* she would give injections at the cafeteria. Hannah became very adept at injecting herself in the stomach under the table so that no one in the room would notice.

One of the main difficulties Hannah faced while at school was trying to find nutritious food.

*The food that was offered in the cafeteria was generally not very good. And if I wanted a snack that was not just a chocolate bar, sometimes it was hard to find.*

*Being low was always a worry for me. You know, being able to find food quickly.*

This problem could easily be overcome by ensuring that she had extra food with her at all times.

Because of Hannah's age, Hannah's mother relinquished the responsibility of notifying teachers of Hannah's diabetes to her daughter. For the most part, Hannah did not discuss her condition with her teachers. *Sometimes I would tell them, but I mean, when you have got five teachers in a day, it wouldn't really matter, because I wouldn't see them again for the rest of the day.* Because her school was so small, many of her teachers were aware of her diabetes, and allowed her to treat the illness within the classroom. If Hannah hadn't eaten in their class for a prolonged period of time, many of the teachers would forget she had diabetes.

*A lot of teachers, I would be in their classroom a lot of the time, and I would have nothing. So when I did eat they would say "I thought I said no snacking," and I would have to remind them that I was diabetic. It was like "Can't you remember this one little thing? I am not doing this to piss you off!" By that time though, I would give it back to them. If they were going to pull rank I would be like, "No, really. This is important." It forced me to be more assertive about my needs.*

When Hannah needed to be excused from class because she was feeling ill, her teachers were generally pretty understanding.

*My teachers knew that I was a good student. They knew that I was going to catch up if I had to miss class. I feel like I developed that trust; I worked hard to earn that trust from them. It wasn't just "I am diabetic. You have to let me out of class," it was "Mr. Matthews, you know I am going to finish this, and you know that I am going to understand. Can I take this time off?" It was really about earning trust and good rapport.*

Because Hannah was administering insulin at school on a regular basis, many of her peers were aware that she was diabetic. At times she would receive mixed reactions from people when they would see her give an injection.

*The first time I met some people, they were like "What is that?" [pointing to the needle]. And then they realised that instead of going into a groddy bathroom, it was just easier to do it in the cafeteria or at my locker.*

A lot of times when Hannah would tell people about her diabetes they reacted with surprise, claiming she didn't look sick. Hannah would then have to explain that diabetics are not necessarily sick people.

Although Hannah has been very open about her diabetes with her friends, with strangers she is a little more reserved.

*I don't hide the fact that I have diabetes. I also don't use it as a selling feature. That is not the first thing I want people to think of when they think of me. I didn't want to single myself out as a diabetic. I didn't want people to see it as a weakness. Diabetics get a bad rap; they have this stigma of they don't take care of themselves, they eat whatever they want. I wanted people to know that is not the case.*



Hannah believes knowing she is diabetic will affect how others see her; however, it won't affect their views *in a negative or positive way; it is just something else they know about me.*

*Diabetes in university.* Hannah is currently completing her Ph.D. in the field of diabetes research. She is conducting research in the hopes of finding a way to transplant human islets, or to replace them with stem cells. Many of the people she works with in the lab are aware of her diabetes, and joke that she is *the resident diabetic of the lab.*

Having attempted to write a chemistry midterm with low blood sugar, Hannah is now aware of how greatly hypoglycemia can affect the learning process.

*I know that if my sugars are off, I cannot learn. I remember trying to write my first year chemistry midterm, and my sugars dropped, and I just did horribly on it. It didn't matter if I treated it or not. There is this brain fart period where you just can't think.*

Now that she is on the insulin pump, Hannah's sugars are more stable.

### *Social Support*

*Family support.* Growing up in a family of four children, Hannah had a vast amount of support. During the early years of Hannah's treatment, her parents and siblings were her main source of support. Because no one in her family had ever been diagnosed with diabetes, it was a time of learning for everyone involved. *It was a huge adjustment for my family. There are four kids, and all of a sudden one of them has type 1 diabetes. This was the first case in the family ever. Luckily my parents were really attentive.*

Hannah recalls how her diagnosis affected her parents:

*My dad used to faint at the sight of needles, so he had to learn not just to see needles, but to give them to his own daughter. For somebody who hates needles,*

*you don't want to give your kid pain. When I was diagnosed, it was like my parents were constantly worried about everything. Whether it was the quantity of food or where I was going to be, did my mom have access to a phone at all times, was there food with me, did the people I was with know that I was diabetic. I mean my parents trusted me, but I think it was an added burden, honestly, on them to have to deal with this.*

With time, Hannah's parents became more accustomed to the demands of treatment and began actively including Hannah in her own diabetes regimen.

Hannah's mother in particular played a large role in Hannah's life, not only ensuring that her treatment needs were met at school and at home, but also acting as a source of emotional support. Hannah's sister also helped Hannah deal with her diabetes. Although at first her sister was jealous of all of the attention Hannah was receiving from her parents, she made sure that she was always available to assist Hannah in the occurrence of a low. Because Hannah's younger brothers were so young when she was diagnosed (the youngest was 4 months old), they could not remember Hannah before she had diabetes. They knew that if Hannah was low or shaky that they needed to get her juice, but Hannah doesn't believe that they ever really understood what was happening or why.

Hannah's extended family members were not as understanding of her condition as her immediate family, often creating conflict in their attempts to shelter Hannah.

*My grandmother would beg my mom on Christmas not to give me a needle. She would say "She doesn't need her insulin. She doesn't want that needle. It is a special occasion." And my great aunt would always make fudge. When she found out that I was diabetic, she would secretly give it out as if I wasn't going to find*

*out. I always felt like people were going over my head like I was fragile. I hated the fact that people made decisions for me.*

Like most teenagers, as Hannah got older, her family played less of a role in her life.

*High school was definitely a time when I had to tell my mom to back off. I know it was hard for her, and that she still worries. You can't undo that. I had a curfew until I was 18. I still went home for dinner every night. They made sure I was eating properly. They were still involved, but I was trying to limit their involvement.*

Although their role has lessened, Hannah still continues to include her parents in issues of health, calling them and giving them frequent updates about her life.

*Friend support.* Throughout her elementary and high school years, Hannah was fortunate enough to have a close group of supportive friends. They would spend their time shopping, going to movies, going for coffee, and sneaking into bars or parties. In Hannah's opinion her diabetes *didn't really stop me from having social interactions.*

Although Hannah's friends were usually helpful, offering to get her food when she needed it, she doesn't believe that they truly understood diabetes. *If I would say I was low, they would say "Well do you need your insulin?" And you are like "Are you stupid? How many times do I have to go over this?"*

Because Hannah was so adept at keeping her diabetes under control, many of her friends underestimated the seriousness of her condition, and the hard work that went into maintaining the balance.

*To a lot of my friends, managing diabetes looked easy. A lot of them downplayed the seriousness of [the disease], and that really pissed me off. I didn't want it to*

*become this thing of I am a sick person. You don't want people to only think of diabetes when they see you. You don't want to look weak. At the same time, you do want them to know that it is not always easy, and that it requires a lot of attention, and that the little things like eating on time and testing your sugars make a big difference. To them it looked easy, and to me I would be like "I am dying here." At times you want to hit people over the head with it. Yes I am still diabetic. I still have to test, I still have to eat, I still have to order my supplies. My skin gets infected. My fingers get sore. And it is not something that I am going to sit here and whine about. It still happens, I still have to do it every day.*

Going out with friends often reinforced the fact that Hannah was different from her peers. She describes how most of her friends didn't eat regular meals, and how she was always eating. Dating also set her apart from other females her age because *I was the girl who actually ate dinner*. For Hannah, drinking was an activity she undertook in an attempt to fit in.

*Drinking was another one of those things where I wanted to fit in. If I had a really sugary drink, my sugars would go up and I would vomit. I guess in high school that used to happen a lot. People always assumed that I was drunk, and I wasn't. I guess I never put the two and two together. I do now.*

While many young people living with chronic illnesses value friendships with others who are living with the same condition, Hannah has avoided forming friendships with other diabetics. *I just felt like we were bonding over the wrong reason. A lot of them had very poor glucose control and didn't understand food. A lot of them really manipulated people around them to do their bidding*. Since having diabetes was never an

excuse for Hannah, she tried to limit her interactions with other people living with diabetes.

*Dealing with the Developmental Challenges of Diabetes*

Having diabetes at a young age meant that Hannah had to deal with many issues that her peers didn't have to. While her friends were writing to Santa Claus asking for the latest toy to hit the market, Hannah was writing to Santa asking not to have diabetes anymore. She frequently fluctuated between feelings of self-loathing, anger, and frustration. *I got very angry at times, extremely frustrated. I would just scream "I did not ask for this. Why do I have to deal with this?"*

The persistence of diabetes and the constant need for attention to the treatment regimen are often difficult for Hannah to deal with. At times, she wishes she had someone to talk to about her troubles.

*You can talk to your doctor about your doses, and you can talk to the dietician about your diet and how to change that, but you want to say "I am really sick of this, and I don't get respite from it. Or I am sick of always having to deal with this." It is not like it just goes away.*

The amount of planning that goes into managing diabetes often meant that Hannah could not partake in certain activities. Unlike her siblings, Hannah could never just go to a friend's house after school.

*Everything had to be pre-thought out. I couldn't just up and go to my friend's house for a party. My mom would have to talk to her mom. Like even in high school, I couldn't just go out after school. Or if I did, I had to remember; do I have my dinner insulin? Do I have food with me? Do I have money? Did I tell my mom? What do I do if the plan changes?*

As a result of the strict nature of the treatment regimen, diabetes has limited Hannah's ability to act spontaneously.

One of the tasks that all individuals face in their lives is to become independent from their parents. For Hannah, this independence occurred at a much younger age than it did for her peers. Because of the lack of diabetes awareness that surrounded her in family, school, and social situations, Hannah was forced to assume complete responsibility for the management of her condition. By the age of 7, Hannah was giving herself injections and testing her own sugars under the supervision of her parents. By the age of 10, she was performing these same tasks with minimal parental intervention.

One of the main motivations for Hannah's early independence arose from her parents' reactions as they attempted to give her insulin.

*My parents would get really nervous giving it to me, and that made me nervous, so it was kind of at the point where I said just let me do it. I am not really a control freak, but when people are hesitant about putting foreign objects in your body, you don't want that. You want them to be really confident and really calm. So the only way was that I would do it myself.*

Although Hannah would have appreciated some help in managing her diabetes, she did not want to be a burden on her family, teachers, or friends. Because Hannah knew what she was doing, she did not see the need to involve other people in her treatment.

For Hannah, her early independence was in some ways a form of self-preservation. Because so few people truly understood diabetes, she *did not want to be at the mercy of some guy on the street*. Hannah worked hard to maintain a healthy blood glucose level so that she would never have to count on others to help her deal with the

lows. She believes it is dangerous to give others that kind of responsibility, especially when there are so many misconceptions surrounding diabetes in the general population.

Not only did Hannah assume responsibility for herself, but took a great amount of responsibility for diabetics in general.

*I have always hated doing stuff that would make people think that diabetics don't know what they are doing. I guess I have always felt like I have to stand up for the diabetics and show people that we know what we are talking about. People have this expectation that diabetics are sick manipulators of the health care system. We are not. We did not ask for this.*

Like most girls with diabetes, puberty was a particularly difficult time for Hannah. *I just felt like I had a lot less control over my body, over my blood sugars, over everything. You develop this internal system where I eat, this is how I feel. I take insulin, this is how I feel. It almost felt like my body was not listening to the system anymore. It was frustrating. All of a sudden what I used to do is no longer sufficient or does not work the same.*

Even though at times Hannah was struggling to keep her head above the water, she did not want to seek help from her mother. *I did not want to say can you help me. Because I wanted to do it myself, and I did not want her to know that I was going through some problems.*

In addition to losing control over her blood sugars, Hannah began gaining weight during puberty. Having grown up in a family of tiny women, there was added pressure on Hannah to maintain a slim frame.

*When I hit puberty I packed on the weight, and I didn't know what to do. I realised that if I took less insulin I wouldn't be as hungry and I would drop*

*weight, so I took less insulin, worked out more, and ate very little. I dropped maybe 20 pounds in Grade 10. My sugars were bad and my grades started dropping. When [my parents] threatened to put me in an anorexia program, I didn't want that, so [my dieting] ended, and I got back into school.*

Although Hannah now has a better grasp on management, she still finds the issue of weight gain frustrating.

*I try to work out, but the problem with working out is that it is really hard to accommodate insulin with that. It is not always a one-to-one system. It is not like you do an aerobics class and that equals this amount of insulin. I couldn't just take less insulin in general, because I don't know if I would be working out every day. So you either take less insulin and hope to balance that by working out, or you don't and you work out and you go low. So you end up treating your low, which gives you more calories, and totally undoes whatever exercise you have done to burn the calories. It becomes this horrible cycle of how will I maintain my body weight or lose the weight when I have to eat. I have got these really powerful drugs that are forcing me to eat; that if I don't eat I am going to go low.*

Having diabetes has taught Hannah a lot about food and about herself. Because of the constant focus on food that is required for proper management of diabetes, Hannah has learned a lot about food perceptions: food in itself, food socially, and food as psychological motivation. *Women especially have weird ideas about food. You know, "I deserve this," or even when we tell our kids to clear their plate and they will get dessert.* She believes that children are being taught negative lessons about proper nutrition, and that teachers, family, and society in general should work together to clear up some of these misconceptions.



Living with a chronic illness has affected how Hannah views herself.

*It made me realise that I was tougher than I thought. I mean, when you feel like crap and you still have to take your injections, you realise that you have no other options, and you have to do it. I had surgery on my stomach [a couple of years ago], and as soon as I had surgery I had to put my insertion site back in. You have to be pretty tough to do that. So it made me realise that if I can do that, I can do a lot of other things. You know, don't wimp out. Don't back down.*

Diabetes has also played a large role in influencing Hannah to pursue a career in science.

*Definitely being diabetic, having to be so aware of your body made me want to ask more questions about what happens or why this happened to me and not to other people. I work all day with islets. And I remember thinking, wow. These are the one thing I don't have.*

Although diabetes is not something that Hannah spends a lot of time thinking about, *it is a fairly significant part [of my life]. It is something that always creeps back in.*

#### *Summary of Hannah's Experiences*

Being diagnosed with diabetes at such a young age, Hannah became responsible for her treatment very quickly. Throughout her life, Hannah has witnessed a severe lack of diabetes awareness from members of her extended family, teachers, and friends. She spends a lot of time re-educating people, and trying to prove that diabetics can be healthy individuals. Although Hannah experiences periods of frustration, for the most part she deals with her diabetes very well. She tries to care for herself so that she is not a burden to others around her. Diabetes has not limited her social interactions, and has provided her with inspiration to pursue a career in research.

## Melinda's Story: A Normal Life

### *Medical Experience*

*I don't really remember life without diabetes. I have pretty much had it for my whole life. I was diagnosed with type 1 diabetes at 2 years old. My mom had noticed that at night my diapers were a lot wetter than they used to be, and that they were changing me way more often. She also said that I looked like I didn't have much energy. At first even the pediatrician didn't think it was anything. He told my mom that I had the flu, and that I would be fine. My mom did not think I was fine, so she went back [to the doctor] a bunch of times and finally they did some blood tests and said I had diabetes. I was sent to the [children's] hospital for about a week.*

Because Melinda was only 2 years old at diagnosis, she does not recall the time she spent in the hospital. The story Melinda tells of this period of her life is comprised of stories told to her by her parents. Melinda focuses more on what is happening to her parents, and less on what is happening to her.

*My parents were really scared. My mom said that she cried a lot during that week, but towards the end of my stay at the hospital she said she realised that there were so many kids in the [children's] hospital that were much worse off, and at least I would be coming home.*

While Melinda was in the hospital, her parents underwent intensive training on how to properly manage their daughter's diabetes. Because they received so much information at once, they were overwhelmed.

*They still didn't know what it was going to mean for me going to school, or what we would do when we would go on vacation or go out for dinner. They didn't*

*really know anyone else who had a kid with diabetes, so they weren't sure what was going to happen, or if I was going to be okay. My parents were going to classes every day with nurses and doctors. They got so much information all at once that they were overwhelmed and thought "We can't do this. What are we going to do when we go home?"*

With time Melinda's parents learned how to deal with the medical aspects of diabetes; however, giving their young daughter injections was difficult on them.

*Because I was so little, it was hard on my parents. You can't really make a 2-year-old eat if they don't want to, or tell them that they can't eat if they are hungry. I used to scream a lot [when they gave me injections]. I think I started hating the needles more around the age of 5 or 6, because I think I realised more what was going on at that age.*

Melinda did not begin learning about diabetes until she began school.

*I started to understand what diabetes was around kindergarten I guess. But my parents never really explained it to me; they just told me I was diabetic, that I had to take an injection in the morning and at dinner. They told me that I had to take this amount of food to school, and that I had to eat what was in my lunch bag at what time.*

Although Melinda's mother was largely responsible for teaching Melinda about diabetes, her doctor was also involved in the education process.

*At my three month checkups, my doctor would take time to teach me how to eat and what to eat at each meal. The old system was counting in servings of fruits starch, and milk. So they taught me how much was one serving of milk, and what was one serving of starch, and what was one of fruit. Other times they would say*

*“Do you want to change it? Do you want to have more at this meal, or less at this meal?” So after a while I got the hang of if I eat more, how much more insulin I have to give myself.*

When Melinda switched to the insulin pump in Grade 8, she once again had to go through a period of extensive training.

In addition to learning how to manage her diabetes, Melinda learned at a very young age how to advocate for herself. She learned that she could overrule any school rule that restricted her from managing her diabetes, and could leave class to eat or drink as required. This ability to self-advocate has proven useful for Melinda as she advocates nation-wide and world-wide for other individuals living with diabetes. Melinda has also developed an ability to detect the early signs of highs and lows, thus allowing her to correct the problem before there are any serious repercussions.

When Melinda initially began treatment, she was placed on a two-needle-a-day regimen of a short-acting and a long-acting insulin. At this time of her life Melinda would test her sugars and give herself an injection in the morning before breakfast, and again before dinner. To keep her blood glucose levels stable, Melinda would have a morning, afternoon, and bedtime snack. It was not until Melinda went on the insulin pump in Grade 8 that she had to start testing her blood sugars at lunch.

Melinda was encouraged from a very young age to adhere strictly to the diabetic regimen, and this strong adherence continued over the course of her life. The team-like interactions among Melinda, her parents, and her doctor helped Melinda to understand how to effectively manage her diabetes, and the importance of following a proper diet. Even when Melinda would stray from the diabetic diet, she was sure to do so in moderation.

*At recess, my friends would bring tons of candy with them, and I wanted to be able to do that too, so I just did it anyways. That was kind of bad, but I was smart, so I knew that if I gave myself more insulin it would be fine. I probably should have gone and told my doctor that I wanted to increase the amount of food that I ate at snacks, but I still managed, I guess.*

### *School Experience*

*Diabetes in elementary school.* Melinda recalls her elementary school experience as being a positive one. *I was always pretty good at school. School just came easily to me.* She attributes the ease with which she was able to manage her diabetes in the elementary school setting to the fact that when you are little *you don't have hormones messing with your diabetes* and that *the school day is pretty structured.* Although low blood sugars wreaked havoc on Melinda's ability to concentrate, hypoglycemia did not overly affect her academic performance during the elementary years because *in elementary school they are not really giving you many difficult tests.*

At this stage, Melinda's doctor and her mother were very involved in Melinda's life, ensuring that the management of diabetes ran smoothly in the school setting.

*I remember every time I had a new teacher, my parents would come [to the school] and have a chat with the teacher, explaining to them "She has to eat at these times and you have to let her eat if her blood sugar is low. You also have to let her go to the washroom whenever she needs to because her blood sugar might be high."*

For the most part, these lessons ensured that teachers allowed Melinda to eat and drink in class as necessary. *My teachers were usually pretty good. If I said that I needed to eat*

*because my blood sugar was low, or if I said that I had to go to the washroom, they would let me. At times, however, Melinda's needs were not met in the classroom.*

*I had one teacher I think it was in kindergarten who wouldn't let me go to the washroom. And then there were the teachers who were just trying to follow the school rules, like no eating in class. Sometimes they would give me trouble about that, so I would just go outside to eat and then come back in when I was finished. Other times during assemblies if I had to go to the washroom the teachers would tell me I couldn't get up, so I would have to try and hold it in.*

Although most of her teachers seemed to understand Melinda's needs, the majority of them had not received formal training on dealing with diabetes in the classroom except for the information Melinda's mother had provided.

*They all knew what my mom would tell them at the beginning of every year; that I had to eat on a schedule, that I needed to be allowed to eat also between scheduled times if my blood sugar was low. So the teachers understood that, and they knew if I needed to go to the washroom to let me go. I guess they didn't really need to know a whole lot beyond that.*

When the teachers held class parties, they were careful to discuss their plans with Melinda's mother.

*When we had class parties, the teachers would try to do it during recess or during lunch, and they would always send a note home before so I could ask my mom what I could eat. She would explain to me that I could have 2 pieces of pizza and one cupcake, or something like that. With Mom's permission I could take some candy and have a little bit of it at recess when it was time to eat again. I didn't feel too left out.*

By consulting with Melinda's mother prior to hosting class celebrations, the teachers ensured that Melinda felt like she was being included in the classroom community.

With the help of her doctor and mother, Melinda's class trips always ran relatively smoothly.

*When we went on day trips with our class, I would usually make sure that I took a little less insulin, because we would be walking around all day. That usually solved most problems. It was only when we started having overnight trips like the outdoor education trip in Grade 6 that things got a little harder. I called my doctor, and he told me what to do for the whole trip. My mom got the teachers to call the outdoor education center and make sure that there was going to be food that I could eat. So beyond that, with the food that they served I had to try to estimate how much I was supposed to eat, and what was a serving. It wasn't my best week as far as blood sugars went, but I didn't have any really bad low blood sugars or high blood sugars, so it was okay.*

Despite her young age, Melinda's teachers were never involved in helping her manage her diabetes at school. Although she believes it may have been helpful during the first few years of school to have had her teachers monitoring what she was doing, she does not believe it was necessary.

*I never really had any serious trouble with my diabetes, like seizures from low blood sugars or a diabetic coma from high blood sugars, so I never really needed their help. I had diabetes for so long that I kind of understood what I was supposed to do if I felt like my blood sugar was low or high. Except for what my mom had told them, the teachers at my school didn't know a whole lot [about*

*diabetes] unless they already knew someone with diabetes. I always just managed the diabetes myself.*

During elementary school, Melinda's classmates were aware of her condition. *Because we had a pretty small school, you stayed with the same kids from Grade 1 until Grade 8. My classmates all knew that I was diabetic. After a while they kind of got the idea that I had some [condition] that made me need to eat certain amounts of food at certain times. I told them I had diabetes, but I didn't really go into a lot of detail about it.*

Melinda was open to answering any questions her classmates had regarding diabetes; however, when she went on the pump in Grade 8, she wished her classmates were a bit more knowledgeable about this chronic condition.

*Everyone kept asking me "What is that?" and they would have a bunch of questions about it, like where does it go, and what does it do? I did get kind of tired with it, but I would just answer their questions anyway.*

*Diabetes in secondary school.* Melinda's academic excellence continued during high school, and she graduated in the top 5% of her class. Because Melinda was always well-prepared for tests and exams, even if she wrote them in a hypoglycemic state, her marks were not overly affected. *Even though low blood sugar makes you anxious, I knew the material so well that I could usually just do the test anyways then eat something afterwards.* Aside from academics, Melinda was involved in several extracurricular activities. *I was still in gymnastics outside of the school, I was on the swim team, and I was in the band.*



Because Melinda was on the pump by the time she entered high school, she no longer had to eat on a schedule. This made eating at the cafeteria and going out for lunch with friends much easier.

*If I wanted to eat more, I could. If I wanted to eat less, I could. It also meant that I didn't have to eat on a schedule, which helped with the [transition into] high school where you don't necessarily get snacks or lunch breaks at a specific time.*

During high school, Melinda assumed full responsibility for notifying her teachers about her diabetes. When Melinda would discuss her condition with her teachers, they were generally pretty understanding. *Most teachers in high school didn't care too much if you ate in class. There were a few that did, but I would just tell them that I was going to have something, and usually they were fine.* Although Melinda would tell her teachers about her diabetes, she *didn't really tell them what to do, just because [nothing bad] had ever happened, and I figured that it would not happen any time soon.*

Melinda was grateful that her teachers allowed her to manage her diabetes in the classroom; however, she did not like when teachers would single her out.

*I had one teacher in high school who always said "Melinda is diabetic, and her health is so good because she is so careful with what she eats and how much she exercises." It made me feel kind of embarrassed. Like really, I am not that special!*

Because Melinda had attended a French elementary and secondary school, most of the classmates she had in high school were people she already knew. If she met someone new, she was quick to tell them about her diabetes. *I was pretty open. I didn't care if they knew.* Although everyone in the school was aware of Melinda's diabetes, she feels that many of them did not truly understand what diabetes was.

*A lot of people have misconceptions about it. Like they think that if they eat too much candy they are going to get diabetes. Or a lot of people say I have too much sugar, which is kind of funny because no, I am not carrying around a bag of sugar in my backpack.*

Because of the pervasive lack of awareness that exists surrounding diabetes, Melinda never allows her sugars to drop so much that she would require the outside help of a friend or stranger.

*A lot of people think that insulin is the same as sugar. So if my blood sugar is low, they think that I would have to give myself insulin, which is why I also don't really let people deal with my low blood sugars or high blood sugars. Because if they would give me insulin when my blood sugar is low I would be toast!*

Melinda's strict regimen adherence is one of the strategies she has developed to avoid situations in which others are in control of her health.

*Diabetes in university.* Melinda is currently enrolled in a biochemistry program at university, and hopes to one day become a doctor. She is a year behind her classmates because she transferred programs in first year. She is currently in her second year of university, and did not speak of her experiences with diabetes in the university setting.

#### *Social Support*

*Family support.* Melinda's family has always played a large role in her life. From the time she was diagnosed, her parents were actively involved in her treatment. They worked alongside Melinda, her doctor, and her teachers to ensure that Melinda could lead as normal and as healthy a life as possible. While Melinda's parents helped their daughter in any way they could, they encouraged her to stand on her own and advocate for her own

needs. Because of their love and support, Melinda was able to excel in numerous aspects of her life, including gymnastics, academics, and health.

As Melinda got older, her parents' role in managing her diabetes decreased. They are still involved to a certain extent, attending doctors' appointments, and preparing meals when she returns home from university.

*In high school my parents weren't doing too much anymore. My mom came and learned about how to use the insulin pump, but I bet if you asked her now she wouldn't be able to tell you. While I lived at home she still took me to my doctor's appointments, but even then my doctor would tell her to beat it, because I had to start doing things for myself. And sometimes he would ask me questions that I wouldn't want to answer in front of my mom. Still when I go home if we are having something for dinner that we have never had for dinner before, she will read the nutritional information on the package for me and tell me it has this many grams of carbohydrates and this many grams of fibre in this serving size. I could check it myself, but she will tell me anyways.*

*Friend support.* According to Melinda, having diabetes *never stopped me from going out with my friends or doing whatever I wanted with them.* Although Melinda spent time hanging out with her classmates, her closest friends were the ones from gymnastics. Melinda and her friends would engage in typical teenage activities, going to the mall, watching movies, going to parties, and hanging out at the gym.

Melinda recalls her friends as being emotionally supportive, but having very little influence over how well she managed her diabetes.

*I always did everything myself, so I don't really remember them having an effect over how well my diabetes was managed. I was never so low that I couldn't get up*

*and get something to eat myself. So I never really needed anyone to do that for me. The only time my friends really had an influence was when we would go out for lunch together but they were taking forever. If my blood sugar started to go low and I told them we had to go eat, they would say "Just a second. We have to do this first." Usually I would just grab a juice box and I would be okay until we got lunch. If I didn't have a juice box, I would just meet them [at the restaurant].*

Melinda considers her friends she met at diabetes camp to be very important sources of support. *They understand what it is like to have diabetes, and they can help me with whatever. You know, sometimes they have little tips that they have picked up because they are diabetic.* Even though they met because they had diabetes in common, Melinda believes that they are *some of my best friends even aside from diabetes.*

#### *Dealing with the Developmental Challenges of Diabetes*

Because Melinda was so young when she was diagnosed, she did not experience any of the psychological turmoil that many older individuals experience upon diagnosis. Instead, it was her parents who bore the psychological brunt of the diagnosis. The uncertainty of Melinda's future was somewhat overwhelming to her parents. *They didn't know what it was going to mean for me going to school, or what we would do when we would go on vacation, or what if we wanted to go out for dinner.* During the days following Melinda's diagnosis, her mother cried incessantly. It was not until her mother spoke to other parents of terminally ill children that she began to appreciate how lucky her family was. Her daughter would be returning home with them, and could lead a healthy life provided her diabetes was properly managed.

As the whole family learned a new way of life, there were often periods of confusion and frustration. Maintaining a positive outlook on the situation helped to ease

the family's difficulties dealing with diabetes. Melinda's parents always made her management a top priority, and encouraged their daughter to do the same. As such, Melinda grew up believing that it was important to eat properly, administer insulin on schedule, and exercise. This regimental adherence allowed Melinda to lead a healthy and *normal life*.

While Melinda found the treatment to be somewhat easy to manage, at times she did experience periods of frustration. In Grade 8, when all of her friends were eating candy she longed to do the same. Knowing that she should probably consult her parents before indulging, Melinda decided that the benefits outweighed the risks. Based on the nutritional information on the back of the candy packaging, Melinda was able to calculate how much insulin to administer in order to prevent her blood sugar from rising.

During the early years of her life, Melinda and her parents took a team approach to managing her diabetes. From doctors, to teachers, to parents, to herself, everyone played an important role in ensuring that Melinda could lead as healthy a life as possible. Melinda began giving insulin injections independently at the age of 9, although her parents still supervised her to make sure that everything went smoothly. Because she became independent so quickly, Melinda never required help from teachers, coaches, or friends in treating the lows.

Although at times during elementary school Melinda hid her food indulgences from her parents and doctors, she was always very careful to ensure that she administered the correct amount of insulin to prevent her blood sugars from rising. In taking responsibility for her own decisions, Melinda was asserting her independence earlier than most children. While her mother encouraged Melinda to become responsible for her own health, she still wanted to be involved in Melinda's life. At times, Melinda and her doctor

had to remind her mother that Melinda was capable of taking care of herself. After a gentle reminder, Melinda's mother would allow her daughter to deal with her diabetes on her own. When Melinda started on the insulin pump in Grade 8, she was completely independent in her management. Although her parents learned how to use the pump, they never helped her with it.

While Melinda can recall periods of frustration in dealing with her diabetes, puberty remains embedded in her memory as being the most difficult time of all.

*My diabetes got frustrating sometimes, especially when I was growing and everything was out of whack. Management is especially difficult for girls, because the menstrual cycle messes with your blood sugars. Sometimes I would be really high or really low for a whole day, and I would be like "what is going on?" I would have no idea. So I would be testing my blood sugar all of the time, and trying to adjust how much insulin my insulin pump was giving me. So that was kind of hard to do, especially when I was trying to do it between classes or during class.*

In Grade 12, Melinda once again struggled to maintain appropriate levels of blood glucose.

*I gained a bit of weight towards the end of high school. Some of it was from not eating well, and some of it was from the birth control I was on. Since I am pretty small, [the weight gain] affected my blood sugars and made it fairly hard to control. Once my doctor told me how to test how much insulin to give when I bolused, I kind of got control of it once more.*

Because Melinda was so young when she was diagnosed, she *can't remember life without diabetes*. Melinda does not believe that her life has changed as a result of her diabetes.

*I don't think diabetes really affected my life all that much. I was a competitive gymnast; I still got to do that. I did really well in high school. I got away with not doing too much work, and still getting above average grades. My diabetes never really stopped me from going out with my friends or doing whatever I wanted with them. We went to the mall, watched movies, or had parties when someone's parents left for the weekend.*

When asked what she would tell someone who was newly diagnosed with type 1 diabetes to expect, she replied that *little things are going to change, and you are going to have to be a little more careful with your health, but generally your life is not going to change that much*.

While Melinda embraces her diabetes as a normal part of life, she is still able to identify many inconveniences that stem from this chronic condition.

*Diabetes is a pretty big part of my life. You are always sort of thinking about what your blood sugar might be, or if it is too high or too low. Being diabetic means planning more than other people. I have to plan to always bring juice and a snack with me. I have to think about when I need to see the doctor next, and when I have to have blood work done. And for diabetics, it is really important to get the flu shot, so I have to think about where and when I am going to get the shot. It is just a few extra things to think about all of the time that other people wouldn't really think about.*

One of Melinda's strategies that has helped her to maintain normal blood glucose levels is to try to anticipate when she might be high or low, and to plan ahead for these occasions.

*You can't avoid having high blood sugar sometimes, so the best thing to do is to think about when you might have a higher blood sugar, and you learn that if you sit around all day studying you are going to have a higher sugar. Or you learn that if you go out for dinner and you aren't sure what you are eating and you are going to have dessert, that you can anticipate when you might have a high blood sugar and you test at those times so that if you are high, you can correct it and not stay high for a long time.*

Although Melinda believes diabetes may have encouraged her to worry more about her overall health, she believes that she still would have many of the same worries even if she didn't have a chronic illness. *I think even if I wasn't diabetic I would be anal about these things. It is in my personality to worry about my grades and how much I exercise, and if I am eating a healthy diet.*

Despite the many inconveniences of living with diabetes, Melinda is able to identify some of the benefits to living with this chronic condition.

*It would certainly make life easier sometimes not to have diabetes. But then I guess I wouldn't be so aware of how important it is to be eating properly and exercising, and keeping my cholesterol and blood pressure down. I wouldn't have my friends from the diabetes camp who even aside from our shared diabetes are some of my best friends. After being on youth panels with diabetes advocates from all over the world, I have realised that I am pretty lucky.*



*Summary of Melinda's Experiences*

Melinda has led what she describes as a “*normal life*.” Having diabetes has never really affected any of her life decisions, and has not held her back. She was able to be a competitive gymnast, excelled in school, went to university, and is now pursuing a career in the medical field. Although Melinda has encountered several people who have limited knowledge of diabetes, she has never had to count on them to help manage her condition. Melinda is an active advocate not only for herself, but for others living with diabetes. While she considers herself lucky to have had such a positive experience with diabetes, it has come with a lot of hard work on her part.

## CHAPTER 6: DISCUSSION

In the previous two chapters, I presented each woman's subjective experience under the headings of medical experience, school experience, social support, and dealing with the developmental challenges of diabetes. In the first part of this chapter, I re-examine each of these areas of life, comparing them to findings in the literature. While portraying the aspects of the women's experiences as separate entities helps to illustrate how various facets of an individual's life can be influenced by diabetes, it risks simplifying an experience that is never simple. In the final part of this chapter I look at the holistic experience of living with diabetes in an effort to answer the underlying research question: what does it mean for these four women to live with diabetes. Using Bury's (1982) and Paterson's (2001) theories of chronic illness as theoretical frameworks, and by comparing the cases to the literature, I examine how each woman has experienced her illness, and what it means to her.

### Medical Experience

Like many illnesses, diabetes passes through a disease progression beginning with the prodromal phase, entering the acute phase, and ending with the chronic phase (Silverthorn, 2001). In the prodromal period, individuals may be aware of changes in their body and overall health, but the signs and symptoms are non-specific (Gould, 2002). It is not until the acute phase that individuals are diagnosed with diabetes, and are required to understand the diagnosis and make decisions about their care (Nelson et al., 2007). In the chronic phase, the time following diagnosis, the individual tries to cope with the demands of life while dealing with the side effects of illness and treatment (Gould, 2002). While much is known about the physiological workings of these phases in diabetes, less is known about the psychological implications of the tasks faced by the chronically ill

individual at each of these stages. Abbey, Olivia, Hannah, and Melinda have provided some insight into what it is like to live with diabetes throughout the progression of the disease.

The prodromal period of diabetes was particularly troublesome for the chronically ill females and their families. At this time, Abbey, Olivia, Hannah, and Melinda were experiencing subtle symptoms of illness, but had not yet been diagnosed by a medical professional. Although all of these participants sought medical attention at the onset of symptoms such as extreme fatigue, thirst, and excessive urination, none of these women was properly diagnosed with diabetes upon her first visit to the doctor. Because the early symptoms of diabetes are non-specific (Koopman, Mainous, & Jeffcoat, 2004), the women's doctors falsely interpreted the symptoms as being the result of influenza, a cold, or a passing phase, downplaying the seriousness of the patients' complaints. It was not until their parents, or the women themselves, insisted on seeing a doctor the second time that they received a proper diagnosis of diabetes. Based on statistics obtained by the Canadian Diabetes Association (CDA, 2007), the missed diagnosis of diabetes by both medical professionals and lay people alike is not surprising. The CDA estimates that there are over two million Canadians currently living with diabetes. Around 35 to 44% of these cases are individuals who have not been properly diagnosed (Public Health Agency of Canada, 2008).

Once the participants' symptoms were properly attributed to their diabetes, these four women entered into the acute phase, or diagnosis phase. This period consisted of the time spent in the hospital, and the weeks following the initial diagnosis of diabetes. Descriptions of the experiences of individuals in the acute period of diabetes have varied greatly in the literature, portraying the diagnosis of a chronic illness as a life-altering

event, a burden, and to some individuals, a relief (e.g., Bury, 1982; Charmaz, 1995; Weekes, 1995). Abbey, Olivia, Hannah, and Melinda displayed similar levels of variation, demonstrating differing psychological consequences and disease-related struggles. While these women differed in their personal reactions to their diagnoses, they all recalled the acute period as being one of intense learning and psychological distress.

Having lived a full year with a false diagnosis of reactive hypoglycemia, the diagnosis of type 2 diabetes came as a relief to Abbey. After struggling for several months to avoid hypoglycemic states, Abbey suddenly had a medical explanation for why the treatment was not alleviating her symptoms. This initial sense of relief was later replaced with feelings of disheartenment when she realised she would have to give herself injections and monitor her diet on a continual basis. Not only did Abbey have to learn to monitor her blood sugars, but she also had to learn to deal with the psychological ramifications of injecting herself with insulin. Abbey described how she frequently felt like a different person, with her emotions fluctuating in response to her blood glucose levels. Adjusting to the strict treatment regimen and to the side effects of the illness was difficult for Abbey, and she yearned for help dealing with the psychological burdens of type 2 diabetes.

Unlike Abbey and the participants in Lo and MacLean's (2001) study who experienced periods of relief upon being diagnosed with a chronic illness, Olivia was devastated by her diagnosis. She went into a state of denial and depression, believing that diabetes would prevent her from accomplishing the goals she had set for the future. Not only did Olivia have to deal with the psychological repercussions of her diagnosis, but she also struggled with the medical aspects of her treatment. Initially placed on antidiabetic pills, Olivia did not receive a proper education at the hospital for dealing with

type 1 diabetes. It was not until she was re-hospitalized because of an allergy to the medication that she learned the specifics of her treatment regimen. For both Abbey and Olivia who were diagnosed with diabetes during their adolescent years, this disease presented a threat to their sense of normality. Having lived the majority of their lives illness-free, the diagnosis of diabetes was identified by both women as being the most significant event in their lives. The struggle to come to terms with a new way of life is one that troubled both of these women continually throughout the acute and chronic phases of illness.

For Hannah and Melinda, the acute phase of diabetes posed less of a threat to their personal well-being. Despite her young age at diagnosis, Hannah is able to vividly recall her time at the hospital, and how scared she had been. She recalls the doctors working furiously to bring down her blood glucose levels, and the nurses holding her down to give insulin injections. Although Hannah understood that the doctors and nurses were trying to make her feel better, it was a traumatic experience for both herself and her parents. Unlike Hannah, Melinda was too young at diagnosis to recall details of her personal experience. Instead, she constructs her understanding of the diagnosis experience from stories told to her by her parents. The diagnosis story she tells does not feature herself as the main character, but instead focuses on how her parents were experiencing their daughter's diagnosis. While Abbey and Olivia were devastated by their diagnoses, neither Melinda nor Hannah recall experiencing this emotion or loss of previous self.

The chronic phase of diabetes represented a time of change, intense learning, and loss of control for Abbey, Olivia, Hannah, and Melinda. Over the course of their illnesses, the women's treatment regimens changed frequently. When their treatment schedules switched from a two-needle-a-day regimen to three or more injections a day, the women

had to relearn how to properly manage their condition, and had to begin giving injections and testing their sugars in public; a task which at first led to feelings of unease and embarrassment (Zambanini, 2003).

While these women faced many challenges throughout their lives, the teenage years were particularly difficult for Hannah and Melinda. Prior to entering adolescence, both Hannah and Melinda had a strong level of control over their diabetes, and were able to predict how their body was going to respond to food, exercise, and insulin. Upon entering puberty, these women lost control over their bodies and disease management, and began experiencing frequent uncharacteristic fluctuations in blood glucose levels. Although the sudden loss of diabetic control associated with puberty has been recognized in the literature, health professionals are divided in their opinions on what initiates this sudden loss of glucose homeostasis (e.g., Du Pasquier-Fediaevsky et al., 2005; Madsen et al., 2002). Because adolescence is typically viewed as a time of non-compliance in which individuals are asserting their autonomy, some researchers suggest that the sudden loss of diabetic control experienced during adolescence may be the result of decreased treatment adherence (e.g., Dabadghao et al., 2001). Because Hannah and Melinda both tried desperately to control their glycemic levels by altering insulin, exercise, and food intake to find a balance that worked for their changing bodies, it is unlikely that their loss of glycemic control was caused by treatment non-compliance. A more likely explanation for the loss of control experienced by these two women is that glycemic levels were altered by fluctuating hormones that are typical of puberty (Gould, 2002). In their 2005 study, Du Pasquier-Fediaevsky, Chwalow, and Tubiana-Rufi found that during puberty, individuals living with type 1 diabetes became more insulin resistant. Hannon, Janosky, and Arslanian (2006) discovered a similar level of insulin resistance in their study, with

insulin sensitivity decreasing approximately 50% during adolescence. The researchers hypothesized that the decrease in insulin sensitivity was driven by the effects of growth hormone; a hormone which is released in greater amounts during puberty.

Because Abbey and Olivia were diagnosed at a later age, neither of them experienced life with diabetes during the pubertal years. Both women, however, did experience periods of loss of control. For Abbey, this inability to maintain constant blood glucose levels occurred a few months after diagnosis. She attributes this loss of control to the end of what health care professionals refer to as the honeymoon period. When individuals with diabetes first begin insulin therapy, the infusion of insulin into the body can stimulate the pancreas to begin producing more insulin. After a period of time, the pancreas once again ceases to produce this digestive hormone, and the person with diabetes will be required to increase the dosage of exogenous insulin (Abdul-Rasoul, Habib, & Al-Khouly, 2006).

Olivia's inability to maintain healthy blood glucose levels resulted from her non-compliance and lack of self-care behaviours. Immediately following her diagnosis, Olivia went through a prolonged period of denial, embarrassment, and depression. Because she did not want others to know about her diabetes, she would frequently refrain from taking needles in an attempt to maintain an identity and sense of self that was free from illness. Whether or not her depression enhanced her destructive self-care behaviours or whether her fluctuating blood glucose levels stimulated her depression is unclear, and this issue requires further research (Engum, Mykletun, Midthjell, Holen, & Dahl, 2005).

#### School Experience

The findings on whether or not diabetes affects a student's overall academic achievement have been mixed in the literature. Some researchers argue that having

unstable blood glucose levels can lead to difficulties in spatial intelligence, attention, and concentration (e.g., Kovacs et al., 1992; Rovet & Alvarez, 1997; Ryan et al., 1990). Since Abbey, Olivia, Hannah, and Melinda all succeeded in school, it does not appear that diabetes has exerted a large effect on their overall academic achievement. Whether it is because of their strong inherent academic abilities, or whether it is the result of their superior glycemic control, all of these women except Olivia excelled in school. While Hannah and Abbey do not believe that diabetes has hurt them from an academic perspective, both women can recall times when they were unable to concentrate due to fluctuations in blood glucose levels. Although these four women may not be experiencing long-term academic deficiencies as a result of diabetes, it is evident that momentary fluctuations in blood glucose levels have exerted an influence over how well they are able to perform in the classroom on some occasions (e.g., Ryan et al., 1990; Sommerfield et al., 2003).

Unlike Hannah, Melinda, and Abbey, Olivia perceived herself as a poor student in high school. She recalls how her overwhelming fatigue and lack of motivation led to poor academic achievement. In Olivia's mind, it is difficult to discern whether her troubles were related to her diabetes, or whether her poor academic standing preceded the onset of symptoms. One of the main difficulties Olivia had at school was paying attention in class. Rovet and Alvarez (1997) discovered a similar disruption to attention in children with type 1 diabetes when compared to a healthy control group. Of all of the women in this study, Olivia had the least amount of success controlling her diabetes during the school years, and frequently experienced episodes of hyperglycemia and hypoglycemia. Based on the findings of Ryan and colleagues (1990), it is possible that fluctuations in blood



glucose levels may have contributed to Olivia's poor academic achievement in high school.

Despite excelling in academics, all of these women identified difficulties experienced at school. For the most part, these difficulties stemmed from a general lack of awareness among school staff. Abbey, Olivia, Hannah, and Melinda spoke of their teachers' limited understanding of diabetes, and of how classroom rules often restricted their ability to manage the disease while in the school setting. Not only did they speak of the inflexible class rules, exclusion from extra-curricular activities, and inability to perform glucose testing in the classroom as was discussed by the participants in Nabors and colleagues' (2003) study, but they also spoke of difficulties associated with class trips and bake sales. For Olivia and Hannah, the lack of healthy food choices in the vending machines at school posed the greatest amount of concern (Hayes-Bohn et al., 2004). Because of the shortage of healthy food on school property, these women had to be sure to carry snacks on them at all times in order to treat a low.

Like Nabors and colleagues' (2003) participants, Abbey, Olivia, Hannah, and Melinda wanted teachers to be more knowledgeable about diabetes, and about the psychological repercussions of the disease. They believed this could be accomplished either by teachers taking a course, talking to the parents, or talking to the individual with diabetes. While the participants all believed establishing open lines of communication with the student was important, these four women also felt that it was important to avoid giving the student unnecessary attention. Class rules need to be more flexible so that children can properly manage their diabetes at school, and so that they are not constantly singled out.

## Social Support

### *Family Support*

Despite differences in the age of diagnosis, Hannah's, Melinda's, Olivia's, and Abbey's families all played a role in their lives following the onset of diabetes. The type of support received, and extent of parental involvement varied among participants. From the moment Hannah and Melinda returned home from the hospital, their parents assumed full responsibility for managing their treatment. As Hannah and Melinda became more familiar with the treatment requirements of diabetes, their parents began relinquishing control and including them in the medical aspects of care, providing them with the skills necessary to manage their diabetes independently at a very young age. Although Palmer and colleagues (2004) warn that allowing children with diabetes to become independent at too young an age may place them at risk for increased complications and hospitalizations, neither Hannah nor Melinda experienced any diabetic complications. This early independence did not threaten the women's overall health, but instead served as a means of self-preservation. In allowing their daughters to assume full responsibility for diabetes treatment upon entering school, Hannah's and Melinda's parents were ensuring that their daughters were equipped with the knowledge to make decisions about their health while away from the watchful eyes of their parents.

Even though Olivia was diagnosed with diabetes during the adolescent years, her previous sense of autonomy was replaced by an earlier stage of dependence. Overwhelmed by the treatment requirements of diabetes, Olivia relied heavily upon the support of her mother to properly manage her condition. Olivia's mother took full responsibility for ensuring that Olivia was eating a proper diet, taking her injections at the correct time, and monitoring her blood sugars. While her mother reassumed the role of

caregiver, Olivia's father became more distant. He was not sure how to help his daughter who was struggling with diabetes, so he assumed the only role he knew; the role of provider. Other studies examining the reactions of fathers to their child's diagnosis of a chronic illness have observed a similar behaviour among men (e.g., Neil-Urban & Jones, 2002; Seiffge-Krenke, 2002). As Olivia became more comfortable with the disease management and realised that she was capable of leading a healthy life, she returned to the more independent lifestyle she had assumed prior to being diagnosed.

Unlike Olivia who became dependent on her parents upon diagnosis, Abbey struggled to maintain the sense of autonomy she held prior to the onset of diabetes. In an attempt to demonstrate her ability to deal with the diagnosis on her own, Abbey limited the time her parents spent with her at the hospital, and excluded them from all aspects of her diabetes management. When Abbey would experience episodes of poor glycemic control she would refrain from telling her parents, since it would cause them to worry and to question her ability to properly manage the illness independently. This withholding of information from parents was a strategy used by all of the participants in this study, and is frequently seen in adolescents with chronic illnesses who are trying to take control over their own health (Christian, D'Auria, & Fox, 1999).

### *Friend Support*

Although many researchers believe that friends can be detrimental to the management of diabetes (e.g., Cheung et al., 2006; Faro, 1999), none of Abbey, Olivia, Hannah, or Melinda believed that their friends had any negative influence over their management. Abbey and Olivia viewed their friends as positive influences in their lives, encouraging them to follow the diabetic regimen, and helping them to come to terms with their new way of life. Hannah and Melinda both reported having a close group of friends;

however, they did not believe that their friends had any influence over their treatment regimen. Because Hannah and Melinda had such good control of their own health, they did not rely on friends for help. While the women's friends did not influence the physical nature of diabetes management, they provided a level of emotional support to these women that increased in prevalence during the teenage years. This shifting of emotional support from parents to friends during adolescence is believed to be an age-appropriate event for both healthy and chronically ill individuals (e.g., Bearman & La Greca, 2002; Greco et al., 2001).

Despite having a close group of friends during high school, Abbey feels that having diabetes has made her more selective in whom she chooses to befriend at university. When choosing to form relationships, Abbey now seeks out individuals who are vulnerable like herself, yet can still provide the emotional support that she yearns for. In their 2006 study, Helgeson and colleagues' participants demonstrated a similar selectivity in friendships, choosing friends who were similar to themselves.

One of the decisions all of these women had to face was whether or not to disclose their illness to others. Although Abbey and Melinda were open about having diabetes, Olivia and Hannah tended to hide their diabetes from friends and peers. Unlike Olivia's decision not to disclose her condition to others, which stemmed from her feelings of shame and intense desire to appear normal (Cheung et al., 2006), Hannah's motivation lay in her desire to be seen as a person, and not just a person with diabetes. Hannah has struggled throughout her life to avoid developing the "diabetic identity" (e.g., Goldman & MacLean, 1998; Tilden, Charman, Sharples, & Fosbury, 2005), and has instead fought to be seen for who she is in spite of her diabetes.

### Dealing with the Developmental Challenges of Diabetes

While dealing with the demands of their disease, individuals with diabetes are required to deal with the normative developmental tasks of their age group (Dovey-Pearce, Doherty, & May, 2007). Although several different theories of development have been proposed, many identify similar milestones associated with childhood and adolescence. According to Havighurst (1972) and Erikson (1968), the childhood years are comprised of learning new skills, and building wholesome attitudes towards oneself as a growing organism. Individuals do not typically develop a sense of identity or independence from their parents until the adolescent years (Erikson, 1968; Havighurst, 1972).

Abbey, Olivia, Hannah, and Melinda all spoke of instances in which their diabetes provided a challenge to their normative development. For Hannah and Melinda, the diagnosis of diabetes forced them into a state of maturity that could be perceived as being beyond their years. While other children their age might spend their time before dinner watching TV or putting the finishing touches on their homework, Hannah and Melinda were calculating how much insulin they needed to give for the amount of carbohydrates in the meal they would be ingesting. By the age of 9, both women were giving themselves insulin injections independently. While some researchers believe that children should not be granted this much independence at such a young age (e.g., Palmer et al., 2004), both Hannah and Melinda believe that they were ready to take on the responsibility of managing their own health. These two women successfully managed their diabetes over the course of their childhood, and knew how to react in instances of high or low blood sugars. For them, this sense of independence was not seen as being a burden, but instead was viewed as a form of self-protection. Hannah and Melinda felt that they were better

suited to manage their diabetes in social and school situations, and did not want others who were less knowledgeable about their condition to have any control over their diabetic regimen.

For all of the women in this study, puberty and adolescence were viewed as the most challenging times in their diabetic lives. According to Havighurst's theory of development (1972), there are eight developmental tasks of adolescence: gaining emancipation from parents, achieving financial and social independence, accepting a new body image, forming clear identity, developing relationships with members of both sexes, developing cognitive skills and ability to think abstractly, and developing the ability to control one's behaviours according to socially acceptable norms and taking responsibility for one's own behaviour. All of the women identified difficulties in achieving at least one or more of these tasks. Abbey, Olivia, Hannah, and Melinda all spoke of difficulties they had maintaining their independence from their parents during adolescence. While Abbey, Hannah, and Melinda succeeded in becoming autonomous, Olivia reverted to an earlier stage of dependence on her parents. It wasn't until Olivia learned more about her diabetes and the proper management that she resumed her independent lifestyle.

Because the costs of diabetic supplies are so high, all of the women had difficulty achieving financial independence. They all relied upon financial support from their parents during adolescence, and have continued to rely on their parents' health care plans into adulthood. Both Abbey and Olivia are concerned about how they will be able to afford their diabetic supplies once they are no longer considered dependent.

Accepting a new body image was perhaps one of the most difficult tasks faced by the women in this study. During puberty and adolescence, all of the females experienced slight gains in weight as a result of insulin therapy. While Olivia and Melinda were able

to lose the excess weight through exercise and proper diet, Hannah found weight loss to be more difficult. In an attempt to lose the weight she had put on, Hannah reduced her insulin intake, decreased the amount of food she was eating, and increased her level of exercise. This form of insulin-purging known as diabulimia is quite common among the female diabetic population, and can lead to a variety of health complications if left untreated (Colton et al., 2004; Jones et al., 2000). Hannah's diabulimic tendencies were short-lived, and there have been no known resultant health effects.

While Abbey and Olivia believe diabetes played a role in their identity formation, neither Hannah nor Melinda believe that diabetes really affected their identity. Dovey-Pearce and colleagues (2007) suggest that "experiencing an altered body directly impacts upon how a young person defines themselves in relation to others and upon their current and future identity goals, causing them to question their personal identities." (p. 80) Because Hannah and Melinda were so young upon diagnosis, it is possible that they were no longer experiencing an altered body at the time of identity formation, but instead accepted their diabetic body as a normal part of life. As such, the illness may not have had a direct impact upon their identity formation.

For Abbey and Olivia, the diagnosis of diabetes came at a time in their lives when they were struggling to find their identity. Having lived the majority of their lives without illness, the sudden onset of diabetes disrupted the life trajectory they had previously set, forcing them to rethink their life's ambitions in relation to diabetes. This phenomenon has been described by many researchers studying a variety of chronic illnesses (e.g., Bury, 1982; Charmaz, 1995; Rasmussen et al., 2007). For Olivia, the effect diabetes had on her self-concept was more intense in the initial stages of illness. When she realised that she

could lead a healthy life in spite of her diabetes, Olivia's previous self-concept resurfaced.

One of the ways that diabetes may have influenced the development of each woman's personality in this study is to shape what the women choose to pay attention to. Having to constantly be aware of their physical health, diabetes encouraged Abbey, Olivia, Hannah, and Melinda to become more health-oriented and aware of what was going on in their bodies. They began focusing on their diet, weight, exercise, and routines in an attempt to maintain a state of good health. In addition to increasing the women's health awareness, diabetes also influenced several of their life choices ranging from decisions relating to travel, family life, and careers. All of these women initially sought out science-related programs in university. Although Abbey switched to a degree in English and Religion because of physical limitations imposed by her diabetes, the other three women continued their education in the medical fields, pursuing careers in diabetes education, medicine, and islet research. While it is possible that having diabetes may have inspired the participants' interest in science-related fields, very little is known about the effect of chronic illness on the adolescent's choice of vocation (Fernandez-Sierra, 1998). Brown and colleagues (2008) and Yazak (1998) are among the few researchers who have examined chronic illness and career identity. Using qualitative interviewing techniques, Brown and colleagues discovered that the majority of the 11 participants who were diagnosed with cancer during childhood had at one time or another aspired to become a doctor or nurse. These researchers offered several explanations for the participants' heightened interest in the medical and helping professions. Referring to Krumboltz' (1979) social learning theory of career decision making, Brown and colleagues explained how through associative learning experiences, the participants may have associated the



hospital setting with life-saving treatment. As such, they may have developed an admiration for health care professionals, and aspired to follow in their footsteps. Because they had spent much of their time in the presence of doctors and nurses, the individuals living with cancer may have accumulated cognitive and behavioural skills that they desired to put to use in their choice of vocation. The final explanation offered was that in pursuing a career in medicine, the participants may have been granted a means through which they could repay their debt to society, the medical world, and a greater being. Yazak (1998) provides an alternate explanation, suggesting that adolescents with chronic illnesses may have been overexposed to a medical model view of the world as a result of their illness, and may have developed a limited notion of careers that were available to them. While these interpretations might offer insight into these four women's motivations to pursue post-secondary education in health-related fields, further research is needed to develop a clear understanding of the relationship between diabetes and career development.

Over the course of their lives, all of the participants in this study fluctuated between loathing and accepting their diabetes. For Abbey, Olivia, and Hannah, diabetes exerted a significant influence over their psychological well-being, leading to feelings of frustration, anger, depression, and denial. While these three women experienced many of the same emotions in relation to their diabetes, the rate at which they fluctuated between emotions differed. Being diagnosed with diabetes later in life, Abbey and Olivia seemed to experience more psychological difficulties than Hannah and Melinda. Olivia fell into a state of depression upon diagnosis, refusing to follow the treatment regimen because of her overwhelming need to maintain a semblance of normality (e.g., Rasmussen et al., 2007; Schur, Gamsu, & Barley, 1999). Although Olivia has overcome her depressive state

and has learned how to live a healthy life, Abbey continues to experience troubles incorporating her diabetes into her way of life. Because Abbey has only been living with diabetes for a year and a half at the time of data collection, it is possible that her difficulties adjusting to her diagnosis may be associated with the short duration of her illness (Sharpe & Curran, 2006).

While each participant experienced varying psychological struggles related to her chronic condition, one emotion that was consistent across all cases was the feeling of frustration. The main sources of frustration for these four women were the lack of diabetes awareness among the general population, the persistence of the disease, the need for constant attention to management, and the stigma associated with diabetes. These inconveniences of diabetes are similar to those identified by participants in Davidson, Penney, Muller, and Grey's (2004) study. Like Davidson and colleagues' participants, Abbey, Olivia, Hannah, and Melinda found the excessive amount of planning and the resultant loss of spontaneity to be a source of great frustration. These women spoke of how they had to worry about issues that most people their age did not have to think about, and how these worries extended beyond the immediate health threats to future health complications, financial burdens, and social issues.

#### Revisiting Bury's Theory of Biographical Disruption

In Chapter 2 of this thesis, I introduced Bury's (1982) notion of chronic illness as a biographical disruption. According to Bury, chronic illness could be perceived as a critical situation that caused disruption to the individual's taken-for-granted assumptions, biography, and resources (Bury, 1982). While Abbey and Olivia displayed initial signs of disruption upon diagnosis, the disturbances to their assumptions, self-concept, and resources were short-lived. As they began reframing their lives in the face of diabetes,

these women assumed a more positive outlook on life, believing their diagnosis of diabetes to be fate providing them with a purpose in life.

Although Bury's notion of chronic illness as a biographical disruption might be useful in studying the initial phase of adjustment to chronic illness among individuals diagnosed during adolescence, this theory is not useful in explaining Hannah's and Melinda's experiences. Because they were so young at diagnosis, diabetes quickly became a normal part of Hannah's and Melinda's daily lives. Despite living with a chronic illness, these women were able to achieve age-appropriate tasks, and went on to live healthy and productive lives. Because Bury views illness as a negative and disruptive experience, his theory is limited in its applicability to individuals living with diabetes. In recent research, there has been an increased interest in the phenomena of health and transformation in illness. Whether or not it is because of medical advances that have allowed for sick individuals to lead healthy lives, or whether it is due to a change in the way medical practitioners deal with illness, one thing remains certain; illness does not have to be a disruptive life-event.

#### The Shifting Perspectives Model of Illness

In acknowledging the existence of both illness and wellness in the chronic disease experience, the shifting perspectives model of illness (Paterson, 2001) provides a more fitting explanation of how the four women in this study experience life with diabetes. According to this model, individuals with chronic illness fluctuate between two perspectives over the course of their lives; the illness in the foreground perspective, and the wellness in the foreground perspective. How chronically ill persons interpret their illnesses and how they perceive their experiences depends greatly on the perspective that they hold at any given moment. According to Paterson (2001), it is the perception of

reality, not reality itself that determines how an individual interprets and responds to his or her illness.

While for the most part the participants in this study consider themselves to be healthy and well individuals, they experience times during which they are forced to look at life with an illness in the foreground perspective. The next section examines the cases of Abbey, Olivia, Hannah, and Melinda in relation to the shifting perspectives model.

### *Illness in the Foreground*

According to Paterson (2001), when individuals are first diagnosed with a chronic illness, they often enter into a period of time where they focus on their illness, suffering, and loss, as well as the burdens associated with having a chronic disease. When assuming an illness in the foreground perspective, they view the chronic illness as destructive to themselves and to others. For Abbey, Olivia, and Hannah, the initial diagnosis of diabetes was seen as destructive not only to their previous way of life, but also to their families. Abbey and Olivia became increasingly aware of the repercussions diabetes had on their existence, abandoning their hopes and dreams for the future in pursuit of new goals that could be achieved within the limitations of their illness. While Abbey's focus on the illness seems to occupy the majority of her time, Olivia has abandoned her primary focus on illness for a wellness in the foreground perspective.

Unlike Abbey, Olivia, and Hannah who adopted an initial illness in the foreground perspective at the onset of diabetes, Melinda was too young upon diagnosis to truly understand what was going on, or what having diabetes would mean for her. Instead, it seems that it was Melinda's parents who went through this initial focus on the illness, wondering what kind of limitations the disease would impose on their lives and on their daughter's life. By the time Melinda was old enough to understand what diabetes was, she

had lived with the disease for so long that it had become a normal routine in her life, and she did not see it posing any immediate threats to her sense of self.

*Shifting to a Wellness in the Foreground Perspective*

Abbey, Olivia, Hannah, and Melinda have all experienced periods in their lives in which they assumed a wellness in the foreground perspective. In viewing their chronic illness as a meaningful occurrence, they have come to accept changes in their relationships with their environment and with others that have occurred as a result of their diabetes. These four women spoke of the positive aspects of the diabetes experience, claiming that diabetes has provided them with a purpose, and has inspired them to lead healthier lives than they would have led in the absence of their disease. This notion of a chronic disease leading to greater health outcomes has been observed in studies of individuals living with cancer, HIV, and rheumatoid arthritis (e.g., Britton & Moore, 2002; Hwang et al., 2004). Although older studies have recognized the perception of wellness in disease, this focus on wellness has historically been misinterpreted as denial. Weekes (1995) describes a phenomenon similar to the wellness in the foreground perspective, referring to it as adaptive denial. In Weekes' opinion, focusing on day-to-day tasks allows individuals who are chronically ill to avoid thoughts of illness, thus escaping from the distress that often accompanies disease. Paterson (2001) does not interpret this focus on health and wellness as a form of denial, but instead views it as reframing of what is possible and normal.

While Paterson (2001) proposes that achievement of a wellness in the foreground perspective requires a separation of the diseased body from the mind, Melinda, Hannah, Abbey, and Olivia are all able to achieve this perspective while maintaining a close relationship with their bodies. Instead of reinforcing the Cartesian mind-body split,

diabetes has led these women to establish a stronger and more respectful relationship with their bodies. The participants in this study do not view their diseased bodies as victims of illness, but instead envision them as tools for achieving wellness. In listening to the subtle cues elicited by their bodies, Hannah, Melinda, Olivia, and Abbey are able to rectify health issues early on so that they may maintain a wellness in the foreground perspective.

*Shifting to an Illness in the Foreground Perspective*

While the illness in the foreground perspective is most often assumed upon diagnosis, this perspective can also be assumed when there is a perceived threat to control such as signs of disease progression, an inability to manage the disease, and disease-related stigma (Paterson, 2001). For Hannah and Melinda, this shift from the wellness in the foreground perspective occurred at times when they had little control over their bodies such as during puberty, and when they involuntarily experienced weight gain. At these points in their lives, Hannah's and Melinda's bodies no longer responded to treatment effectively, and they were forced once again to focus on the illness in an attempt to regain control. Olivia was forced to assume an illness in the foreground perspective after each hospitalization she experienced for serious hypoglycemia, and Abbey had to focus on her diabetes following the end of the honeymoon period.

Paterson (2001) suggests that individuals with a chronic illness such as diabetes can be persuaded to assume an illness in the foreground perspective by other people who treat them as helpless or incapable of maintaining health. Self-help groups can cause a shift to an illness in the foreground perspective, encouraging individuals to focus on their illness in order to partake in discussions (Paterson, 2001). To evade such persuasions, Hannah has avoided becoming friends with individuals with diabetes because she does

not want to bond over their common illness, and does not want to assume poor management habits that other persons with diabetes might possess.

Though it may appear that the illness in the foreground perspective is an undesirable perspective to hold, this is not the case. In focusing on the illness, individuals are granted the opportunity to learn about their disease, and to come to terms with their medical condition. When everything is running smoothly, there are very few indications that an individual is living with diabetes. By focusing on the symptoms of the disease, the person is able to provide evidence to others that the illness is real (Paterson, 2001). At several times in her life, Hannah has been forced to abandon her preferred wellness in the foreground perspective and focus on her illness. Because Hannah has such good control over her health, other people in her life have often forgotten that she has diabetes. When this occurs, Hannah must shift to an illness perspective, reminding her friends and teachers that she is still living with a chronic illness, and that she still requires certain accommodations.

#### *Strategies to Maintain a Wellness in the Foreground Perspective*

Despite fluctuating between perspectives, Abbey, Olivia, Hannah, and Melinda strive to maintain a focus on wellness. One of the strategies used by all participants to maintain this point of view is to limit the information they share about their illness with their families. While they all maintain frequent contact with their mothers and fathers, these four women choose not to tell their parents about events in which they have little control over their blood sugars. By reducing their parents' level of worry, the participants feel their parents are more likely to believe they are capable of managing their own illnesses and of maintaining a state of good health.

To reduce the risk of disease-related complications, Hannah and Melinda assumed full control over their diabetes management at a young age so that their health would never be placed in jeopardy by an uneducated individual. In avoiding the onset of disease-related effects, these women were able to maintain their focus on wellness. Melinda did not always assume an independent stance in managing her disease, but also relied on the team-like support of her parents, doctors, teachers, and friends. She surrounded herself with individuals who valued her health, and who were able to provide emotional support as she dealt with her chronic condition daily.

In addition to the overt attempts made by the four women to maintain a wellness in the foreground perspective, advances in medical technology may have facilitated the attainment of this focus on health (Thorne et al., 2002). Olivia, Hannah, and Melinda have all experienced life with diabetes on the needles and on the pump. Despite an initial reluctance to invest in an insulin pump, all three of these women believe that the pump has made their lives much easier. This device acts more like a natural pancreas than injections, providing gradual infusions of insulin into the body at different times of the day. The use of the insulin pump has allowed Hannah, Olivia, and Melinda more freedom in their diets, and has freed them from the strict scheduling restraints imposed by other methods of diabetes treatment.

#### *Paradoxes that Arise*

One of the major paradoxes of living in the wellness in the foreground perspective in relation to diabetes is that although individuals wish to focus mainly on health rather than illness, in order to maintain a sense of wellbeing, they must focus on the diabetic regimen in a disciplined way. Thus in order to be able to ignore their illness, they must pay attention to their illness. Paterson (2001) does not address whether or not focusing on



the treatment regimen is placing illness in the foreground. Based on Hannah's and Melinda's stories, it appears that the insulin regimen is merely a tool for maintaining wellness, and does not lead to a focus on illness. In the cases of Abbey and Olivia, however, it appears that the treatment regimen is a constant reminder to them that they have diabetes. The process of giving an injection seems to reinforce the illness in the foreground perspective for Abbey and Olivia, because they view the injections as burdensome, and threatening to their ability to blend in with the normal crowd.

Another paradox arising from the shifting perspectives model is that people who maintain a wellness in the foreground perspective are often required to assume an illness in the foreground perspective if they are to receive healthcare services or have their needs met in the school setting (Paterson, 2001). All of the participants in this study were required to focus on their illness when advocating to their teachers about their own needs. Even Hannah and Melinda who did not believe they needed a lot of help still had to notify teachers of their personal requirements for proper management of diabetes.

### Limitations

When considering limitations of a study, one must look not only at the restrictions imposed by the researcher's study design, but also at the inherent limitations of the selection of methodology. Upon completion of this study, I have come to recognize the limitations that exist within the selection of participants, the interview process, and the use of illness narratives.

In selecting my participants from a small list of individuals who had attended the Youth Diabetes Advocacy workshop, I immediately restricted the type of individuals under study. Although I had purposely selected these young people because of their articulate nature and willingness to share their personal experiences, my selection criteria

returned a sample of individuals who were similar in many ways. All of the women who participated in this study came from loving middle class families, and had access to full medical coverage over the course of their lives. They all had the opportunity to pursue degrees in post-secondary institutions, were active advocates for diabetes, and had excellent levels of control over their health. Although their cases cannot be used to make general statements about individuals living with diabetes, they help us to understand the women's unique experiences living with diabetes.

The second limitation encountered in this study involved the interview process. In writing the interview guide for this study, I relied heavily upon the works of Bury (1982) and Charmaz (1995, 2002). As such, the questions were designed in a way that could potentially have influenced the participants to focus on the negative aspects of the illness experience. Although I feared that the questions might have led Abbey, Olivia, Hannah, and Melinda to responses focusing on the illness, these women spoke more of the transformative experience of illness, and how it had been a positive aspect of their lives. Although conducting several interviews with each participant may have provided a more holistic view of their experiences, monetary restrictions prevented me from performing a second face-to-face interview with these participants. While I had considered conducting a second telephone interview with each participant, upon evaluating the transcripts for completeness, I decided a second interview was not necessary, and if conducted might take up too much of the women's time. Paterson (2001) suggests that how an individual makes sense of or perceives her experience depends on the perspective the individual is holding at a given moment. It is possible that if I had conducted these interviews on a different day, the women's portrayals of their experiences with diabetes may have been different. In the week leading up to my interview with Abbey, Abbey had been

experiencing bouts of illness. She did not decide to do the interview until the day before I was to meet her, because she was unsure of how she would be feeling that day. Although Abbey was healthy at the time of our meeting, her recent illness may have forced her to focus more on the negative aspects of life with diabetes, thus biasing how she chose to portray her overall experiences with diabetes.

The decision to rely upon autobiographical recall data to discern the experiences of these four women living with diabetes may have led to a bias in data. According to Leung and Bryant (2000), individuals with type 1 diabetes are slower than healthy individuals in recalling memories, with a greater difficulty in accessing specific memories of positive experiences. Since people's long-term recollections of the past are often influenced by current attitudes and behaviours, they may not provide an accurate portrayal of the events that actually took place. Regardless of whether the illness narrative reflects the true experiences of the individual, the narratives are told in a way that portrays the perceived reality of the teller. As such, it is important to acknowledge the fact that the narrative may not portray actual details of situations, but instead portray how the individual interprets those situations and makes meaning of them.

#### Suggestions for Teachers

In speaking with Abbey, Olivia, Hannah, and Melinda, I was granted the rare opportunity to discuss with these women what they believe teachers can do for students with diabetes, and what they would have liked their teachers to know. This section provides their solutions to some of the challenges that these women faced in both elementary and secondary school classrooms.

*Just do some Research!*

All of the participants felt that teachers needed to know more about diabetes. While they believe it is important to know about the medical complications associated with the disease, Abbey feels that teachers should also be aware of the psychological repercussions of diabetes. *It is up and down all day long for some people, and when you are dealing with that, kids get emo about it.* Abbey and Olivia suggest that teachers should be required to take a course on diabetes and depression in general. This course should be longer than a single session, as Abbey explains, because *you can't take an information session and expect to know everything.* Teachers can do their own research by talking to parents, students, and medical professionals, and by reading memoirs. While Abbey realises some teachers will not go through this research process until there is a student in their class with diabetes, she believes it is better to be aware of diabetes now *because four years from now you will have four more diabetics in your class because it is on the rise. If you do your research now, you don't have to deal with it later.*

*Notice the Signs*

As teachers, we are educated to look for signs of a variety of learning disabilities and exceptionalities in our students. We can notice when a child has difficulties reading, and when he or she needs help in math. What some are not able to recognize are the subtle signs of poor health. Extreme fatigue may be misinterpreted as the result of a late night or trouble sleeping; a drop in weight may be perceived as the adolescent female's unrelenting desire to be thin. Because Olivia's teachers were not able to recognize the early signs of diabetes, she knows first-hand how important it is for teachers to be aware of health issues. *Catching it earlier is helpful. It saves your kidneys, it saves your eyes. Maybe I wouldn't have had to get glasses if I had caught it before it started changing my*

eyes. Because teachers spend so much time with children and adolescents, Olivia believes that they should be more *health-conscious in general*.

Not only is it important to be able to notice changes in health, but it is also important to notice changes in a student's behaviour. During an episode of hypoglycemia, a child with diabetes may react in an aggressive or violent manner. When Olivia was in college, she experienced a low in which she yelled at the professor and was sent to the Dean's office. None of the faculty was aware of her condition, and did not recognize her uncharacteristic behaviour as being a sign of severe hypoglycemia. Because hypoglycemia can be a life-threatening event, teachers must be able to distinguish between signs of hypoglycemia and hyperglycemia, and know how to react in both cases. Olivia cautions that *the first instance you feel something is different, not necessarily wrong or right, the second they are different, immediately turn your attention to them*. Melinda explains how if you are not sure if the student is high or low, treat it like a low *because you will only make them higher. If you give them insulin they are toast*.

#### *Teach the Class about it*

All of the participants believe it is important for the teacher to teach the class about diabetes. This can be done in a variety of ways. Olivia suggests having the student talk to the class about diabetes, *but only if they are ready*. Other options include having the parent, a member of the local health unit, or an older individual living with diabetes come in and talk about it. Olivia believes it is important to educate the whole school about diabetes.

*[In high school] we had people come in and talk to us about drinking and driving.*

*Why didn't we have someone from the diabetes association come in and talk to*

*us? People think you can only get diabetes when you are old, or that you are born with it...but that is not true. You can get diabetes at any age.*

As part of a volunteer placement with the Canadian Diabetes Association, Olivia goes around to local schools and businesses and talks about her personal experiences because she feels it is important for others to know that *I was very athletic, I didn't have diabetes in my family, and I still got it. There is nothing you can do to prevent it, but here are the signs to catch it early.*

While the participants believe it is important to teach the class about diabetes, they feel that it is also important to increase the amount of time spent teaching about health in general. As Olivia explains, *our world is very sick, and it needs to be taught more in schools, because nobody takes care of themselves anymore.* Hannah suggests bringing in a local dietician to give lessons on food in an attempt to dispel some of the common myths surrounding food, and to promote healthier eating. Olivia believes it would be helpful to have a health fair at the school, or to have weekly guests come in to speak about a wide range of health issues.

#### *Keep the Child from Feeling Excluded*

At one time or another in their school careers, all of these participants felt excluded or separated from others in the class. For Hannah, it was the inflexibility of classroom rules that caused her the most distress. When it came to eating in class, Hannah *always knew that I could supersede that rule, but I always felt like I had to hide it or I had to sneak it in.* Being the only student in the room who was allowed to eat a snack during class time, Hannah often felt singled-out. For this reason Hannah suggests that teachers *get rid of all of those stupid asinine rules about eating. If your student is hungry, let them eat whether they are diabetic or not.* She also stresses the importance of maintaining a

proper schedule, even when on class trips. Not only do teachers need to be more flexible in allowing students to eat in the classroom, but they should also give the student with diabetes *time to test their blood sugars during class*.

Melinda also felt excluded when her teacher singled her out in gym class, indicating to the whole class that Melinda led a healthy life despite living with diabetes. The participants all agree that teachers should not give unnecessary attention to the student, but should instead base the level of attention and accommodations on the individual's personal strengths and needs. As Melinda explains, *some kids [need help], but some kids are fine by themselves*. Hannah agrees that in some cases individuals with diabetes may need assistance, but that teachers should be respectful of the student's ability to self-manage his or her illness, and not interfere unless asked for help.

To make the student feel like a valued member of the learning community, Abbey, Hannah, Melinda, and Olivia all suggest that the teacher should maintain open lines of communication with the student and not only the parents. As Hannah explains, *what you get when you are in front of your parents is going to be a different answer from when it is just you*. Olivia believes that by talking openly with the diabetic student, teachers can *make the kid feel like it is okay, because when you don't talk about it and you don't learn about it, it makes it feel like it is wrong, or that they should be ashamed of it*. In making themselves accessible to their students, teachers can help them deal with the psychological issues of life with diabetes.

Based on the suggestions offered by the participants, it appears that the most important thing that teachers can do for their diabetic students is to remain flexible, sensitive, and aware. Teachers should be sensitive to changes in the students' overall health, behaviours, and needs. Although it is important for teachers to have an

understanding of the wide range of influences diabetes can have over every aspect of life, they must also recognize the subjective nature of the illness experience, and learn specifically about the individual student's needs in the classroom.

#### Future Directions for Diabetes Education

Many programs aimed at increasing the level of understanding surrounding diabetes in schools have proven to be ineffective in increasing the overall knowledge of school personnel (e.g., Cunningham & Wodrich, 2006; Husband et al., 2001). While it may be the method in which information is delivered that is to blame for the poor results (e.g., Mamary & Charles, 2005), the participants in this study suggest that it may instead be the content of these lessons that is lacking. During a brief volunteer stint with the local branch of the Canadian Diabetes Association, Abbey had the opportunity to read through several information sheets that are commonly distributed to schools. Recalling that particular experience, Abbey pointed out the shortfalls of these handouts. *They really need to deal more with the psychological aspects of diabetes, because teachers are insensitive to it.* Olivia and Hannah agree with Abbey, suggesting that there needs to be more of a focus on psychological and social issues surrounding life with diabetes. By shifting the educational content to a broader encompassment of the diabetes experience, it is possible that diabetes educators might be able to increase the teacher's overall understanding of this chronic condition.

Not only did Abbey consider the current diabetes educational materials to be lacking in content, but also found them to be difficult to read. *There were just some things I found were too scientific or too wordy. It sounded as though it was written by some PhD student trying to make it sound complex and wordy.* By focusing on the medical aspects of diabetes, these handouts may have been incorporating too much medical jargon that



was not accessible or known to the untrained reader. By simplifying the text, and reducing the amount of information thrown at the reader, Abbey believes these information sheets would be more accessible to the general population and teachers alike.

Although the recommendations that have been made throughout this thesis may prove to be useful in increasing the overall level of understanding surrounding diabetes in the schools, it is important to remember that they were derived from the experiences of four young women who are in no way representative of the general population of individuals living with diabetes. While Abbey, Olivia, Hannah, and Melinda showed no real difficulties socially, academically, or in maintaining control over their diabetes, it is possible that another individual may exhibit greater difficulties in any or all of these areas. Since the diabetes experience is highly subjective, it is important that teachers are able to speak directly with the student and his or her parents to gain an understanding of the kind of assistance and accommodations the child or adolescent might require in the school setting. In promoting parental, teacher, and student interactions, diabetes educators may experience more success in increasing the level of teacher awareness regarding the needs of diabetic students in the classroom (Jarrett et al., 1993).

#### Suggestions for Further Research

Although this study has provided a glimpse into the lives of four young women living with diabetes, there are many other children and adolescents living with diabetes in Canada who may experience their illness in different ways. By increasing the number of participants and incorporating aspects of observation into a longitudinal study design, it may be possible to acquire a clearer understanding of the experiences of individuals living with this particular chronic illness.

In obtaining an information-rich description of each participant's experience with diabetes, this study has unearthed several topics which require further investigation. Because of the limited number of studies examining the psychological experiences of children and adolescents with diabetes, it is important that future studies focus on the repercussions of depression and of eating disorders in association with this metabolic disorder. While this study focused on the female perspective of life with diabetes, it is also important to explore the experiences of males living with diabetes. Such an inquiry may provide insight into how the female and male experiences of diabetes are similar and different.

One of the interesting findings that came out of this study was that diabetes exerted a large influence over the women's life choices and career decisions. While the four women's similar interests in health-related fields may have been coincidental, it is possible that having a chronic illness influenced their choice of career. By conducting research on career choices of diabetic individuals, it will be possible to discover if there is a common trend toward careers in the helping professions, and whether or not it is necessary to provide chronically ill individuals with career counselling so that they are aware of the wide range of occupational choices available to them.

#### The View from the Outside

When I began my foray into the world of diabetes, it was as if I was peering down a long dark street at a row of houses, wondering what it would be like to live within those four walls. With every paper I read, I moved one small step closer to the threshold of the house. It was not until Abbey, Olivia, Hannah, and Melinda invited me into their lives that I truly began to realise what life could be like with a chronic condition such as diabetes.

Having struggled with my own blood sugar issues, I had expected to hear stories of how difficult it was to live with diabetes, and of how the disease had influenced these women's life events. What I did not expect to hear was that having diabetes was a positive experience that provided a life path and a means for a healthier existence. Abbey, Olivia, Hannah, and Melinda taught me that children with diabetes don't necessarily require help or accommodations from teachers in the school setting, but that teachers should be aware of their needs, sensitive, and ready to act in the case of a medical emergency. Based on their personal experiences, I have come to realise the importance of teachers being flexible, approachable, and knowledgeable.

Having extensively reviewed journal articles on the lived experience of diabetes, I was surprised to find that these four women were not limited by their chronic condition in the ways that other researchers had described. None of them except Olivia struggled with school, and they were all fairly accepting of their illness. Upon studying the shifting perspectives model of illness, I came to realise that it is not necessarily the reality of an illness that dictates the limitations imposed on an individual's abilities, but instead how that individual perceives his or her limitations. Abbey, Hannah, Melinda, and Olivia all believed that they were capable of achieving what they sought to achieve in life, and did not let their diabetes hold them back. These women have taught me that not all exceptional students will fit the textbook description of their exceptionality; these descriptions must be used only as a starting point in coming to understand the needs of students. If teachers are to provide appropriate accommodations for learners in the classroom, they must take the time to speak with the student and the student's parents to identify his or her individual needs. By speaking openly with the student in a friendly

manner, teachers can help pupils come to terms with their own abilities, and set realistic goals for the future.

Abbey, Olivia, Hannah, and Melinda have taught me that diabetes does not have to be seen as an illness or disruptive life event, but that it can be seen as a blessing in disguise— a bittersweet existence. For this valuable insight, I will be forever grateful.

## REFERENCES

- Abdul-Rasoul, M., Habib, H., & Al-Khouly, M. (2006). The honeymoon phase in children with type 1 diabetes mellitus: Frequency, duration, and influential factors. *Pediatric Diabetes, 7*, 101-107.
- Adili, F., Larijani, B., & Haghghatpanah, M. (2006). Diabetic patients: Psychological aspects. *Annals of the New York Academy of Sciences, 1084*, 329-349.
- Anderson, J. C., & McGee, R. (1994). Comorbidity of depression in children and adolescents. In W. M. Reynolds & H. F. Johnson (Eds.), *Handbook of depression in children and adolescents* (pp. 581-601). New York: Plenum.
- Anderson, R. J., Freedland, K. E., Clouse, R. E., & Lustman, P. J. (2001). The prevalence of comorbid depression in adults with diabetes. *Diabetes Care, 24*, 1069-1078.
- Asprey, A., & Nash, T. (2006). The importance of awareness and communication for the inclusion of young people with life-limiting and life-threatening conditions in mainstream schools and colleges. *British Journal of Special Education, 33*(1), 10-18.
- Atkinson, R. (1998). The life story interview. *Sage university papers series on qualitative research methods, 44*. Thousand Oaks, CA: Sage.
- Bearman, K. J., & La Greca, A. M. (2002) Assessing friend support of adolescents' diabetes care: The diabetes social support questionnaire-friends version. *Journal of Pediatric Psychology, 27*, 417-428.
- Boice, M. M. (1998). Chronic illness in adolescence. *Adolescence, 33*, 927-939.
- Britton, C., & Moore, A. (2002). Views from the inside part 2: What children with arthritis said, and the experiences of siblings, mothers, fathers, and grandparents. *British Journal of Occupational Therapy, 65*, 413-419.

- Brown, C., Pikler, V. I., Lavish, L. A., Keune, K. M., & Hutto, C. J. (2008). Surviving childhood leukemia: Career, family, and future expectations. *Qualitative Health Research, 18*, 19-30.
- Bryden, K. S., Neil, A., Mayou, R. A., Peveler, R. C., Fairburn, C. G., & Dunger, D. B. (1999). Eating habits, body weight, and insulin misuse: A longitudinal study of teenagers and young adults with type 1 diabetes. *Diabetes Care, 22*, 1956-1960.
- Bryden, K., Neil, A., Peveler, R., Mayou, R., Stein, A., & Dunger, D. (2001). Clinical and psychological course of diabetes from adolescence to young adulthood. *Diabetes Care, 24*, 1536-1540.
- Buki, L. P., Kogan, L., Keen, B., & Uman, P. (2005). In the midst of a hurricane: A case study of a couple living with AIDS. *Journal of Counseling & Development, 83*, 470-479.
- Bury, M. (1982). Chronic illness as a biographical disruption. *Sociology of Health and Illness, 4*, 167-182.
- Canadian Diabetes Association. (2008). *Children in School*. Retrieved on May 1, 2008 from [www.diabetes.ca/section\\_advocacy/advchildren.asp](http://www.diabetes.ca/section_advocacy/advchildren.asp)
- Canadian Diabetes Association. (2007). *Incidence of type 1 diabetes in Canada*. Retrieved on May 3, 2007 from [www.diabetes.ca/lit/diabetes\\_answers/what\\_is\\_type\\_1\\_diabetes/risk\\_factors\\_for\\_type\\_1\\_diabetes.aspx](http://www.diabetes.ca/lit/diabetes_answers/what_is_type_1_diabetes/risk_factors_for_type_1_diabetes.aspx)
- Canadian Diabetes Association. (1994). *Standards of care for students with type 1 diabetes in school*. Retrieved December 7, 2006 from [www.limestone.on.ca/parents/documents/health\\_issues.pdf](http://www.limestone.on.ca/parents/documents/health_issues.pdf)

- Carroll, A. E., & Marrero, D. G. (2006). The role of significant others in adolescent diabetes a qualitative study. *The Diabetes Educator, 32*, 243-252.
- Charmaz, K. (2002). Stories and Silences: Disclosures and self in chronic illness. *Qualitative Inquiry, 8*, 302-328.
- Charmaz, K. (1995). The body, identity, and self: Adapting to impairment. *The Sociological Quarterly, 36*, 657-680.
- Cheung, R. N., Young, C. V., & Canham, D. L. (2006). Quality of life in adolescents with type 1 diabetes who participate in diabetes camp. *The Journal of School Nursing, 22*(1), 53-58.
- Christian, B. J., D'Auria, J. P., & Fox, L. C. (1999). Gaining freedom: Self-responsibility in adolescents with diabetes. *Pediatric Nursing, 25*, 225-260.
- Ciechanowski, P., Katon, W., & Russo, J. (2000). Depression and diabetes: Impact of depression on adherence, function, and cost. *Archives of International Medicine, 160*, 3265-3278.
- Collie, K., & Long, B. C. (2005). Considering meaning in the context of breast cancer. *Journal of Health and Psychology, 10*, 843-853.
- Colton, P., Olmsted, M., Daneman, D., Rydall, A., & Rodin, G. (2004). Disturbed eating behaviour and eating disorders in preteen and early teenage girls with type 1 diabetes. *Diabetes Care, 27*, 1654-1659.
- Colton, P., Olmsted, M., Daneman, D., Rydall, A., & Rodin, G. (2007). Five-year prevalence and persistence of disturbed eating behaviour and eating disorders in girls with type 1 diabetes. *Diabetes Care, 30*, 2861-2862.
- Cox, D. J., & Gonder-Frederick, L. (1992). Major developments in behavioural diabetes research. *Journal of Consulting and Clinical Psychology, 60*, 628-638.

- Cunningham, M. M., & Wodrich, D. (2006). The effect of sharing health information on teacher's production of classroom accommodations. *Psychology in the Schools, 43*, 553-564.
- Dabadghao, P., Vidmar, S., & Cameron, F. J. (2001). Deteriorating diabetic control through adolescence—do the origins lie in childhood? *Diabetic Medicine, 18*, 889-894.
- Daley, K. B., Wodrich, D. L., & Hasan, K. (2006). Classroom attention in children with type 1 diabetes mellitus: The effect of stabilizing serum glucose. *Journal of Pediatrics, 148*, 201-206.
- Davidson, M., Penney, E. D., Muller, B., & Grey, M. (2004). Stressors and self-care challenges faced by adolescents living with type 1 diabetes. *Applied Nursing Research, 17*(2), 72-80.
- De-Graft Aikins, A. (2003). Living with diabetes in rural and urban Ghana: A critical social psychological examination of illness action and scope for intervention. *Journal of Health Psychology, 8*, 557-572.
- De Groot, M., Anderson, R., Freedland, K. E., Clouse, R. E., & Lustman, P. J. (2001). Association of depression and diabetes complications: A meta-analysis. *Psychosomatic Medicine, 63*, 619-630.
- DePaepe, P., Garrison-Kane, L., & Doelling, J. (2002). Supporting students with health needs in schools: An overview of selected health conditions. *Focus on Exceptional Children, 35*(1), 1-24.
- Diabetes Control and Complications Trial Research Group [DCCT]. (1993). The effect of intensive treatment of diabetes on the development and progression of long term



complications in the diabetes control in insulin dependent diabetes mellitus. *New England Journal of Medicine*, 329, 977-983.

Douglass, W. A. (2000). In search of Jaun de Onate: Confessions of a cryptoessentialist.

*Journal of Anthropological Research*, 56, 137-162.

Dovey-Pearce, G., Doherty, Y., & May, C. (2007). The influence of diabetes upon

adolescent and young adult development: A qualitative study. *British Journal of Health Psychology*, 12, 75-91.

Du Pasquier-Fediaevsky, L., Chwalow, A. J., & Tubiana-Rufi, N. (2005). Is the

relationship between adherence behaviours and glycaemic control bi-directional at adolescence? A longitudinal cohort study. *Diabetes Medicine*, 22, 427-433.

Egede, L. E., & Zheng, D. (2003). Independent factors associated with major depressive

disorder in a national sample of individuals with diabetes. *Diabetes Care*, 26, 104-111.

Engum, A., Mykletun, A., Midthjell, K., Holen, A., & Dahl, A. A. (2005). A large

population-based study of sociodemographic, lifestyle, and clinical factors associated with depression in type 1 and type 2 diabetes. *Diabetes Care*, 28, 1904-1909.

Erikson, E. (1968). *Identity: Youth and crisis*. New York: W. W. Norton Company.

Faircloth, C. A., Boylstein, C., Rittman, M., Young, M. E., & Gubrium, J. (2004). Sudden

illness and biographical flow in narratives of stroke recovery. *Sociology of Health & Illness*, 26, 242-261.

Falsetti, D., Charron-Prochownik, D., Serelka, S., Kitutu, J, Peterson, K., Becker, D., et

al., (2003). Condom use, pregnancy, and STDs in adolescent females with and without type 1 diabetes. *The Diabetes Educator*, 29, 135-143.

- Faro, B. (1999). The effect of diabetes on adolescents' quality of life. *Pediatric Nursing*, 25, 247-253.
- Fernandez-Sierra, J. (1998). Psycho-educational action for teenagers with diabetes. *British Journal of Guidance & Counselling*, 26, 449-461.
- Feudtner, J. C. (2003). *Bittersweet: Diabetes, insulin, and the transformation of illness*. Chapel Hill: The University of North Carolina Press.
- Flaton, R. A. (2006). "Who would I be without Danny?" Phenomenological case study of an adult sibling. *Mental Retardation*, 44, 135-144.
- Frey, M. A., Guthrie, B., Loveland-Cherry, C., Park, P. S., & Foster, C. M. (1997). Risky behaviour and risk in adolescents with IDDM. *Journal of Adolescent Health*, 20, 38-45.
- Furman, W., & Buhrmester, D. (1992). Age and sex differences in perceptions of networks of personal relationships. *Child Development*, 63, 103-115.
- Gesteland, H. M., Sims, S., & Lindsay, R. N. (1989). Evaluation of two approaches to educating elementary schoolteachers about insulin-dependent diabetes mellitus. *The Diabetes Educator*, 15, 510-513.
- Goldman, J. B., & Maclean, H. M. (1998). The significance of identity in the adjustment to diabetes among insulin users. *The Diabetes Educator*, 24, 741-748.
- Goldston, D. B., Kelley, A. E., Reboussin, D. M., Daniel, S. S., Smith, J., Schwartz, R., et al. (1997). Suicidal ideation and behaviour and noncompliance with the medical regimen among diabetic adolescents. *Journal of the American Academy of Child and Adolescent Psychiatry*, 36, 1528-1536.
- Goldston, D. B., Kovacs, M., Ho, V., Parrone, P., & Stiffler, L. (1994). Suicidal ideation and suicide attempts among youth with insulin dependent diabetes mellitus.

*Journal of the American Academy of Child and Adolescent Psychiatry*, 33, 240-246.

Gormanous, M., Hunt, A., Pope, J., & Gerald, B. (2002). Lack of knowledge among Arkansas public elementary teachers: Implications for dieticians. *Journal of the American Dietician Association*, 102, 1136-1139.

Gould, B. E. (2002). *Pathophysiology for the health professions*. Philadelphia: W.B. Saunders Company.

Greco, P., Pendley, J. S., McDonell, K., & Reeves, G. (2001). A peer group intervention for adolescents with type 1 diabetes and their best friends. *Journal of Pediatric Psychology*, 26, 485-490.

Groleau, D., Young, A., & Kirmayer, L. J. (2006). The McGill Illness Narrative Interview (MINI): An interview schedule to elicit meanings and modes of reasoning related to illness experience. *Transcultural Psychiatry*, 43, 671-691.

Hains, A. A., Berlin, K. S., Hobart Davies, W., Parton, E. A., & Alemzadeh, R. (2006). Attributions of adolescents with type 1 diabetes in social situations: Relationship with expected adherence, diabetes stress, and metabolic control. *Diabetes Care*, 29, 818-822.

Hannon, T. S., Janosky, J., & Arslanian, S. A. (2006). Longitudinal study of physiologic insulin resistance and metabolic changes of puberty. *Pediatric Research*, 60, 759-763.

Havighurst, R. (1972). *Developmental tasks and education* (3<sup>rd</sup> ed.). New York: Longman.

- Hayes-Bohn, R., Neumark-Sztainer, D., Mellin, A., & Patterson, J. (2004). Adolescent and parent assessments of diabetes mellitus management at school. *Journal of School Health, 74*, 166-169.
- Helgeson, V. S., Reynolds, K. A., Shestak, A., & Wei, S. (2006). Brief report: Friendships of adolescents with and without diabetes. *Journal of Pediatric Psychology, 31*, 194-199.
- Hilsman, R., & Garber, J. (1995). A test of the cognitive diathesis-stress model of depression in children: Academic stressors, attributional style, perceived competence, and control. *Journal of Personality & Social Psychology, 69*, 370-380.
- Hood, K. K., Huestis, S., Maher, A., Butler, D., Volkening, L., & Laffel, L. M. (2006). Depressive symptoms in children and adolescents with type 1 diabetes. *Diabetes Care, 29*, 1389-1391.
- Hopkins, D. (2004). Exercise-induced and other daytime hypoglycemic events in patients with diabetes: Prevention and treatment. *Diabetes Research and Clinical Practice, 65*(5), 35-39.
- Husband, A., Pacaud, D., Grebenc, K., & McKiel, E. (2001). The effectiveness of a CD-ROM in educating teachers who have a student with diabetes. *Canadian Journal of Diabetes Care, 25*, 286-290.
- Hwang, E. J., Kim, Y. H., & Jun, S. S. (2004). Lived experience of Korean women suffering from rheumatoid arthritis: A phenomenological approach. *International Journal of Nursing Studies, 41*, 239-246.
- International Diabetes Federation. (2007). *Diabetes facts and figures*. Retrieved February 22, 2007 from [www.idf.org/home/index.cfm?node=6](http://www.idf.org/home/index.cfm?node=6).

- Jack, L. (2003). Biopsychosocial factors affecting metabolic control among female adolescents with type 1 diabetes. *Diabetes Spectrum, 16*, 154-159.
- Jarrett, L., Hillam, K., Bartsch, C., & Lindsay, R. (1993). The effectiveness of parents teaching elementary school teachers about diabetes mellitus. *The Diabetes Educator, 19*, 193-197.
- Jones, J. M., Lawson, M. L., Daneman, D., Olmsted, M. P., & Rodin, G. (2000). Eating disorders in adolescent females with and without type 1 diabetes: Cross sectional study. *British Medical Journal, 320*, 1563-1566.
- Kaufman, F. R. (2006). Consequences of weight gain associated with insulin therapy in adolescents. *Endocrinologist, 16*, 155-162,
- Kelly, S. D., Howe, C. J., Hendler, J. P., & Lipman, T. H. (2005). Disordered eating behaviours in youth with type 1 diabetes. *The Diabetes Educator, 31*, 572-583.
- Kirscht, J. P., Haefner, D., Kegeles, S., & Rosenstock, I. (1966). A national study of health beliefs. *Journal of Health and Human Behaviour, 3*, 248-254.
- Koopman, R. J., Mainous, A. G., & Jeffcoat, A. S. (2004). Moving from undiagnosed to diagnosed diabetes: The patient's perspective. *Family Medicine, 36*, 727-732.
- Korbel, C. B., Wiebe, D. J., Berg, C. A., & Palmer, D. L. (2007). Gender differences in adherence to type 1 diabetes management across adolescence: The mediating role of depression. *Children's Health Care, 36*, 83-98.
- Kovacs, M., Goldston, D., & Iyengar, S. (1992). Intellectual development and academic performance of children with Insulin-Dependent Diabetes Mellitus: A longitudinal study. *Developmental Psychology, 28*, 676-684.

- Kovacs, M., Iyengar, S., Goldston, D., Stewart, J., Obrosky, D. S., & Marsh, A. (1990). Psychological functioning of children with insulin-dependent diabetes mellitus: A longitudinal study. *Journal of Pediatric Psychology, 15*, 619-632.
- Krumboltz, J. D. (1979). A social learning theory of career decision making. In A. M. Mitchell, G. B. Jones, & J. D. Krumboltz (Eds.), *Social learning and career decision making* (pp. 19-49). Cranston, RI: Carroll.
- La Greca, A. M., Swales, T., Klemp, S., Madigan, S., & Skyler, J. (1995). Adolescents with diabetes: Gender differences in psychosocial functioning and glycemic control. *Children's Health Care, 24*, 61-78.
- LaRusso, M. D., Romer, D., & Selman, R. L. (2007). Teachers as builders of respectful school climates: Implications for adolescent drug use norms and depressive symptoms in high school. *Journal of Youth and Adolescence, 37*, 386-398.
- Lavigne, J. V., & Faier-Routman, J. (1992). Psychological adjustment to pediatric physical disorders: A meta-analytic review. *Journal of Pediatric Psychology, 17*, 113-157.
- Leung, P., & Bryant, R. A. (2000). Autobiographical memory in diabetes mellitus patients. *Journal of Psychosomatic Research, 49*, 435-438.
- Lewinsohn, P. M., Clarke, G. N., Seeley, J. R., & Rohde, P. (1994). Major depression in community adolescents: Age at onset, episode, duration, and time to recurrence. *Journal of the American Academy of Child & Adolescent Psychiatry, 33*, 809-818.
- Lightfoot, J., Mukherjee, S., & Sloper, P. (2001). Supporting pupils with special health needs in mainstream schools: Policy and practice. *Children & Society, 15*(2), 57-69.

- Limestone District School Board. (2006). *Health issues handbook*. Retrieved December 7, 2006 from [www.limestone.on.ca/parents/documents/health\\_issues.pdf](http://www.limestone.on.ca/parents/documents/health_issues.pdf).
- Lo, R., & MacLean, D. (2001). The dynamics of coping and adapting to the impact when diagnosed with diabetes. *Australian Journal of Advanced Nursing, 19*(2), 26-32.
- Lustman, P., & Clouse, R. (2005). Depression in diabetic patients: The relationship between mood and glycemic control. *Journal of Diabetes and its Complications, 19*, 113-122.
- Lustman, P., Griffith, L. S., Freedland, K. E., & Clouse, R. E. (1997). The course of major depression in diabetes. *General Hospital Psychiatry, 19*, 138-143.
- Madsen, S. D., Roisman, G. I., & Collins, W. A. (2002). The intersection of adolescent development and intensive intervention: Age-related psychosocial correlates of treatment regimens in the Diabetes Control and Complication Trial. *Journal of Pediatric Psychology, 27*, 451-459.
- Mamary, E. M., & Charles, P. (2005). On-site to on-line: Barriers to the use of computers for continuing education. *Journal of Continuing Education in the Health Professions, 20*, 171-175.
- Mayou, R., Bryant, B., & Turner, R. (1990). Quality of life in non-insulin-dependent diabetes and a comparison with insulin-dependent diabetes. *Journal of Psychosomatic Research, 34*, 1-11.
- McMillan, J. H., & Schumacher, S. (2006). *Research in education: Evidence-based inquiry* (6<sup>th</sup> ed.). New York: Pearson Education.
- Meltzer, L. J., Bennett Johnson, S., Prine, J. M., Banks, R. A., Desrosier, P. M., & Silverstein, J. H. (2001). Disordered eating, body mass, and glycemic control in adolescents with type 1 diabetes. *Diabetes Care, 24*, 678-682.

- Moor, S., Macguire, A., McQueen, H., Wells, J. E., Elton, R., Wrate, R., et al. (2007). Improving the recognition of depression in adolescence: Can we teach the teachers?. *Journal of Adolescence*, *30*, 81-95.
- Moustakas, C. (1994). *Phenomenological research methods*. Thousand Oaks, CA: Sage.
- Mu, P. F., & Tomlinson, P. (1997). Parental experience and meaning construction during a pediatric health crisis. *Western Journal of Nursing Research*, *19*, 608-636.
- Mukherjee, S., Lightfoot, J., & Sloper, P. (2000). The inclusion of pupils with a chronic health condition in mainstream school: What does it mean for teachers?. *Educational Research*, *42*(1), 59-72.
- Nabors, L., Lehmkuhl, H., Christos, N., & Andreone, T. L. (2003). Children with diabetes: Perceptions of supports for self-management at school. *The Journal of School Health*, *73*, 216-221.
- Neil-Urban, S., & Jones, J. B. (2002). Father-to-father support: Fathers of children with cancer share their experience. *Journal of Pediatric Oncology Nursing*, *19*(3), 97-103.
- Nelson, J. E., et al. (2007). Communication about chronic critical illness. *Archives of International Medicine*, *167*, 2509-2515.
- Nichols, P. J. (2002). A systematic literature review of the effectiveness of diabetes education of school personnel. *The Diabetes Educator*, *28*, 405-414.
- Nolen-Hoeksema, S. (2001). Gender differences in depression. *Current Directions in Psychological Science*, *10*, 173-176.
- Ontario Code of Human Rights. (2005). Retrieved December 7, 2007 from [www.ohrc.on.ca/english/code/index.shtml](http://www.ohrc.on.ca/english/code/index.shtml)



- Ontario Education Act. (1990). Retrieved July 19, 2007 from [http://www.e-laws.gov.on.ca/html/statutes/english/elaws\\_statutes\\_90e02\\_e.htm](http://www.e-laws.gov.on.ca/html/statutes/english/elaws_statutes_90e02_e.htm)
- Ontario Teachers' Federation (1996). *We the teachers of Ontario* (18<sup>th</sup> ed.). Toronto, ON: Ontario Teacher's Federation.
- Ottawa-Carleton District School Board. (2002). *Diabetes management in schools*. Retrieved December 7, 2006 from [www.ocdsb.edu.on.ca/Policies\\_Procedures/PR%20632%20sc0%20Diabetes%20Mgmt](http://www.ocdsb.edu.on.ca/Policies_Procedures/PR%20632%20sc0%20Diabetes%20Mgmt)
- Ott, J., Greening, L., Palardy, N., Holdreby, A., & DeBell, W. (2000). Self-efficacy as a mediator variable for adolescents—Adherence to treatment for insulin-dependent diabetes mellitus. *Child Health Care, 29*(1), 47-63.
- Palmer, D. L., Berg, C. A., Weibe, D. J., Beveridge, R. M., Korbel, C. D., Upchurch, R., et al. (2004). The role of autonomy and pubertal status in understanding age differences in maternal involvement in diabetes responsibility across adolescence. *Journal of Pediatric Psychology, 29*, 35-46.
- Paterson, B. L. (2003). The koala has claws: Applications of the shifting perspectives model in research of chronic illness. *Qualitative Health Research, 13*, 987-994.
- Paterson, B. L. (2001). The shifting perspectives model of chronic illness. *Journal of Nursing Scholarship, 33*(1), 21-26.
- Paterson, B., Thorne, S., Crawford, J., & Tarko, M. (1999). Living with diabetes as a transformational experience. *Qualitative Health Research, 9*, 786-802.
- Patton, M. Q. (2002). *Qualitative research and evaluation methods* (3<sup>rd</sup> ed.). Thousand Oaks, CA: Sage.

- Public Health Agency of Canada. (1999). *Diabetes in Canada; National statistics and opportunities for improved surveillance, prevention, and control*. Retrieved April 14, 2008 from [http://www.phac-aspc.gc.ca/publicat/dic-dac99/d04\\_e.html](http://www.phac-aspc.gc.ca/publicat/dic-dac99/d04_e.html)
- Raile, K., Kapellen, T., Schweiger, A., Hunkert, F., Nietzsche, U., Dost, A., & Kiess, W. (1999). Physical activity and competitive sports in children and adolescents with type 1 diabetes. *Diabetes Care*, *22*, 1904-1905.
- Rasmussen, B., O'Connell, B., Dunning, P., & Cox, H. (2007). Young women with type 1 diabetes' management of turning points and transitions. *Qualitative Health Research*, *17*, 300-310.
- Rodin, G., Olmsted, M. P., Rydall, A. C., Maharaj, S. I., Colton, P. A., Jones, J. M., Bianucci, L. A., & Daneman, D. (2002). Eating disorders in young women with type 1 diabetes mellitus. *Journal of Psychosomatic Research*, *53*, 943-949.
- Rovet, J. F., & Alvarez, M. (1997). Attentional functioning in children and adolescents with IDDM. *Diabetes Care*, *20*, 803-810.
- Rovet, J. F., Ehrlich, R. M., Czuchta, D., & Akler, M. (1993). Psychoeducational characteristics of children and adolescents with insulin-dependent diabetes mellitus. *Journal of Learning Disabilities*, *26*, 7-22.
- Ryan, C. M., Atchison, J., Puczynski, S., Puczynski, M., Arslanian, S., & Becker, D. (1990). Mild hypoglycemia associated with deterioration of mental efficiency in children with insulin-dependent diabetes mellitus. *Journal of Pediatrics*, *117*, 32-38.
- Rydall, A. C., Rodin, G. M., Olmsted, M. P., Devenyi, R. G., & Daneman, D. (1997). Disordered eating behaviour and microvascular complications in young women

with insulin-dependent diabetes mellitus. *New England Journal of Medicine*, 336, 1849-1854.

Sabrina's Law. (2005). Retrieved January 10, 2008 from [http://www.e-laws.gov.on.ca/html/statutes/english/elaws\\_statutes\\_05s07\\_e.htm](http://www.e-laws.gov.on.ca/html/statutes/english/elaws_statutes_05s07_e.htm)

Sacks, O. (1987). *Awakenings*. New York: Summit Books.

Schroff Pendley, J., Kasmien, L. J., Miller, D. L., Donze, J., Swenson, C., & Reeves, G. (2002). Peer and family support in children and adolescents with type 1 diabetes. *Journal of Pediatric Psychology*, 27, 429-438.

Schur, H. V., Gamsu, D. S., & Barley, V. M. (1999). The young person's perspective on living and coping with diabetes. *Journal of Health Psychology*, 4, 223-236.

Seidman, I. E. (1991). *Interviewing as qualitative research: A guide for researchers in education and the social sciences*. New York: Teachers College Press.

Seiffge-Krenke, I. (1998). Chronic disease and perceived developmental progression in adolescence. *Developmental Psychology*, 34, 1073-1084.

Seiffge-Krenke, I. (2002). "Come on, say something dad!": Communication and coping in fathers of diabetic adolescents. *Journal of Pediatric Psychology*, 27, 439-470.

Shannon, C., Story, M., Fulkerson, J. A., & French, S. A. (2002). Factors in the school cafeteria influencing food choices by high school students. *Journal of School Health*, 72, 229-234.

Sharpe, L., & Curran, L. (2006). Understanding the process of adjustment to illness. *Social Science & Medicine*, 62, 1153-1166.

Silverthorn, D. U. (2001). *Human physiology: An integrated approach* (2<sup>nd</sup> ed.). Upper Saddle River, NJ: Prentice Hall.

- Sommerfield, A. J., Deary, I. J., McCaulay, V., & Frier, B. M. (2003). Short-term, delayed, and working memory are impaired during hypoglycemia in individuals with type 1 diabetes. *Diabetes Care*, *26*, 390-396.
- Stewart, S. M., Rao, U., Emslie, G. J., Klein, D., & White, P. C. (2005). Depressive symptoms predict hospitalization for adolescents with type 1 diabetes mellitus. *Pediatrics*, *115*, 1315-1319.
- The Quotations Page (2007). *Quotations from Richard Feynman*. Retrieved on February 6<sup>th</sup>, 2007 from [www.quotationspage.com/quote/26933.html](http://www.quotationspage.com/quote/26933.html).
- Thomas, G. (2006). Do I have to administer medicine to my student? *ATA News*, *40*(14), 2-3.
- Thorne, S., Paterson, B., Acorn, S., Canam, C., Joachim, G., & Jillings, C. (2002). Chronic illness experience: Insights from a metastudy. *Qualitative Health Research*, *12*, 437-452.
- Tilden, B., Charman, D., Sharples, J., & Fosbury, J. (2005). Identity and adherence in a diabetes patient: Transformations in psychotherapy. *Qualitative Health Research*, *15*, 312-324.
- Touchette, N. (2002). Kids and type 2 diabetes. *Diabetes Forecast*, *53*(11), 79-84.
- Urquhart Law, G. (2002). Dissimilarity in adolescent and maternal representations of type 1 diabetes: Exploration of relations to adolescent well-being. *Child: Care, Health, and Development*, *28*, 369-378.
- Valdovinos, M., & Weyland, D. (2006). Blood glucose levels and problem behaviour. *Research in Developmental Disabilities*, *27*, 227-231.
- van Manen, M. (1990). *Researching the lived experience*. London, ON: Transcontinental Printing.

- Van Tilburg, M. A., McCaskill, C. C., Lane, J. D., Edwards, C. L., Bethel, A., Feinglos, M. N., et al. (2001). Depressed mood is a factor in glycemic control in type 1 diabetes. *Psychosomatic Medicine*, *63*, 551-555.
- Verhulst, F. C., Koot, H. M., Van Der Ende, J. (1994). Differential predictive value of parents' and teachers' reports of children's problem behaviours: A longitudinal study. *Journal of Abnormal Child Psychology*, *22*, 531-545.
- Wagner, J., Heapy, A., James, A., & Abbot, G. (2005). Brief report: Glycemic control, quality of life, and school experiences among students with diabetes. *Journal of Pediatric Psychology* *31*, 764-769.
- Warren, R. E., Deary, I. J., & Frier, B. M. (2003). The symptoms of hyperglycemia in people with insulin-treated diabetes: Classification using principal components analysis. *Diabetes/Metabolism Research and Reviews*, *19*, 408-414.
- Wechsler, H., Brener, N. D., Kuester, S., & Miller, C. (2001). Food service and food and beverages available at school: Results from the school health policies and programs study. *Journal of School Health*, *71*, 313-324.
- Weekes, D. P. (1995). Adolescents growing up chronically ill: A life-span developmental view. *Family & Community Health*, *17*(4), 22-34.
- White, N. H., Cleary, P. A., Dahms, W., Goldstein, D., Malone, J., & Tamborlane, W. V. (2001). Beneficial effects of intensive therapy of diabetes during adolescence: outcomes after the conclusions of the Diabetes Control and Complications Trial. *Journal of Pediatrics*, *139*, 804-812.
- Wiebe, D. J., Berg, C. A., Korbel, C., Palmer, D. L., Beveridge, R. M., Upchurch, R., et al. (2005). *Journal of Pediatric Psychology*, *30*, 167-178.

- Williams, G. C., Freedman, Z., & Deci, E. L. (1998). Supporting autonomy to motivate patients with diabetes for glucose control. *Diabetes Care*, 21, 1644-1651.
- Williams, S. J. (2000). Chronic illness as biographical disruption or biographical disruption as chronic illness? Reflections on a core concept. *Sociology of Health & Illness*, 22, 40-67.
- Witherell, C., & Noddings, N. (1991). *Stories lives tell: Narrative and dialogue in education*. New York: Teachers College Press.
- Wysocki, T. (1993). Associations among teen-parent relationships, metabolic control, and adjustment to diabetes. *Journal of Pediatric Psychology*, 18, 441-452.
- Yazak, D. (1998). *Chronic illness and school to work transition*. Retrieved on May 12, 2008 from [http://eric.ed.gov/ERICDocs/data/ericdocs2sql/content\\_storage\\_01/0000019b/80/15/23/0c.pdf](http://eric.ed.gov/ERICDocs/data/ericdocs2sql/content_storage_01/0000019b/80/15/23/0c.pdf)
- Zambanini, A. (2003). Injection related anxiety in insulin-treated diabetes. *Diabetes Research and Clinical Practice*, 46, 239-246.

## APPENDIX A: EMAIL LETTER OF RECRUITMENT

## Living with Type 1 Diabetes Mellitus: A Phenomenological Study

Dear \_\_\_\_\_,

I am a graduate student in the Faculty of Education at Queen's University, and am currently working on my Master's of Education thesis. I am writing to request your participation in a study entitled Living with Type 1 Diabetes Mellitus: A Phenomenological Study. Like you, I attended the Canadian Diabetes Youth Advocacy Workshop 2007 in Toronto, and obtained your email address from the contact list of individuals attending this workshop.

Recent studies show that teachers and peers of children and adolescents with type 1 diabetes often lack an understanding of this chronic illness and how it affects the individual. Although there have been several programs designed to increase the level of diabetes awareness among school staff and students, these programs are often unable to meet the goal of increasing diabetes awareness. The purpose of my study is to gain an understanding of what it has been like for four young adults to live with type 1 diabetes. In listening to each person's experiences inside and outside of the classroom setting, I hope to learn more about how diabetes affects everyday life, and what teachers and peers can do to help students with diabetes within the classroom.

I am looking for participants who are 18-25 years of age, reside in Ontario, and who were diagnosed with type 1 diabetes during either elementary school or high school. Participants must be willing to share their personal experience of living with diabetes, and provide suggestions as to how teachers and peers can support individuals with type 1 diabetes in the classroom. Your decision to participate in this study is entirely voluntary, and you are able to withdraw from the study at any time without consequence.

Participation in this research would involve one interview lasting approximately 90 minutes, with the possibility of a follow-up interview if there are any questions requiring elaboration or clarification. The interview would take place at your convenience in your hometown at a location of your choice.

If you are interested in participating in this research, please contact Kate Walker at 613-547-3043, or by email at [Oktw@qlink.queensu.ca](mailto:Oktw@qlink.queensu.ca) within **one week** of receiving this email. Should you choose to participate, I will send you a letter of information and consent form, providing you with additional details regarding the study.

Yours Sincerely,

Kate Walker

## APPENDIX B: LETTER OF INFORMATION

Title: Living with Type 1 Diabetes Mellitus: A Phenomenological Study

I am a graduate student in the Faculty of Education at Queen's University, Kingston, ON, and am currently working on my Master's of Education thesis. I am writing to request your participation in research aimed at understanding the experience of living with type 1 diabetes. The ultimate goal of this research is to learn what it is like to live with this chronic illness on a daily basis, and what teachers and peers can do to support a student with type 1 diabetes in the school setting.

In this research, I wish to document a first-hand account of an individual who is currently living with type 1 diabetes. I am looking for participants who are between the ages of 18-25 years, and who were diagnosed with type 1 diabetes while in elementary school or high school.

If you agree to participate in this study, you will be asked to take part in one interview lasting approximately 90 minutes, with the possibility of a follow-up interview in the event that any responses require clarification. Interviews will be scheduled at your convenience, and will occur at a neutral location of your choice. The interviews will be audiotaped, and will be typed on the computer along with any notes taken by the researcher during the interview. A pseudonym will be applied to the transcripts following the interview, and none of the data will contain your name. Data will be kept in a secure location in the researcher's residence, and will be accessible only to the researcher and her thesis committee.

There are no foreseen risks in your participation in this research. Your participation is entirely voluntary, and you are free to withdraw from the study without consequence. If there are any questions you find objectionable, you are not required to answer them. No remuneration will be offered for your participation.

This research may result in publications of various types including my master's thesis, journal articles, books, or instructional materials. Your name will not be attached to any form of the data that you provide.

Should you require further information before making a decision about participation, please feel free to contact me, Kate Walker, at 613-547-3043 (oktw@qmlink.queensu.ca), or my supervisor, Dr. Nancy Hutchinson, at 613-533-3025 (hutchinn@educ.queensu.ca).

Questions, concerns, or complaints about the research ethics of this study should be directed towards the Dean of the Faculty of Education, Dr. Rosa Bruno-Jofré, (613) 533-6210 (brunojor@educ.queensu.ca) or the Chair of the Queen's University General Research Ethics Board, Dr. Stephen Leighton, (613) 533-6081 (greb.chair@queensu.ca).

Yours Sincerely,  
Kate Walker



## APPENDIX C: CONSENT FORM

- I agree to participate in the study entitled Living with Type 1 Diabetes Mellitus: A Phenomenological Study, conducted by Kate Walker through the Faculty of Education at Queen's University.
- I have read and retained a copy of the Letter of Information and Consent Form, and the purpose of the study is explained to my satisfaction.
- I have had any questions answered to my satisfaction.
- I understand that, upon request, I may have a full description of the results of the study after its completion.
- I understand that the researchers intend to publish the findings of the study.
- I understand that participation is voluntary, and that I am free to withdraw from this study at any time without negative consequences.
- I have been assured that confidentiality will be maintained, and that my name will not be attached to any form of the data.
- I am aware that if I have any questions about this study I can contact the researcher, Kate Walker, at 613-547-3043 (oktw@qmlink.queensu.ca), or I can contact her supervisor, Dr. Nancy Hutchinson, at 613-533-3025(hutchinn@educ.queensu.ca). I am also aware that for any questions, concerns, or complaints about the research ethics of this study, I may contact the Dean of the Faculty of Education, Dr. Rosa Bruno-Jofré, at 613-533-6210 (brunojor@educ.queensu.ca) or the Chair of the Queen's University General Research Ethics Board, Dr. Stephen Leighton, at 613-533-6081 (greb.chair@queensu.ca).
- **Please sign one copy of this Consent Form and return to Kate Walker. Retain the second copy for your records.**

I HAVE READ AND UNDERSTOOD THIS CONSENT FORM AND I AGREE TO PARTICIPATE IN THE STUDY.

Name (Please Print): \_\_\_\_\_

Signature: \_\_\_\_\_

Date: \_\_\_\_\_ telephone number: \_\_\_\_\_

## APPENDIX D: INTERVIEW GUIDE

### Interview Questions for Individual Diagnosed During Elementary School

N. B.: Questions that are bolded are the main questions to be asked of each participant. The questions underneath are optional, and should only be asked if the participant has not already answered them.

#### Background information

**1. Please tell me a bit about yourself, and your background in relation to your diabetes. I am interested in things like your age of diagnosis, and how diabetes has contributed to who you are as a person.**

- How old are you?
- When were you diagnosed with type 1 diabetes?
- How many people are in your family?

**2. When you talk about type 1 diabetes, what is it that you are talking about?**

- What does diabetes mean to you?
- How would you describe type 1 diabetes to someone who is not familiar with this condition?

#### Pre-diagnosis Questions

**1. Please think back to the years before you were diagnosed with type 1 diabetes. What was your life like before you had diabetes?**

- What memories do you have from before you had diabetes?
- How was your life different back then?

#### Diagnosis Questions

**1. When did you realise that you had diabetes? Please describe this experience.**

- What physical or medical changes were you experiencing?
- What were you going through emotionally?
- How did others in your life react during this time period?
- What got you through this difficult time?
- What was your visit to the hospital like?
- How did your diagnosis change how you saw yourself? How others saw you?
- Who helped you with your management regimen during the initial months following your diagnosis?

#### Elementary School Questions

**1. How did your family, friends, and teachers react when you were first diagnosed with diabetes?**

- How did they cope with your diabetes?
- Were you aware of what was going on? Did you really understand it?

**2. What was it like for you to have diabetes during the elementary school years?**

- Socially
  - Did people know about your diabetes at school? If so, how did they react?
  - Who taught your classmates about diabetes? The teacher or your parents?

- Did anyone else in your school have diabetes?
- What are some of the struggles you faced? What are some of the triumphs?
- How did your friends support or impede the management process?
- Academically
  - Please describe your academic achievements during the elementary school years.
    - Do you feel that your overall health played a role in your academic achievements?
    - Did you feel that your teachers and peers were knowledgeable about diabetes?
    - How did your teachers help you during this time? What could they have done better to help you?
    - What do you remember learning about diabetes growing up?
  - What types of things in the school made it harder for you to manage your diabetes? What made it easier?
- Emotionally
  - How did it make you feel dealing with diabetes at such a young age?
  - Did you really understand what was going on?
  - Did your diabetes affect your childhood? How did it make you feel?
- Medically
  - How did you manage your diabetes while at school?
    - Would you have done blood testing in front of other children? If so, how did they react?
    - Did you have to have insulin injections while at school?
    - How did you manage your diet through the school day?
    - How much exercise did you have while at school? How did you manage your diabetes in gym class?
    - Did you have any serious episodes of hypoglycemia while at school?
    - You probably had some interesting experiences while at school. Can you recall any of them?

### Secondary School Questions

#### **1. Tell me about your experiences moving to a secondary school.**

- Academic
  - How did you do in school?
  - Did your diabetes affect your overall achievement?
  - Were the staff and students at your school knowledgeable about diabetes?
  - Please describe your school environment. Was it conducive to managing your diabetes effectively? Talk about school rules, cafeteria, gym class, or extra-curricular activities, etc.
- Social
  - Did you tell your peers about your diabetes? If so, how did they react? If not, why not?

- Have you ever felt that others didn't completely understand your condition? How do you deal with this lack of awareness?
- How did your diabetes affect your social interactions with others?
- What did you do for fun or entertainment?
- How has your diabetes changed the way others look at you?
- What was your parents' role in your life at this point?
- What did you do if you went to a pub or club in your teens?
- What would you say was the most significant event of your teenage years?
- Emotional
  - Tell me about your teenage years. How did you adapt to normal teenage life?
  - What were some of the struggles you faced? Triumphs?
  - Did your diabetes influence any of your life decisions? A career choice, for example?
  - What pressures did you feel as a teenager, and where did they come from?
  - What did you learn about yourself during your teenage years?
  - How difficult was it for you to go through your teenage years while battling a metabolic condition?
- Medical
  - The teenage years are notoriously a time of loss of control. What were your teens like?
  - How was your health at this time of your life?
  - Did you have any episodes of hypoglycemia while at school or in a social situation? How did others react?
  - Did you notice a change in your health at this point of your life?
  - How did your diabetes change as the years went by?
  - What did your treatment regimen entail at this time?
    - Would you have done blood testing in front of others? If so, how did they react?
    - Did you have to have insulin injections while at school?
    - How did you manage your diet through the school day?
    - How much exercise did you have while at school?
    - Did you have any serious episodes of hypoglycemia while at school?
    - You probably had some interesting experiences while at school. Can you recall any of them?
  - Was there ever a time when you either took yourself off your medication intentionally or considered ignoring the diabetes regimen intentionally?

### Reflections

#### **1. What does diabetes mean to you?**

#### **2. How big a part of your life is diabetes?**

- Do you think your life would have been different if you didn't have diabetes? How so?

#### **3. Are there any positive aspects to having diabetes?**

- 4. If you were talking to an individual who has been newly diagnosed with type 1 diabetes mellitus, what would you tell him or her to expect?**
- 5. Do you have any advice for teachers or peers about how they can help others with T1DM?**

### Interview Questions for Individual Diagnosed During Secondary School

#### Background information

**1. Please tell me a bit about yourself and your background in relation to your diabetes. I am interested in things like your age of diagnosis, and how diabetes has contributed to who you are as a person**

- How old are you?
  - When were you diagnosed with type 1 diabetes?
  - How many people are in your family?
- 2. When you talk about type 1 diabetes, what is it that you are talking about?**
- What does diabetes mean to you?
  - How would you describe type 1 diabetes to someone who is not familiar with this condition?
  - What are the symptoms?

#### Pre-diagnosis Questions

**1. Please think back to the years before you were diagnosed with type 1 diabetes. What was your life like before you had diabetes?**

- What memories do you have from before you had diabetes?
- How was your life different back then?

#### Diagnosis Questions

**1. When did you realise that you had diabetes? Please describe this experience.**

- What physical or medical changes were you experiencing?
- What were you going through emotionally?
- How did others in your life react during this time period?
- What got you through this difficult time?
- What was your visit to the hospital like?
- How long did it take for you to gain control of your diabetes?
- How did your diagnosis change how you saw yourself? How others saw you?
- Who helped you with your management regimen during the initial months following your diagnosis?

#### Elementary School Questions

**1. Please describe your elementary school experience.**

- Socially
  - Describe your group of friends. What did you do for fun?
  - Were you involved in activities outside of the school?
- Academically

- Please describe your academic achievements during the elementary school years.
  - What do you remember learning about diabetes growing up?
- Emotionally
  - When you look back on your elementary school years, what emotions arise?
- Medically
  - Did you have any medical issues during the elementary school years?

### Secondary School Questions

#### **1. How did your family, friends, and teachers react when you were first diagnosed with diabetes?**

#### **2. Tell me about your experiences in secondary school.**

- Academic
  - How did you do in school?
  - Did your diabetes affect your overall achievement?
  - Were the staff and students at your school knowledgeable about diabetes?
  - Please describe your school environment. Was it conducive to managing your diabetes effectively? Talk about school rules, cafeteria, gym class, or extra-curricular activities, etc.
- Social
  - Did you tell your peers about your diabetes? If so, how did they react? If not, why not?
  - Have you ever felt that others didn't completely understand your condition? How do you deal with this lack of awareness?
  - How did your diabetes affect your social interactions with others?
  - What did you do for fun or entertainment?
  - How has your diabetes changed the way others look at you?
  - What was your parents' role in your life at this point?
  - What did you do if you went to a pub or club in your teens?
  - What would you say was the most significant event of your teenage years?
- Emotional
  - Tell me about your teenage years. How did you adapt to normal teenage life?
  - What were some of the struggles you faced? Triumphs?
  - Did your diabetes influence any of your life decisions? A career choice, for example?
  - What pressures did you feel as a teenager, and where did they come from?
  - What did you learn about yourself during your teenage years?
  - How difficult was it for you to go through your teenage years while battling a metabolic condition?
- Medical
  - The teenage years are notoriously a time of loss of control. What were your teens like?
  - How was your health at this time of your life?

- Did you have any episodes of hypoglycemia while at school or in a social situation? How did others react? How did others describe it to you?
- Did you notice a change in your health at this point of your life?
- How did your diabetes change as the years went by?
- What did your treatment regimen entail at this time?
  - Would you have done blood testing in front of others? If so, how did they react?
  - Did you have to have insulin injections while at school?
  - How did you manage your diet through the school day?
  - How much exercise did you have while at school?
  - Did you have any serious episodes of hypoglycemia while at school?
  - You probably had some interesting experiences while at school. Can you recall any of them?
- Was there ever a time when you either took yourself off your medication intentionally or considered ignoring the diabetes regimen intentionally?

### Reflections

**1. What does diabetes mean to you?**

**2. How big a part of your life is diabetes?**

- Do you think your life would have been different if you didn't have diabetes?  
How so?

**3. Are there any positive aspects to having diabetes?**

**4. If you were talking to an individual who has been newly diagnosed with type 1 diabetes mellitus, what would you tell him or her to expect?**

**5. Do you have any advice for teachers or peers about how they can help others with T1DM?**

## APPENDIX E: CASE PROFILE STORIES

## Abbey's Story: The Long Bumpy Road

Life [before diabetes] was more carefree. I just wasn't worried about what I am now. I was definitely a happier person back then; I think a more well-rounded feeling. I kind of understood myself...or at least I thought I did. But then again with the high school angst, you never know what you are thinking.

I was diagnosed with reactive hypoglycemia on my 16<sup>th</sup> birthday. I was in Driver's Ed, and I had a candy necklace. I felt really low and shaky, and had heart palpitations after eating it. I went straight to my doctor and explained that I just ate candy and felt like I was going to pass out. The doctor didn't do any blood work on me or anything to find out what was going on. He just suspected that it was reactive hypoglycemia, so I just stopped eating candy and simple sugars, and it was fine after that.

My diabetes affected me for the first time during my first set of Grade 12 exams. I normally did really well in school. I was a high 80s and 90s student, and I received highest honours four years in a row. I was experiencing really bad symptoms in January and February, right when they do the exams in high school. I failed my chemistry exam because I couldn't concentrate. At that time I hadn't been diagnosed yet, but my teacher kind of let me off the hook and gave me a 70 because she knew I was doing well in the class and I just couldn't concentrate. The teachers were pretty understanding at that time; they knew there was something wrong.

When I was in Grade 12 biology we had to do an independent study on a disease of our choice, so I picked reactive hypoglycemia. As I was researching it, I found out that I had all of the symptoms for diabetes. I called my doctor and told him that I wanted a



blood test for diabetes. After my mom yelling at him and me getting on his case about it, I finally got a blood test, and I have it.

I was diagnosed with type 2 diabetes at a really weird time of my life, around February of 2006. I was 17 years old at the time. Nobody in my family had diabetes, so it was a new experience for everybody. I am insulin resistant, and I don't produce enough insulin. It is really rare in my age group. When I first found out I had diabetes it was a shock, and then it turned to relief when everything started going away and I could think clearly again. It went from shock, to relief, then back to shock. It still goes in cycles.

The doctor called me at school and told me I had diabetes. When I went to the hospital, it took two and a half hours just to poke my finger [with a lancet]. I wouldn't do it. I was needle phobic. When they told me that I had to start injecting myself with insulin, they actually had to put me in the hospital for four days. I refused to give myself insulin, and I refused to let anyone that was living in my house give me insulin except a trained and certified nurse. The nurses tried to get me to leave the hospital and come back during the day, but I told them that I needed to stay there. I just couldn't deal with it at home, or I would go crazy. It was new territory, and I really didn't need my parents there all of the time worrying about me. My mom was at the hospital with me most of the time, but it was nice to be able to get away from her and kind of breathe, because it was a lot to take in, especially at 17. I finally did manage to give myself some insulin, and that was probably the hardest thing I have ever had to do in my life. I wasn't diagnosed at a super-high, I was diagnosed at a 23.9. I think it took me 6 to 8 weeks to get my blood glucose under control.

[My diagnosis] was hard on my parents. I think it was the first thing that my parents couldn't teach me. They felt helpless. My parents worry about me when I am

away from home like any parent, but it is 10 times worse, because I am sick and I am dealing with it myself. It is just me.

I think the process of adjusting to diabetes is still going on. No one is really helping me with it; I am trying to deal with it on my own. It has only been a year and a half since I was diagnosed, so really I am not so sure that I am ready to deal with all of it. The first little while I kind of went into a really strict diet; I was almost obsessive compulsive about it. And with time, I became more relaxed. You start to realise that [you] really hate this, and that it is not something that is going to go away. You have to live with this for the rest of your life, and it is horrible. It is not easy to accept. Physically I can handle it. The doctors thought that after six weeks they would put me on pills, but it has been a year and a half, and I am still on insulin. I tend to give myself an injection about three to four times a day. I normally test my blood sugar two to three times a day. I carry snacks with me all of the time. I have those 100 calorie bags of sweets, and I carry them in my purse. The only thing I don't like is that when it comes to traveling or going away, it is extra planning. Do I have enough meals? Do I have enough test strips? Do I have enough alcohol swabs? Do I have enough insulin? You always have to deal with all of that.

Another thing that you have to deal with is injecting yourself with hormones. That kind of messes with your head. Sometimes I feel like I just go nuts; I go crazy. When you start injecting yourself with hormones like that, your blood sugar is up and down like an elevator. You feel like a different person; you are kind of outside of your body. It is kind of like being bipolar, but it is because of your meds.

My school was small, so everyone knew what was going on. Everyone was supportive when I was going through the adjustment [period]. When I had to eat, the

teachers were pretty good at letting me eat in class. Some of my classmates were a little oversensitive about my diabetes, and some of them were under sensitive about it, saying “Abbey, there is nothing wrong with you. You can eat that. You can get wasted with everyone else.” With friends like that it doesn’t bother me [when they downplay the seriousness of diabetes] especially since I am not normally too close with the people who do that. My friends in particular made it easier for me [to adjust]. When I needed to talk about it, they just listened. They ate the same types of food [as me]. We wouldn’t go out for dinner or lunch. Instead we would eat in or have potluck dinners because I couldn’t really go out. It wasn’t good for me. Normally on nights like that I would let myself go and just eat what I wanted and then figure out my insulin after. I would indulge if I needed to, because [having diabetes] is like being on a permanent diet. If you restrict yourself from everything, you get emotional and start hating yourself.

At first I did not want to give an insulin injection in front of people. But my friends made it easier. They were like “you can do it at the table, it’s okay, you don’t have to go to the bathroom.” Which was a big thing, because when you have to go to the bathroom and give yourself an injection all of the time, it is kind of a pain. To leave the table and come back is a 10-minute ordeal. And trying to find a bathroom, especially if you are in a public place or something is always fun. [I started giving injections] in the cafeteria just at the table. I did it in my stomach, so most people couldn’t even see what was going on.

In school I had a lot of people around me who could tell when I was starting to get low, so they never let me get really low. There were a couple of times where I felt like I was going to pass out, and I would go to the sick room to eat something if I didn’t feel like I could be in class. The worst episode of hypoglycemia I had wasn’t actually at

school. It was at home, and it was about two o'clock in the morning. I don't know what happened, because I wasn't really lucid, but I ended up in my parents' closet. I have a lot of lows still. I go low three to four times a day. There was one time just recently when I was on campus and I had no food or money on me. I was probably sitting at a 2, and I had to walk to an ATM and get money to buy food on campus. I had to call my dad to keep me awake while I went to get food.

I think it was more difficult for me to transition from high school to university. I was debating about taking a year off and maybe staying at home and dealing with things. I decided at the last minute that I was going to go to school, because, who wants to be a year behind all of their friends? But I ended up being a year behind all of my friends anyways. In my first year of university I really wanted to be a biochemist. I had a hard time in the labs with my low blood sugar and high blood sugar affecting the stability of my hands. Working with DNA and genes, it is way too difficult to control a science experiment when you can't control your own body. I had to go home from university that year because I was sick. My blood sugar was high, and I couldn't get it under control. I had become resistant to the insulin I was on. My diabetes has become a little harder to control now, I think because you go through this honeymoon period where your pancreas starts working again after you start injecting insulin. My carb to insulin ratio is going higher, but it is okay.

Living with diabetes has definitely changed me. I became more self-conscious and worried about letting people into my life. I am always wondering, are they prepared to deal with me? Are they going to be able to take care of me? Can they support me emotionally or even financially if we become involved? You kind of start picking your friends around how stable they are, and you start to choose people who are like you; who

are really vulnerable. I have learned that I am probably not as strong a person as I used to think I was. I used to think that I would be able to take anything; that you could throw anything at me and I could handle it. I don't think I can handle everything anymore. I am not the same person that I used to be. I used to want children. I used to want to travel the world. I used to want to do everything. I have the desire; I just know I can't necessarily do it as easily. I can't take off for a year and expect it all to be okay. It is not always going to work out.

[Having diabetes], you stress about the future a lot; about life, about moving on, about being able to afford this for the rest of your life. I need a job that either has really good health benefits or makes enough money that I can afford to stay alive, because you can't mooch off your parents or friends [forever]. I think that is one of the most stressful parts about it. Even in university, I really should be studying science because I know I will probably get a better job with more health benefits, but I don't want to study it anymore. I can't be unhappy for the rest of my life just because I need to be able to afford to stay alive.

[If someone asked me what to expect after being diagnosed with diabetes, I would say to] expect a long bumpy ride. You are going to have to work. You are going to cry. You are going to get frustrated. You are going to change your plans. You are going to hate it. You are going to hate yourself. But you are going to get through it, because there is no point in just killing yourself. You have got to live for something. Take care of yourself. It is not a day thing; it is not something you come to grips with in a day. It is definitely a process.

I have had quite the experience the past year and a half. I think in more ways it has shaped me for the better. I definitely feel like I have something to work towards. I can

help people in different ways. I feel lucky that I can open people's eyes to different things and make them more compassionate. My diabetes gives me purpose, because what is the point of getting something like this if you are just going to let it sit and not do anything with it?

#### Olivia's Story: Learning to Live with the Terrible Roommate

If I could say one thing to individuals diagnosed with type 1 diabetes, it would be to tell them that everything is going to be fine. Nobody ever told me that. I was diagnosed with type 1 diabetes in the summer of my final year of high school when I was 18 years old. I was working two different waitressing jobs in two different cities to earn money for school in the fall, so I was constantly busy. I was really tired, and could not get out of bed in the morning. By the end of the year in June, I no longer made it to my morning classes. I was too tired, and physically could not get out of bed. I didn't have the motivation to go to school, and when I was in school, I was literally sleeping on the desks. I had a lot of detentions and I accepted it, because you are not supposed to sleep in class. I couldn't pay attention in class, and I wasn't studying either. When I would try to read the required books [for class] it didn't really work, because when I would read I would fall asleep. By my final exams, my marks had dropped.

Besides being tired, I was really skinny. My average weight was around 120 pounds; when I was diagnosed I weighed only 92 pounds. People in high school used to talk about me all of the time, whispering and gossiping that I was anorexic. But nobody said hey, maybe you should go see a doctor; nobody would talk to me about it. When my uniform at work didn't fit me anymore, I went to see my doctor.

At first my doctor didn't know what it was. I told her that I had lost weight, I was tired, and that all of a sudden I needed glasses. That triggered something in her head,

because she turned around and asked if I was really thirsty all of the time. At work while I was waitressing I was drinking a couple of pitchers of water and at least a pitcher of milk a day. The doctor tested my sugar, and it was 36.6 which is near comatose levels. The doctor grabbed my hands and she sat down and told me that I had diabetes. I remember asking if that was good. I didn't know what diabetes was. I had heard of it, but no one in my family and none of my friends had it. So it was psychologically overwhelming, I guess you could say. I fell apart. I thought I was going to die. I didn't know that diabetes could be controlled; I didn't know that if you take care of it you can be healthy. I didn't know what a high was or what a low was, or what happens in your body. I had no clue! I didn't know how I would feel or what it would mean for other things in my life. All I knew was that I was going to die.

At the time of diagnosis my doctor told me that I would probably have to take some pills. She never said anything about needles, or where I would have to go or that I would have to see a dietician and an endocrinologist. She was very brief about all of the things that were going to happen over the next few weeks. Initially I received no training whatsoever; I was only sent home with medication. I was put on pills for two weeks. I was allergic to them and ended up in the emergency room where I stayed while I was being trained on needles. It took me three full weeks to give myself the needle; every time I would try to take the needle myself, I just couldn't, so the nurse would do it for me. I wasn't motivated to conquer the disease; I was just motivated to get out of the hospital. I didn't want to be there anymore, and I was getting more and more depressed. So I tried it, and my first needle hurt like hell because I hit a nerve. It took me another two days before I would even try again. The next needle I didn't even feel. It was kind of like when you just start to drive a car. You don't know what you are doing; you are really scared. But

the more you do it, the more you get used to it. So the more I gave myself injections, the more I found out which spots hurt, and I would stay away from them.

My family didn't know much about diabetes, so my mom was a nervous wreck. Even still today, she is a nervous wreck, wondering if I am alive, if I am okay, if I have taken my needle. It took three months to see the dietician to get the full intense diabetes training, so my mom and I went to free seminars at a hospital nearby. I didn't really care to learn. I became totally dependent. I turned into an 8-year-old child. I didn't do anything for myself. My mom did everything for me again; my laundry, my cooking, making me take my needles. She even tested my sugar for me. My dad had a hard time with it. It made him depressed because he didn't know what to do. He didn't know how he could help because I wasn't a little kid anymore; I was 18. It broke his heart that I had diabetes because there was nothing he could do to help. If I needed to go somewhere, my dad would drive. Or if I needed money for something he would give me money. But he was really quiet for a couple of years.

For four years I was in denial about having diabetes and I was depressed. I didn't agree with my diagnosis. I didn't want it because I didn't understand how manageable it is. I was 18 going on 19; I was getting ready to graduate high school and go off to college to be with my friends. I just didn't want anything to do with not being normal. Some days I wouldn't get out of bed; I would just stay in bed all day. Some days I wouldn't even brush my hair. I would just throw a hat on, or pull it back in a ponytail. I didn't care. I didn't wash my face, and I never wore makeup even though I was big on having a good appearance in high school. I just didn't care anymore.

That summer I didn't go out; didn't go to the beach, didn't do any of that. Because wherever I went, I had to have these stupid needles, so I basically became a hermit. If I



did go out, I didn't take my needles. I would leave them at home; I didn't even bring them in my purse. I didn't want anyone to see me take it, because I had lived 18 years not having to do that. I was ashamed of having [diabetes], so I never hung out with my friends. I didn't want to have to answer any questions because I didn't really know anything about it. And I was still mad that I had it. It took about a year for me to take my needles all of the time.

Until I was 22 years old, I was terrible with the diabetes management. I would eat whatever I wanted, because if you count the sugar on the back of the [nutrition] label, you can match it with the insulin. So I would eat chocolate bars and French fries and all of that, and I was very skinny because I wasn't taking enough insulin. My body was trying to find energy somewhere, so it was breaking down body fat just like before I was diagnosed. I didn't really understand the consequences of what I was doing to my body. I didn't understand that it was very hard on my kidneys, very hard on my heart and arteries running my sugar that high. By the age of 22 I had gained a lot of weight and didn't know why. The whole weight thing bothered me, and that is what got me to take care of myself, not the fact that I have diabetes and should take care of myself. It was because I had gained a lot of weight. So I just ate well, and I felt really good. I felt like I didn't have diabetes anymore. It was at that time that I fell out of the whole depression and denial phase and thought that if I just eat well and take care of myself, I will feel a lot better. It just might take awhile.

When I went off to college, things got worse. Every first year post secondary school is a learning experience. You live on your own most of the time while going through those life changes. Plus, I was learning the whole diabetes thing. I would miss classes steadily. My attendance in the first year was about 60%. [Being in college], my

lunch was different every day. I was having lows and highs in class, missing class, and panicking and not knowing what to do, so they put me on a four times a day needle regimen instead of the previous two times a day regimen. Even being on the four times a day regimen, I still had several lows. One time I didn't have my Medic Alert bracelet on and I got very mouthy with one of my professors. [After telling] him to F-off, I got sent to the Dean's office. As I was waiting to go into the Dean's office my roommate walked by and saw that I was really pale, that I was sweating, and that it was 2:00 in the afternoon. She came over and asked if I was alright, but at that point I couldn't even talk. She ran to get me a bottle of pop and then tested my sugar and I was very low. I don't even know how I made it that far without passing out. The Dean and professor thought that I was intoxicated because my breath smelled like booze. That is what happens when your blood sugar goes really low; your breath smells like alcohol. My roommate went into the Dean's office and explained everything, and then she went back to the professor. He was very educated about diabetes but he didn't know that I had it because I didn't tell anybody.

Until about two years ago I wouldn't tell anybody [about my diabetes] because I didn't want diabetes. I didn't want to talk about it; I didn't want to learn about it, I didn't want to hear about it. I just wanted to avoid it and everything about it. Now I am completely open about it. Now I would talk to anybody about anything [regarding diabetes]. And the more people I meet, it is usually one of the first things that comes up. I wear my insulin pump where it is visible. I wear a Medic Alert bracelet now. I test my sugar in public. I do everything in front of people, because if someone would have done that around me, maybe I would have known more about diabetes, maybe I would have been interested, maybe I would have seen it and thought I need to know more about this.

Having diabetes is like having a terrible roommate; you have got to live with them, so you may as well just get along with them. I had to wean myself into accepting the disease. I think that teaching people about it and talking to people about it makes me feel better. Hiding it from people was making me feel alone and depressed.

If I had to have one disease in the world, I would choose diabetes. I wouldn't even choose lactose intolerance over this. All this disease does is teach you how to live a healthy life. Now that I know eating right is best for me, I am one of the healthiest people in my family. At least in the way I eat. Maybe not my organs and immune system and everything. But my diet is the healthiest diet out of my entire family and friends. It is controllable. I may still live a shorter life, but I can still do everything a normal person does.

Diabetes is an annoying disease. It is a 24 hours a day 7 days a week job. Diabetes is a habit, it is my life now. It is not something I have, it is my life. Everything I do in my life has to do with diabetes. I can't do anything without worrying what my sugar is going to do. Breathing, taking a shower, sleeping, everything I put in my mouth, everywhere I go, what kind of purses I buy, what kind of shoes I wear, how tight my belt is, everything! There is nothing that I can do besides eat celery, cucumbers, or green peppers without worrying about my sugars. I eat really well because I know what will happen if I don't. I drink a lot more water. I force myself to exercise even though I might not want to. I do a lot of things that are really good for me that I probably wouldn't have before. I think when I was diagnosed it was almost fate giving me a path for something, because all I have done is full gear towards diabetes.

### Hannah's Story: Not Just a Sick Person

I was diagnosed with type 1 diabetes at the age of 5. It was really bad timing, because my family had just moved here. My youngest brother had just been in the hospital for a month with whooping cough and he was only a month old, and my dad had just gotten a new job. I started dropping weight and falling asleep in kindergarten, and I drank liquids like I couldn't drink enough. I couldn't go anywhere without drinking. My mom took me to the doctor, and he said not to worry about it, that I was just going through a phase. When I was admitted to the hospital, my blood sugar was 56. The doctor looked at me and said he had never seen a kid walk in on her own two feet with sugars that high. I was scared, but at that point I knew I was sick. I knew something was not right and I was feeling so awful that I would do anything to make it feel better. I was terrified, because [the nurses and doctors] started running around and yelling while attaching heart monitors. They were worried that I was going to have seizures when my sugars finally came down. The whole week that I was in the hospital, the nurses would come in and hold me down to give me my injections. At that point I definitely thought that I was being ambushed. The next day my mom sat down with me and said "okay honey, you have diabetes." I had heard the word before; I had seen it on Sesame Street. I remember thinking I do not want that. That means needles every day. And I thought "No. Not me."

It was a huge adjustment for my family. There were four kids in my family, and all of a sudden, one of them had type 1 diabetes. This was the first case in the family; nobody else had it. When I was first diagnosed, I didn't understand it at all. I guess I had the information; I have to eat this at this time, and I can't have regular coke anymore, but it didn't really go in. I remember feeling hungry once and going down to the kitchen and

getting a bowl of cereal at eight o'clock at night. I knew I wasn't supposed to eat sugar, so I was eating bran flakes. My mom came down and screamed "Hannah! What are you doing?" and pulled the bowl away from me and dumped it down the sink. I started crying and said "Mommy what is wrong? I don't understand. I am eating healthy. I am hungry." And she said "Okay well we need to sit down and talk about this." I have always had a good appetite, so I learned that I could have either extra green vegetables or extra meat if I was still hungry. I learned that having a glass of milk is different than having a cookie, is different than having a banana. Different foods have different effects, and you have to have all of the food groups in the same meal.

When I was 5, I started having temper tantrums every time I had to get a shot. As soon as I got over having little temper tantrums, my parents would ask me how much insulin I needed. They included me in the treatment very early on. I started off slow. They would give me the needle and let me push down the plunger, or they would let me pick out what injection site I wanted. Then they would have me pull the needle out, or put it in myself. Eventually after a while I would load the needle and they would check it. By the time I was doing the injections completely independently, I was about 7.

At times I got very angry, and extremely frustrated. I would just scream "I didn't ask for this! Why do I have to deal with this?" I used to ask on my Christmas list not to have diabetes anymore. Unfortunately having diabetes is not like having cancer where you either live or you die and then it is done. It is every day. [When] you are having a really crappy day, or you get the flu and you are vomiting, you still have to take your shots and you still have to eat something. And then you vomit it up again. You feel completely powerless.

I used to go low a lot when I was younger. Like if I was excited for my birthday party, I would drop like crazy. If I didn't eat on time, I would definitely go low. I used to have really bad lows in the night. I would wake up, and I wouldn't be able to move half of my body. Or I would know that I was low, but I couldn't actually make the process of getting to the fridge, opening the door, and getting the juice. I remember once I woke up and I wanted to go get juice, but I ended up falling and my bookshelf fell on top of me. My parents woke up when they heard this thundering crash. Eventually I kept a little box under my bed that had juice and granola bars and stuff. So if I could think it through, I would definitely treat the lows myself. If not, I had to go get my sister or yell for my parents.

In elementary school I was a good student. I liked school for the most part. At the beginning of every school year, my mom would find out ahead of time who my teacher was, and then we would go in and meet with the teacher and the principal. My mom would go over everything with them; she needs to eat at noon no matter what; she has to have her snacks or she goes low. I think people are just head noddors. They say they understand, but they really don't. Or they take in parts of the information, but they don't really get it. I think some of my teachers were terrified by it. They definitely saw it as another burden; another special needs student in the classroom. So I always felt like I had a strike against me when teachers found out I was diabetic; because I thought that they would think that I was just going to be some hassle. Some of my teachers were fine, but most of them as long as I said I knew what I was doing, they were like "whew! Better you than me." But I also knew that I really couldn't rely on them. If I had said "I need your help" they would have helped me, but I would have had to walk them through it.

By Grade 8, I had to give myself an injection at school. The teachers would ask if I wanted to go to the nurse's office, but having somebody who doesn't really know what is going on have more control than the person who does is scary. I hated feeling that I had to go and sit in front of the nurse's office like I was in trouble, to give an injection in front of somebody who didn't even know what was going on. So I chose to do it in the bathroom instead. Maybe it was just that I am weird, but I just didn't see the need to involve people in [the treatment], because I knew that they would resent it after a while. I knew what I was doing. Because I was so young when I was diagnosed, it was something that I just did. I didn't think about it all that much.

Having access to food at all times was a big struggle for me. A lot of teachers had a no gum-chewing, no snacking, and no drinking in class rule. I always knew that I could supersede that rule, but I always felt like I had to hide it or I had to sneak it in. I never wanted to get up in the middle of class and walk over to my backpack. I wanted to be part of the group; I didn't want to draw any attention to something that is not cool. If you have the attention because you have a new jacket, that is cool. If you are the kid who is always singled out because you need to drink your juice, no. You are just the kid who eats all of the time.

Field trips were always sort of a landmine, because the teachers would say they were going to give you lunch, and sometimes they wouldn't. Or sometimes they would change the program around and you would eat at 2:00 instead of noon. And that was just treacherous. I remember once we went to the sugar bush for the pancake breakfast at 10:00 in the morning. I can't eat a pancake that has maple syrup on it at 10 in the morning, so it was a feeling that this place is really neat with the huge Clydesdale horses

and the log cabin, but now everyone is eating their pancake breakfast and I am not. And then you would feel totally left out of the group.

A lot of the time I spent having to re-educate the students about diabetes. You know, I am not allergic to sugar; I don't have to take needles because I am bad. I can't swallow a pill because it won't work. I think a lot of people just didn't get it though. They knew there was something about needles; they knew there was something about food. Even my friends that I had had for years, they just didn't get it. If I said I was low, they would ask me if I needed my insulin. Obviously to me it is like second nature by now, but to them it was something that they didn't want to deal with.

I don't hide the fact that I have diabetes. I also don't use it as a selling feature. That is not the first thing I want people to think of when they think of me. I didn't want to single myself out as diabetic. I didn't want people to see it as a weakness. I have always hated doing stuff that would make people think that diabetics don't know what they are doing. I guess I have always felt like I have to stand up for the diabetics and show people that we know what we are talking about. I always took so much responsibility for that. Diabetics get a bad rap; they have this stigma of they don't take care of themselves, they eat whatever they want. I wanted people to know that is not the case.

To a lot of my friends, managing diabetes looked easy. A lot of them downplayed the seriousness of [the disease], and that really pissed me off. I didn't want it to become this thing of I am a sick person. You don't want people to only think of diabetes when they see you. You don't want to look weak. At the same time, you do want them to know that it is not always easy, and that it requires a lot of attention, and that the little things like eating on time and testing your sugars make a big difference. At times you want to hit people over the head with it. Yes I am still diabetic. I still have to test, I still have to eat, I



still have to order my supplies. My skin gets infected. My fingers get sore. And it is not something that I am going to sit here and whine about. It still happens, I still have to do it every day.

In high school I was still a good student. I think some of the teachers knew that I was diabetic, but I didn't tell them that I had diabetes. At this point my parents were no longer going to bat for me or talking to [my teachers] because I didn't want them to. I mean, the last thing you want in high school is for your parents to get involved. In high school things were better. There was a lot more freedom than in elementary school. You are more of your own person by high school; you have your own agenda. Maybe it was just because I was more assertive at that point. I was older; I was more confident. My teachers knew that I was a good student. They knew that I was going to catch up if I had to miss class. I feel like I developed that trust; I worked hard to earn that trust from them. It wasn't just "I am diabetic. You have to let me out of class," it was "Mr. Matthews, you know I am going to finish this, and you know that I am going to understand. Can I take this time off?" It was really about earning trust and good rapport.

Being low was always a worry for me. The food that was offered in the cafeteria was generally not very good. And if I wanted a snack that was not just a chocolate bar, sometimes it was hard to find. As long as I had food with me, it was not an issue. I always had candy in my backpack, or juice, or a granola bar. Things that had a long shelf-life that you could whip out at a moment's notice. My friends used to joke a lot that I could whip out a full course meal from my backpack.

I guess all of the teen angst I was experiencing was compounded by the fact that I was diabetic, and that I had to worry about all of this crap on the side. Wanting to fit in, not wanting to eat all of the time, going out, and weight issues [occupied my thoughts].

When I hit puberty I felt like I had a lot less control over my body, over my blood sugars, everything. You know, you develop this internal system where if I eat this is how I feel. If I take insulin, this is how I feel. It almost felt like my body was not listening to the system anymore. I was frustrated and overwhelmed, but the last thing I wanted to say was “Mom, can you help me?” Because I wanted to do it myself. And I did not want her to know that I was going through problems. When I hit puberty I packed on the weight, and I didn’t know what to do. I realised that if I took less insulin I wouldn’t be as hungry and I would drop weight, so I took less insulin, worked out more, and ate very little. I dropped maybe 20 pounds in Grade 10. My sugars were bad and my grades started dropping. When [my parents] threatened to put me in an anorexia program, I didn’t want that, so [my dieting] ended, and I got back into school.

In high school my friends and I did the typical teenage things; shopping, going to the movies, parties, and coffee. Drinking was another one of those things where I wanted to fit in. If I had a really sugary drink, my sugars would go up and I would vomit. I guess in high school that used to happen a lot. People always assumed that I was drunk, and I wasn’t. I guess I never put the two and two together. I do now.

High school was definitely a time when I had to tell my mom to back off. I know it was hard for her, and that she still worries. You can’t undo that. I had a curfew until I was 18. I still went home for dinner every night. They made sure I was eating properly. They were still involved, but I was trying to limit their involvement.

When I reached university, I went on the pump. I put off getting a pump for about four years because I didn’t want to be attached to a machine. I didn’t want people to physically see something different about me. But for me, the flexibility [afforded by] the pump, I would never go back to injections. They are awful.

Diabetes has taught me a lot about food; food in itself, food socially, and food as psychological motivation. It has also made me listen to my body. I am hyper-aware of what is going on. I can tell if I am sick or if I have an infection before it is raging out of control. Diabetes influenced my decision to go into science, or more specifically research. I work all day with islets; the one thing I don't have. Diabetes is a fairly significant part of my life. I don't think about it all of the time, but it is something that always creeps back in.

#### Melinda's Story: A Normal Life

I don't really remember life without diabetes. I have pretty much had it for my whole life. I was diagnosed with type 1 diabetes at 2 years old. My mom had noticed that at night my diapers were a lot wetter than they used to be, and that they were changing me way more often. She also said that I looked like I didn't have much energy. At first even the pediatrician didn't think it was anything. He told my mom that I had the flu, and that I would be fine. My mom did not think I was fine, so she went back [to the doctor] a bunch of times and finally they did some blood tests and said I had diabetes. I was sent to the [children's] hospital for about a week. My parents stayed there all day every day while I was at the hospital. They were really scared. My mom said that she cried a lot during that week, but towards the end of my stay at the hospital she said she realised that there were so many kids in the [children's] hospital that were much worse off, and at least I would be coming home. It made them feel a bit luckier, but they still didn't know what it was going to mean for me going to school, or what we would do when we would go on vacation or go out for dinner. They didn't really know anyone else who had a kid with diabetes, so they weren't sure what was going to happen, or if I was going to be okay. My parents were going to classes every day with nurses and doctors. They got so much

information all at once that they were overwhelmed and thought “we can’t do this. What are we going to do when we go home?”

Because I was so little, it was hard on my parents. You can’t really make a 2 year old eat if they don’t want to, or tell them that they can’t eat if they are hungry. I used to scream a lot [when they gave me my injections]. I think I started hating the needles more around the age of 5 or 6, because I think I realised more what was going on at that age. I started to understand what diabetes was around kindergarten I guess. But my parents never really explained it to me; they just told me I was diabetic, that I had to take an injection in the morning and at dinner. They told me that I had to take this amount of food to school, and that I had to eat what was in my lunch bag at what time. I remember every time I had a new teacher, my parents would come [to the school] and have a chat with the teacher, explaining to them “she has to eat at these times and you have to let her eat if her blood sugar is low. You also have to let her go to the washroom whenever she needs to because her blood sugar might be high.”

My teachers were usually pretty good. If I said that I needed to eat because my blood sugar was low, or if I said that I had to go to the washroom, they would let me. I had one teacher I think it was in kindergarten who wouldn’t let me go to the washroom. And then there were the teachers who were just trying to follow the school rules, like no eating in class. Sometimes they would give me trouble about that, so I would just go outside to eat and then come back in when I was finished. Other times during assemblies if I had to go to the washroom the teachers would tell me I couldn’t get up, so I would have to try and hold it in. When that happened, Mom would usually call the school and say “listen, you can’t do that.”

When we had class parties, the teachers would try to do it during recess or during lunch, and they would always send a note home before so I could ask my mom what I could eat. She would explain to me that I could have two pieces of pizza and one cupcake, or something like that. With Mom's permission I could take some candy and have a little bit of it at recess when it was time to eat again. I didn't feel too left out. I think it was around Grade 7 or 8 that I wanted to just be able to eat. At recess, my friends would bring tons of candy with them, and I wanted to be able to do that too, so I just did it anyways. That was kind of bad, but I was smart, so I knew that if I gave myself more insulin it would be fine. I probably should have gone and told my doctor that I wanted to increase the amount of food that I ate at snacks, but I still managed, I guess.

When we went on day trips with our class, I would usually make sure that I took a little less insulin, because we would be walking around all day. That usually solved most problems. It was only when we started having overnight trips like the outdoor education trip in Grade 6 that things got a little harder. I called my doctor, and he told me what to do for the whole trip. My mom got the teachers to call the outdoor education center and make sure there was going to be food that I could eat. So beyond that, with the food that they served I had to try to estimate how much I was supposed to eat, and what was a serving. It wasn't my best week as far as blood sugars went, but I didn't have any really bad low blood sugars or high blood sugars, so it was okay.

My teachers were never really involved in my diabetes management. I never had any serious trouble with my diabetes, like seizures from low blood sugars or a diabetic coma from high blood sugars, so I never really needed their help. I had diabetes for so long that I kind of understood what I was supposed to do if I felt like my blood sugar was low or high. Except for what my mom had told them, the teachers at my school didn't

know a whole lot [about diabetes] unless they already knew someone with diabetes. I always just managed the diabetes myself. I think that managing diabetes always came really easy to me, because I had a good sense of whether my blood sugar was high or low.

In Grade 8 I went on the pump. For the first time ever, I had to start testing my blood sugar in school. Because we had a pretty small school, you stayed with the same kids from Grade 1 until Grade 8. My classmates all knew that I was diabetic. After a while they kind of got the idea that I had some [condition] that made me need to eat certain amounts of food at certain times. I told them I had diabetes, but I didn't really go into a lot of detail about it. Because they all knew about my diabetes, I would test my blood in class. I guess I would have liked them to know a bit more about it when I got the insulin pump, because everyone kept asking me "what is that?" and they would have a bunch of questions about it, like where does it go, and what does it do? I did get kind of tired with it, but I would just answer their questions. Being on the pump definitely made things a whole lot easier. If I wanted to eat more, I could. If I wanted to eat less, I could. It also meant that I didn't have to eat on a schedule, which helped with the [transition into] high school where you don't necessarily get snacks or lunch breaks at a specific time.

My friends were always pretty supportive. I always did everything myself, so I don't really remember them having an effect over how well my diabetes was managed. I was never so low that I couldn't get up and get something to eat myself. So I never really needed anyone to do that for me. The only time my friends really had an influence was when we would go out for lunch together but they were taking forever. If my blood sugar started to go low and I told them we had to go eat, they would say just a second. We have

to do this first. Usually I would just grab a juice box and I would be okay until we got lunch. If I didn't have a juice box, I would just meet them [at the restaurant].

I don't think diabetes really affected my life all that much. I was a competitive gymnast; I still got to do that. I did really well in high school. Grade 9 was really easy for me. I got away with not doing too much work, and still getting above average grades. It got a little bit harder in Grade 11, but I figured out that if I studied a bit more, I could still get the same grade. I was always well prepared for exams and quizzes, so even if my blood sugar was a little low, I would have something to eat and then write the test anyways. When your blood sugar is low, it makes you a bit anxious, but I knew the material so well that I could usually just do it anyways.

In high school I was involved in a lot of extra-curriculars. I was still in gymnastics outside of the school, I was on the swim team, and I was in the band. I was mostly in classes with the same people again in high school. There were a few new people, so I would just tell them about my diabetes because I figured they would find out eventually. A lot of people have misconceptions about [diabetes]. They think if they eat too much candy they are going to get diabetes. Or they say that I have too much sugar, which is kind of funny, because no, I am not carrying around a bag of sugar in my backpack. And then a lot of people think that insulin is the same as sugar. So if my blood sugar is low that I would have to give myself insulin. This is one of the reasons why I don't really let people deal with my low blood sugars or high blood sugars. Because if they would give me insulin when my blood sugar is low, I would be toast.

My diabetes never really stopped me from going out with my friends or doing whatever I wanted with them. We went to the mall, watched movies, or had parties when someone's parents left for the weekend. By the time I reached high school my parents

weren't really doing too much anymore. I do everything myself now. Pretty much from the time I got my insulin pump, my parents allowed me to manage most of the diabetes on my own, and they quit checking up on me.

My diabetes got frustrating sometimes, especially when I was growing and everything was out of whack. Management is especially difficult for girls, because the menstrual cycle messes with your blood sugars. During Grade 11 and 12 I had more difficulty managing my diabetes, I think it was a lot because of [fluctuating] hormones, and I had gained weight. Since I am pretty small, that affected my blood sugars and made it fairly hard to control. Once my doctor told me how to test how much insulin to give when I bolused, I kind of got control of it once more. Weight seems to be something that is harder for diabetics to control. It is even more important because we are diabetic to keep a good weight. I made sure to start exercising more, and to be more careful about what I am eating.

I would say diabetes is a pretty big part of my life. You are always sort of thinking about what your blood sugar might be, or if it is too high or too low. Being diabetic means planning more than other people. I have to plan to always bring juice and a snack with me. I have to think about when I need to see the doctor next, and when I have to have blood work done. And for diabetics, it is really important to get the flu shot, so I have to think about where and when I am going to get the shot. It is just like a few extra things to think about all of the time that other people wouldn't really think about I guess. It would certainly make life easier sometimes not to have diabetes. But then I guess I wouldn't be so aware of how important it is to be eating properly and exercising, and keeping my cholesterol and blood pressure down. I wouldn't have my friends from the diabetes camp who even aside from our shared diabetes are some of my best friends.



After being on youth panels with diabetes advocates from all over the world, I have realised that I am really lucky.