Adults Living with Type 1 Diabetes, Reflections of their Youth: A Phenomenological Study

By

Laura Nordin

B.A., University of Saskatchewan, 1998
B.S.W., University of Regina, 2000

THESIS SUBMITTED IN PARTIAL FULFILLMENT OF THE REQUIREMENTS FOR
THE DEGREE OF MASTERS OF SOCIAL WORK

THE UNIVERSITY OF NORTHERN BRITISH COLUMBIA
October 2010

© Laura Nordin, 2010
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.

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

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

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 protège cette thèse. Ni la thèse ni des extraits substantiels de celle-ci ne doivent être imprimés ou autrement reproduits sans son autorisation.

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

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

Type 1 diabetes is a chronic medical condition. Effective illness management requires numerous, continuous self-care procedures to ensure a healthy life free of complications. This study asks, what do adults with type 1 diabetes recall about living with a chronic health condition during their youth? By interviewing adults about the different types of relationships and the experiences they had in their youth, the research examines if relationships influence diabetes self-care. Using a phenomenological approached called the Vancouver School of Phenomenology, the researcher drew themes from nine participant interviews. These include: diabetes knowledge, the impacts of diabetes, constructive and deconstructive factors in relationships, and self-awareness and identity in youth and adults with type 1 diabetes. In the sample, this particular composition of participants displayed characteristics that were not consistent with the majority of literature findings regarding persons living with type 1 diabetes. As a result, the data in this study revealed that relationships, and being highly motivated, organized, capable, cognitively intact and functional within the realities of daily life plays a critical role in diabetes self-care and this role changes and evolves over time.
## TABLE OF CONTENTS

Abstract ii
Table of Contents iii
List of Tables vi
Acknowledgments vii

### Chapter One: Introduction
- Statement of the Problem 1
- Research Question 6
- Purpose for Studying the Topic 6
- Summary 9

### Chapter Two: Review of the Literature
- Focus of the Review 11
- Key Terms 11
- Incidents of Type 1 Diabetes 15
- Prevalence of Type 1 Diabetes 16
- Services for Type 1 Diabetes in the Prince George Area 16
- Challenges for Youth Living with Type 1 Diabetes 18
- Mortality and Quality of Life 21
- Effective Illness Management 22
- Financial Considerations when Living with Type 1 Diabetes 23
- Eating Disorders and Mental Health 23
- Family Relationships 27
- Peer Relationships 30
- Service Provider Relationships 33
- Community Relationships 36
- Summary 38

### Chapter Three: Method and Methodology
- Phenomenology 40
- Types of Phenomenology 41
- Methodology-The Vancouver School of Phenomenology 44
- Step 1-Participant-Dialogue Partners 46
- Step 2-Silence 47
- Step 3-Data Collection-Participating in a Dialogue 48
- Step 4-Data Analysis-Sharpened Awareness of Words 48
- Step 5-Coding-Beginning Consideration of Essences 49
- Step 6-Constructing Initial Case Structure 49
- Step 7-Verification of a Single Case with the Participant/Co-Researcher 50
Step 8-Constructing the Essential Structure of the Phenomenon-Meta-Synthesis  51
Step 9-Comparing the Essential Structure with the Data  51
Step 10-Indentifying the over-riding Theme Describing the Phenomenon  52
Step 11-Verifying the Essential Structure with the Participant/Co-Researcher  53
Step 12-Writing up the Results  53
Relevance, Rigor and Feasibility of this Study  53
Situating the Writer in the Research  56
Summary  58

Chapter Four: Results  60
Step 1-Participant-Discourse Partners  60
Step 2-Silence  61
Step 3-Data Collection-Participating in a Dialogue  61
Step 4-Data Analysis-Sharpened Awareness of Words  63
Step 5-Coding-Beginning Consideration of Essences  63
Step 6-Constructing Initial Case Structure  64
Step 7-Verification of a Single Case with the Participant/Co-Researcher  65
Step 8-Constructing the Essential Structure of the Phenomenon-Meta-Synthesis  66
Step 9-Comparing the Essential Structure with the Data  66
Step 10-Indentifying the over-riding Theme Describing the Phenomenon  66
Step 11-Verifying the Essential Structure with the Participant/Co-Researcher  67
Step 12-Writing up the Results  67
Demographic Analysis  68
Summary  77

Chapter Five: Discussion  79
Thematic Analysis  79
Knowledge  81
Acquiring and Learning Knowledge  81
Sharing and Learning Knowledge  83
Knowing and Intuitive Knowledge  86
Impacts of Diabetes  89
Impacts of Food  89
Impacts of Medicine  92
Financial Impacts  95
Social Impacts  96
Constructive and Deconstructive Factions in Relationships  103
Constructive Factors: Connectedness and Support  104
Deconstructive Factors: Connectedness and Support  106
Constructive Factor: Knowledge  109
Deconstructive Factors: Knowledge  112
## LIST OF TABLES

<table>
<thead>
<tr>
<th>Table</th>
<th>Description</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>1.0</td>
<td>Participant Response as a Youth; Age at Diagnosis, and Family Composition</td>
<td>69</td>
</tr>
<tr>
<td>2.0</td>
<td>Participant Response for Employment Status and Education Level</td>
<td>72</td>
</tr>
<tr>
<td>3.0</td>
<td>Participant Youth and Current Insulin Administration</td>
<td>74</td>
</tr>
<tr>
<td>4.0</td>
<td>Types of Service Providers used between the ages of 13-18 Years and Number of Hospital Admissions after original Diagnosis</td>
<td>76</td>
</tr>
<tr>
<td>5.0</td>
<td>List of Themes and Sub-Themes</td>
<td>79</td>
</tr>
</tbody>
</table>
ACKNOWLEDGEMENTS

I would like to acknowledge my husband, Stacy, and stepson, Lloyd, whose tolerance, patience and sacrifice of family time during the Master’s process has been extraordinary. The love I have for those two is immeasurable. A special recognition goes to my supervisor, Dr. Si Transken, and other members of my supervisory committee, Dr. Glen Schmidt and Josée G. Lavoie, the thesis crew at Intersect Youth and Family Services, First Friday Group and the meetings with the monthly thesis women’s group. Without all of your advice, support, encouragement, and information, this project would have been a difficult process. To Ms. K. Adams and Dr. C. Gingell, a sincere thank you and appreciation for the time you both took to assist me though the editing process. Finally, I have to express my gratitude towards the women and men who have provided me with the privilege of recording, listening, and unearthing meaning out of their experiences.
Chapter One: Introduction

This study has recorded the reflections of adults successfully living with type 1 diabetes as they recall their experience of receiving a diagnosis of this condition, living with type 1 diabetes during their adolescence, and now how they live with the illness as adults in the Prince George, BC area. The participants have provided their thoughts on how living with type 1 diabetes has influenced their relationships with others, their day-to-day lives, their health, their self-awareness, and identity. Some of the patterns of living successfully with type 1 diabetes, are discussed throughout and will be discussed further in areas of future research.

In Canada, one in every 180 people lives with type 1 diabetes (Canadian Diabetes Association, 2010g). It is the second most common chronic childhood illness, affecting approximately 1 in 500 school-age children (Woodrich & Cunningham, 2008). The disease affects males and females equally; the peak onset of the disease is between the ages of five and seven years (Friedrich, 2007; Sperling, 2005). The cause of the illness is unknown. Typically, the diagnosis of this autoimmune disease occurs in people under the age of 30, most often during childhood or in their teens (Canadian Diabetes Association, 2010c).

Currently, this disease is known by three names: type 1 diabetes, diabetes mellitus or IDDM (insulin dependent diabetes mellitus). In the past, insulin-dependent diabetes or juvenile diabetes were the two names given to describe the illness (Canadian Diabetes Association, 2010f). In this study, the term ‘type 1 diabetes’ will be used throughout to describe the disease.
Type 1 diabetes occurs when the body stops producing insulin (Canadian Diabetes Association, 2010f; Walsh & Roberts, 2000). Insulin is a hormone that ensures that a body’s energy needs are met. Without insulin, the body is weak, it consumes itself for energy and eventually the person dies. Currently, there is no cure. Insulin injections remain the primary means of disease management.

The people afflicted with this ailment live with a chronic illness that influences every aspect of their existence. Coffen and Dahlquist (2009) described the regime diabetic patients perform to maintain their health. They found 25 item categories that include 600 tasks, many that required daily attention. The complexities of managing this health condition can often create a struggle for a person living with type 1 diabetes, her/his family, and the medical community. When poor management occurs, the health implications can negatively affect life expectancy and quality of life.

**Statement of the Problem.**

Youth living with type 1 diabetes have a different life experience than youth living free of the condition. Living with type 1 diabetes is more complex than living free of this condition. My research has focused upon how living with this chronic health condition influences a person, her/his relationships with others, and identity as a person. There are six topics related to my research that provide initial background information regarding the problems that occur for youth living with type 1 diabetes. Much of the research conducted has been on these topics: struggles when living with diabetes; self-sufficiency (growing up early); autonomy; service provider interactions; relationships with parents; peers; and community member relationships, and medical aspects of the condition.
Karlsson et al. (2008) state youth living with type 1 diabetes struggle with the daily challenges of managing their health and daily challenges throughout their adolescence. For youth living with type 1 diabetes, relationships are often different from other adolescents, as the diabetes self-care behaviours set them apart from peers who do not have the condition (Helegeson et al., 2007). Children and youth who live with type 1 diabetes acquire self-sufficiency skills earlier than children and youth who do not have the condition. Schilling et al. (2006) state self-management typically begins at the age of eight years and self-sufficiency for self-care reaches maturity at 19 years old. The reason for increased self-sufficiency is that children managing a chronic illness participate in self-care out of necessity, unlike other children who develop those skills based upon developmental milestones. In essence, children living with type 1 diabetes grow up early due to their increased self-care requirements.

Furthermore, Wysocki et al. (1996), in studying children who live with type 1 diabetes from five to seventeen years, showed that these children are more likely, as they grow older, to assume higher levels of diabetic self-care responsibility because of their illness. It is important to note that although youth living with diabetes are in charge of much of their self-care tasks, they often lack the psychological maturity of an adult and the result is a decreased adherence to diabetes regimen tasks.

A third important aspect of research regarding youth living with diabetes is identity. One of the processes of identity building is through acquiring autonomy throughout adolescence. For youth living with type 1 diabetes, managing the illness and yearning for the autonomy enjoyed by youth living free of diabetes frequently become a complex process. This difficult progression often produces disagreements with adults in
their lives about their diabetic self-care. For this population, conflict in relationships has been a popular topic of discussion (Hood et al., 2007; Schilling et al., 2006). Conflicts about diabetes with caregivers, parents, professionals assisting with their care, adults in the community involved in their care, siblings, and peers are likely to occur (Hood et al., 2007; Karlsson et al., 2008). Although conflicts regarding diabetes self-care are typical for this population, other disagreements about values, beliefs, and life skill tasks are an additional source of conflict. For example, the research has investigated quarrels that result from clashes over management (Hood et al, 2007; Karlsson et al, 2008).

Service provider interactions have been a focal point of study for many nursing and medical researchers as persons living with diabetes interact with a large number of service providers (Kyngas, 1998; Rubin & Blumer, 2005). Three key issues are identified in relationships between service providers and individuals with diabetes. The first is the availability of services for this population (Lewis, 2004). The second issue is the transition of care over developmental milestones. Diabetic children transition paediatric to adult diabetes care as they reach adulthood (Frank, 1992; Franklin et al., 2004). Third, there is the importance of a diabetes team in the life of a diabetic (Bodil et al., 2001; Dairman, 2007; Friedrich, 2007; Home, 1989; Mulcahy, 1999).

A fifth area of study explores relationships between the youth living with diabetes, her/his parents, diabetes service providers, teachers, and peers. Most of the research has focused upon the youth’s relation to her/his family. Extensive research exists on relationships between the youth living with diabetes and her/his caregivers (Hood et al., 2007; Karlsson et al., 2008; Wysocki et al., 1996). Areas of study for youth living with diabetes and their caregivers include autonomy and family conflict in relation to self-
management (Hood et al.; 2007; Johnston, 1973; Karlsson et al.; 2008; Wysocki et al.,
1996). The importance and influence of relationships is a key element in diabetes
management.

Within the study of relationships adolescents have with others, studies peer
relationships have yielded mixed information about the influence and importance of peer
connections (Gardner, 1998; Greco et al., 2007; Silverstein & Bandyopadhyay, 1995). Although many children experience bullying, teasing, name-calling, and psychological
stress from peers, individuals with diabetes experience an unconventional reality in this
context. Storch et al. (2004) state that one in five youth living with diabetes experience
on-going peer torment that consists of overt and covert psychological distress because of
their condition. The researchers note that these youth are different from their peers
because of responsibilities associated with their condition. These include blood glucose
checks, insulin injections, dietary constraints, and wearing diabetes related items such as;
medical alert, bracelets, and insulin pumps.

However, research on the influence of other relationships is lacking in the literature.
Research regarding social interactions between other community members and youth
living with diabetes is limited. In terms of relationships outside of family and service
providers, the next body of research emerges from education. This research examines the
extent to which persons with type 1 diabetes are cared for in educational institutions
(Hains et al., 2009; Hellems & Clarke, 2007; Peters et al., 2008).

Finally, although research exists concerning youth living with diabetes and their
relationships, diabetes research has primarily focused upon the medical processes of the
illness. The typical topics of study have included blood glucose levels, effectiveness of
drug therapies, exercise, diet, genomes, islet cells, mental health, and self-management (Hislop et al., 2008; Hood et al; 2007; Schilling et al., 2006; Wysocki et al., 1996).

However, sporadically, research has examined the influence and impact of relationships when living with type 1 diabetes (Hentinen & KyngAxe, 1993; Greco et al., 2005, Silverstein & Bandyopadhyay, 1995; Dovey-Pearce et al., 2007; Hood et al., 2007; Karlsson et al, 2008).

In conclusion, the problem of being a youth living with diabetes is that living with diabetes is different from living free of the illness. Living with diabetes has many challenges that create a multifaceted aspect to relationships, health, daily living, self-awareness, and identity. This brief outline has demonstrated how the struggles when living with diabetes, self-sufficiency (growing up early), autonomy, service provider interactions, relationships with parents, peer, community member relationships and medical aspects of the condition are important aspects I have considered in completing this study.

**Research question.**

This study aims to discuss with adults who currently live with type 1 diabetes experienced adolescence. The central question guiding this study is:

What do adults living with type 1 diabetes recall about their relationships with others, during their youth and what was it like living with a chronic health condition?

**The purpose for studying this topic.**

The purpose of a phenomenological study according to Polkinghorne (1989) is that the reader of the information should come away with the feeling that “I understand better what it is like for someone to experience that” (p.44). This discussion outlines the
purpose for studying what it is like to live with type 1 diabetes, the rationale for choosing this population, and my personal connection to this subject manner.

Research from an adult’s perspective on living with type 1 diabetes during adolescence has a wide variety of impacts and there are four motivating factors for my decision to study this group of people. First, the knowledge gleaned from this study could help professionals, family members, peers, and community members have empathy, and understanding for youth with type 1 diabetes. In addition, the results could provide information to change delivery of programs designed to assist those youth currently managing type 1 diabetes. For service providers, understanding of a client’s experience desirable and relevant and knowledge that contextualizes out work and leads us to create effective programs for the populations we serve. Families reading this work may acquire a better appreciation of another person’s lived reality and an identification of the impact and influence of the disease on the family unit. Empathy, awareness of the condition, and insight into friendship could be benefits for peers. Third, for the participants of this research, the information exchanged allows for the gift of knowledge of a private personal nature to enhance the lives of social groups mentioned and for participants to enrich their own personal growth, reflection, and inspire others. Finally, for myself, I have a keen interest in this subject matter as I am a social worker, working with youth, and I live with type 1 diabetes.

There are two underlying principles for exploring this topic through adult participants instead of adolescents. First, obtaining consent for participation in a study is more easily obtained than obtaining consent from a parent of an adolescent. An adult simply reads the consent form and decides to consent to the study whereas in a study that
recruits youth participants, the adolescent’s parent must sign the form for the researcher to obtain consent to interview the youth. Second, adults may be more likely to disclose personal information about their youth, as they are now adults and are not currently living the experience they about which are being interviewed about. Adolescents may feel that they have less freedom to say what they want because parents or other adults will be upset with them if they say something critical. Diabetic adults may have a better understanding of their experience as a youth as they are not currently living it, and they offer a unique perspective on their experience through the recollection of their memories.

A final consideration for researching this topic is the lived experience of the researcher. I am a social worker living with type 1 diabetes whose social work practice has primarily focused on youth. I believed that I had the ideal skill set to investigate this population. I have been living with type 1 diabetes for fifteen years; diagnosis for me occurred when I was 20 although attending university. I decided that my own experience of living with the illness and my passion for understanding youth would give me insight into this group of people. A further examination of my place within this research study is discussed in following chapters; my methods and methodology, discussion, and concluding chapter.

**Summary.**

Type 1 diabetes is an autoimmune disease that typically appears in children and adolescents. The research suggests that management of this illness is complex and poor care will result in long-term health complications (Helegeson et al., 2007; Rubin & Blumer, 2005). The purpose of this study is to build upon current understanding of the impact, influence, and significance of relationships in lives of youth who live with type 1
diabetes. Ideally, by understanding the interconnectedness and complexities of relationships for this population, steps towards understanding youth living with diabetes, their relationships with others, and self-care during this period will result.

Chapter One offers an introduction to the problem, the purpose of the study, and the research question. Chapter Two provides a literature review of key terms in this research area, incidence and prevalence, challenges for youth, mortality, quality of life, effective illness management, mental health, family relationships, peer relationships, service provider relationships, and community relationships. Chapter Three presents the philosophical basis for this study, describes the methodology used, as well as relevance, rigor, and feasibility of the study, and situates the writer in the context of the research. Chapter Four provides a description of the results from conducting the procedure as outlined in the previous chapter, the demographic analysis and a discussion on how the sample size and composition heavily influenced the conclusions in this study. Chapter Five, the discussion chapter, examines the thematic analysis of the interviews. Here, I identify four main themes; knowledge, the impacts of diabetes, constructive and deconstructive factors in relationships, and self-awareness, and identity. Within each of these main themes, underlying sub-themes materialize. Chapter Six discusses the limitations, ethical considerations, future research in this area, and the implications for social work practice, participant life lessons, and final thoughts regarding this study.
Chapter Two: Review of the Literature

Focus of the Review

There is an abundance of literature regarding type 1 diabetes. Therefore, it is necessary to limit the focus of this research to the pertinent issues regarding youth with type 1 diabetes and their relationships. The purpose of the review is to provide the reader with a background understanding of the research regarding youth with type 1 diabetes, their relationships, and the management of the illness.

To begin, it is important to identify key terms in order to familiarize the reader with the language and understanding of the management of this illness. Then the discussion will shift to examine the incidence of the illness, the prevalence of the disease, services for youth in the Prince George living with the disease, the challenges experienced by the youth. This literature review also explores the issues of mortality, the quality of life, effective management of this condition, mental health and financial considerations when living with type 1 diabetes. To conclude, this section reviews the literature regarding four areas about the impact of living with diabetes on family relationships, peer relationships, service provider relationships, and community relationships.

Key terms.

Youth. Schilling, Knafl, and Grey (2006), in their qualitative research on diabetes management with adolescents, defined a youth as a person who begins to engage in more self-care. The writers state this typically begins at eight years and self-sufficiency reaches maturity at 19 years. The rationale for this definition is that children and youth managing a chronic illness participate in self-care out of necessity unlike, other children and youth,
who develop those skills based upon chronological developmental milestones. For the purposes of this study, the definition of a youth will be when participants in this study began to provide more self-care, typically between the ages of twelve to nineteen years.

**Family members.** For the purpose of this study, family members are adults, relatives, or siblings of a youth living with diabetes. These individuals usually live with the person who has type 1 diabetes and likely participate in some care giving activities regarding the youth’s health. A family is a combination of two or more people linked through birth, adoption, and/or consent to living together through marriage or as common-law partners (Hick, 2002). This connection fosters a feeling of love, a caregiving system, and a manner in which to organize and fulfill tasks that are necessary to participate in society. A family member may also consist of an adult caregiver or siblings when a child is involved in the foster care system.

**Peers.** Individuals form a group based upon linking their own characteristics to others that who are similar to themselves. They view others in the group to be their equals and they conform to the same norms (Helegeson et al., 2007). During adolescence, peers are the main source of influence, information, and identify formation. These persons may be of the same age, share common interests (school, extra-curricular activities, religion, and culture), same or different gender; linkages occur by some combination of these variables. Adults in this study will be reflect upon the peer relationships they experienced during their adolescence. Peers in this study are both youth living with diabetes and youth living free of diabetes. When discussing participant peer relationships with the adults in this study, a distinction occurs if the peer relationship is with a peer who does not live with type 1 diabetes or a peer living with type 1 diabetes.
Community members. Hick (2002) defines community as “a group of people having common ties or interests and/or living in the same locality or district” (p. 275). In this investigation, the term community refers to the geographic location that the participant grew up in and the interests that are located in that community. Examples of community members include soccer coaches, teachers, and a minister. Examples of community groups are a youth group, dance troupe, and Church youth group.

Service providers. For the purpose of this study, service providers consist of persons who are part of a team of people who gather to assist, support, educate, and/or encourage people with type 1 diabetes to manage their illness. These people join the team under two circumstances. The person with diabetes requests their presence or they may join the team because of complications from the diabetes or other circumstance (Bodil et al., 2001).

Diabetes team. A diabetes team consists of a group of professionals that assist youth living with type 1 diabetes in managing the illness (Bodil et al., 2001, Canadian Diabetes Association, 2010g). Each person has different roles and responsibilities. Team members can include a family doctor, paediatrician, pharmacist, diabetes nurse educator, dietician, podiatrist, endocrinologist, ophthalmologist, social worker, psychiatrist, and psychologist (Canadian Diabetes Association, 2010g; Rubin & Blumer, 2005).

Disability. A disability is defined as when “there is any restriction or lack of ability (resulting from the impairment) to perform an activity in the manner or within the range considered normal for a human being” (Hick, 2002, p. 275). For persons with type 1 diabetes, a disability can occur through complications from poor management of the disease and/or by the disease itself. There are both long and short-term complications.
Examples of physical dangers include, increased risk for coma (short term), blindness, amputation, kidney dialysis, nerve damage, slower healing time from illnesses/injuries, risk of infection in injuries, heart disease, stoke, infertility, mental health issues, and sleep disorders (long-term) (Diabetes Day-Care Unit-CHUM-Hotel-Dieu, 2005; Rubin & Blumer, 2005).

**Blood sugar or blood glucose.** This refers to the measurement of blood glucose in a person’s body (Diabetes Day-Care Unit-CHUM-Hotel-Dieu, 2005). The normal range for a person’s blood sugar is between 4-7mmol/L and 7-10mmol/L, two hours after a meal. To check a person’s blood sugar, a personal home monitoring system is used.

**Hyperglycaemia.** This condition arises when a blood sugar level rises above the targeted level. The condition develops when the amount of insulin in the blood is not sufficient to handle the amount of glucose released into the bloodstream (Diabetes Day-Care Unit-CHUM-Hotel-Dieu, 2005). Symptoms include trembling, heart palpitations, sweating, vision changes, difficulty speaking, headache, dizziness, difficulty concentrating, anxiety, hunger, nausea, tingling, moodiness, and indecisiveness (Rubin & Bulmer, 2005).

**Hypoglycaemia.** This condition occurs when a person’s blood sugar is below normal levels, below 4 mmol/L (Diabetes Day-Care Unit-CHUM-Hotel-Dieu, 2005). This takes place when there is too much insulin in the blood relative to the amount of glucose entering the circulation. Symptoms vary from confusion and nervousness to sweating, shaking in the hands, moodiness, and numbness in the arms and hands (Walsh & Roberts, 2000). Left untreated, severe hypoglycaemia can cause loss of consciousness or convulsions.
**Ketoacidosis.** Ketoacidosis is a temporary condition that results when the body does not have enough insulin. This condition can be life threatening and is characterized by nausea, vomiting, abdominal pains, fruity breath, rapid breathing, extreme tiredness, and drowsiness (Walsh & Roberts, 2000).

**Insulin pump.** This programmable device, about the size of a pager sends a continuous stream of insulin into the blood stream (Walsh & Roberts, 2000). The device replaces insulin injections by having a plastic catheter attached to either a teflon infusion set or a small metal needle inserted through the skin for gradual absorption into the blood stream (pp. 264).

**Incidence of Type 1 Diabetes.**

Type 1 diabetes has become a global phenomenon. The incidence or frequency at which type 1 diabetes is occurring varies from country to country. The hope is to find possible causes, possibly predicting the pattern of the illness as the disease is increasing world wide, particularly in children under the age of five (Sperling, 2005). Karvonen et al. (2000) report in their study of fifty countries, there were 19,164 diagnoses of the illness in 75.1 million children. Finland and Sardinia had the highest incidence with 36.8/100,000 and 36.5/100,000, and China and Venezuela were the lowest at 0.1/100,000. The countries that had an increasing rate of type 1 diabetes in children were Canada, Norway, Sweden, Portugal, New Zealand, and the United Kingdom from the years 1990-1994.

Newhook’s et al. (2004) study reported the highest incidence of type 1 diabetes in children in Canada was in the Avalon Peninsula in Newfoundland; there were 294 children with the illness found over a 16-year period (1987-2002). This was deemed one
of the highest incidence rates worldwide. In British Columbia, Halton (1992) has the overall incidence rate of 80 persons/100,000 living with the condition.

**Prevalence of Type 1 Diabetes.**

Epidemiologists have begun to study the prevalence, or many people live with this disease. In Canada, type 1 diabetes effects 555/100,000 persons (Canadian Diabetes Association, 2010g). Researchers suspect that one reason for Canada’s high rates of type 1 diabetes is the types of people that live in Canada. Demographics may account for the influx of persons with this illness. Canada is a country with multi-generational immigrants from Europe and since there is a higher number of type 1 diabetes in some European countries, the prevalence of the illness shifts due to population demographics. Halton (1992) notes in British Columbia, children under the age of 18 live with type 1 diabetes, which is a rate of 166/100,000.

**Services for Type 1 Youth living with diabetes in the Prince George Area.**

British Columbia Children’s Hospital is the primary centre for children in need of medical care. Halton (1992) mentioned that the province’s Children’s Hospital followed over 900 children with type 1 diabetes in 1992. For type 1 diabetic children and youth, this hospital provides a lending library of resources, diabetes management information and education, assessment and support for children, youth, and their families. However, most families in the Prince George area receive services locally.

In Prince George, a diabetes clinic is located at the University Hospital of Northern British Columbia. The diabetes team at that location consists of a nurse educator, a dietician, and a physician specializing in diabetic care. Referrals to the team occur through the family physician. This team supports a person after her/his initial diagnosis
and provides care. Care consists of nutritional information, medication education, referrals to Children’s Hospital, and access to a doctor that specializes in diabetes issues. A 2007 survey of resources for children in the Prince George area reported that sixty families at that time were currently accessing services from this diabetes team (Friedrich, 2007).

In addition to a diabetes clinic, Prince George has a local chapter of the Canadian Diabetes Association. This agency provided education on diabetes management, cooking classes, and guest speakers. The organization estimates there are 120 persons that identify as having type 1 diabetes (personal communication, February 21, 2009). A key service the Canadian Diabetes Association offers is its diabetes camps for children. Designed specifically for children and youth with diabetes, the camp has medical personnel for the campers, appropriate nutrition, an understanding of the day-to-day workings of the illness, and provides fun for the campers. I attempted to collect the total number of youth with type 1 diabetes in Prince George area. However, due to privacy issues I was unable to gather the information from the diabetes clinic located in the University of North British Columbia Hospital (personal communication, August 12, 2010). However, in the Prince George area there are resources in the medical field (diabetes centre, family physician) and a non-government organization (Canadian Diabetes Association) to serve this population.

**Challenges of Youth Living with Type 1 Diabetes.**

Becoming an adolescent produces an onslaught of physiological, emotional, and psychological changes (Grey et al., 2001; Karlsson et al., 2008). Puberty for adolescents with type 1 diabetes involves a multitude of risks and challenges. During adolescence, a
hormonal imbalance occurs that is specific for youth living with diabetes. They have no insulin production and their body is experiencing developmental hormonal changes. At the biological cellular level, the youths’ bodies have insulin and hormones competing for entry into the cell system (Friedrich, 2007). This competition results in insulin resistance, which creates fluctuating blood sugars (Amiel et al., 1986; Grey et al., 2001). The instability of blood sugars creates short-term risk. These risks range from moodiness and hypoglycaemia, hospitalization, diabetic coma, and death (Rubin & Blumer, 2005). The more volatility there is in blood sugars, the more the increase in long-term risks. These risks typically will not manifest for 10-12 years after adolescence. Youth living with type 1 diabetes may not understand the impact of poor management because the damage to their bodies will not appear for several years (Diabetes Day-Care Unit-CHUM-Hotel-Dieu, 2005).

Youth with type 1 diabetes are naturally developing autonomy through the struggle to gain independence in identity formation and as manager of their health (Karlsson et al., 2008). Besides the demands of diabetes, they are also working through the developmental milestones of maturity and adulthood. These tasks consist of developing their sense of self, acquiring autonomy in all areas of life, and beginning to broaden their focus from the salient tasks of childhood; such as friendships, academic success, and community conduct, to include emerging tasks of adulthood such as work, intimate relationships, and future life-goals (Roisman et al., 2004).

Youth living with diabetes are learning to manage their health although they are experiencing a developmental process. During this phase of development, there is the continual push and pull effect between adolescents and their parents. Hood et al. (2007)
state that this shifting of autonomy impacts diabetes related decisions. The diabetes influences not only decisions but also the psychological profile of the individual. A study by Buchbinder et al. (2005) concluded that, “Participants revealed that…diabetes rendered them as ‘other’ during a time in their lives when they are intensely self-conscious and in which conformity is a survival skill, indicating the potent influence that diabetes can have on adolescents’ psychosocial wellbeing” (p. 12). Adolescence becomes increasingly complicated for this population. It is during this period that there are added responsibilities to manage their care and some adolescents lack the ability to complete the tasks required. This result produces a lower compliance with a treatment regime than at other stages of development and this lowered management practice affects the long-term outcomes for this population (Charron-Prochownik & Arslanian, 1997; Grey et al. 2001).

**Mortality and Quality of Life.**

Managing type 1 diabetes involves a complex series of events that a person must carry out to maintain and prolong her/his health. The tasks required are demanding and never ending. Coffen and Dahlquist (2009) reviewed the complexities of diabetes management. They estimated that the regimen for type 1 diabetics has on average about 25 areas of management that contain over 600 tasks. Their research revealed that youth living with diabetes needed to have a working knowledge base in the following domains: etiology, pharmacology/insulin, insulin technique, monitoring, healthy eating, being active, hypoglycaemia, hyperglycemia, ketoacidosis, stress/illness, traveling, continuous/subcutaneous insulin infusion, complications, general knowledge about the illness, and miscellaneous items. The sheer magnitude of this list can be daunting for some people living with diabetes. The ability of a person to cope and manage effectively
becomes a factor in the health of the patient. The tasks may become overwhelming, or be easily forgotten by youth living with type 1 diabetes or wilfully neglected in an attitude of rebellion. Both results produce poor management, a situation where a youth living with type 1 diabetes finds her/his health is at risk.

From this set of circumstances, it is not surprising that 15% of youth with type 1 diabetes will die by the age of 40 (Portuese & Orchard, 1995). In addition, the Canadian Diabetes Association states that life expectancy for people with type 1 diabetes can be shortened by as much as 15 years (Canadian Diabetes Association, 2010b). Soedamah-Muthu et al., (2006) compared diabetic and non-diabetic mortality rates in a seven-year period (1992-1999) in the United Kingdom. They concluded that mortality rates continue to be greatly elevated in those with type 1 diabetes. In the United States, type 1 diabetes is the fifth leading cause of death and a major health problem affecting nearly 130,000 American children and adolescents (Grey et al., 2001). In 2008, the American Diabetes Association reported the number of persons with type 1 diabetes under the age of twenty is 186,300 or one in every 400 to 600 children. (American Diabetes Association, Statistics, 2010). For youth diagnosed with this disease, their prognosis is poor and their lives are changed.

With the complexities of management, the never-ending array of tasks then amplifies the risk of complications from this disease. Cardio-vascular disease is a complication that results from poor management of diabetes. In fact, up to 80% of people with diabetes will die from a heart attack or stroke (Canadian Diabetes Association, 2010e). People with diabetes may develop heart disease 10 to 12 years earlier and die from these events at rates much higher compared to people living free of diabetes. The
rate for developing heart disease is three times higher for diabetic men and five times higher for diabetic women compared to the general population (Canadian Diabetes Association, 2010e). With the risks of heart and stroke disease for this population, medical professional stresses the importance of effective management to their patients. For youth with type 1 diabetes, this means effective self-management strategies for their diabetes now. These short-term and long-term risks may cause quality of life issues for these youth in their futures.

**Effective Illness Management.**

The research indicates that when youth with type 1 diabetes manage their illness in an effective manner, the complications from the illness drop considerably during adulthood. Many studies focus upon how to get youth living with type 1 diabetes to maintain optimum metabolic control (Grey et al., 2001; Hood et al, 2007; Hislop et al., 2008).

The objective for effective illness management is to have stable metabolic control over blood sugar levels. When the blood sugar levels are optimal, the prognosis for youth with type 1 diabetes is that of an average person. Good metabolic control reduces the physical complications of the illness and the threat of impaired mental health.

**Financial Considerations when Living with Type 1 Diabetes.**

The Canadian Diabetes Association (2010a) notes on their website that a person with diabetes usually incurs medical costs that are much higher than a person who does not live with diabetes. These costs include: diabetes management supplies such as syringes, glucose testing meters, test strips and insulin pumps; insulin and/or other diabetes drugs and therapeutics; other medication to lower cholesterol and blood pressure,
more frequent medical visits; diagnostic tests and specialized home care visits; and rehabilitation or permanent residential care should debilitating complications arise. The Canadian Diabetes Association also reports that provincial and territorial government drug plans and medical supply costs differ throughout the country (2010a). This organization on their website notes problems in the medical system with some plans covering almost all costs for all the medication, supplies, and devices, which are needed to adequately manage diabetes, although other jurisdictions provide little or no coverage for these same items (2010a).

In British Columbia, there is a variety of financial programs to assist families who care for youth or children living with type 1 diabetes (Government of British Columbia, Ministry of Health, Medical Supply Coverage, 2010). Families in this province are eligible for financial assistance if they are under a certain income and insulin pumps are free to children under 19 years of age. However, the cost of infusion sets and reservoirs, necessary items for the insulin pump to impacts are not included and can cost up to $200 per month. The cost of living with type 1 diabetes, varies from person to person, depending upon eligibility for drug programs and extended health and insurance coverage, which fluctuates from person to person (Government of British Columbia, Ministry of Health, Medical Supply Coverage, 2010).

Mental Health Issues.

Youth with type 1 diabetes have an increased risk of developing a mental health issues than the average population (Friedrich, 2007; Rodin & Daneman, 1992). The research also shows mixed results on the influence of type 1 diabetes on mental health in adolescence. Many studies associate type 1 diabetes with an increased prevalence of
mental health difficulties, including anxiety and depression, which ranges from childhood into old age (Hislop et al., 2007; Lawrence et al., 2006; Lloyd et al., 2004). Youth with type 1 diabetes are at a higher risk of mental health issues than the rest of the population. Symptoms of depression are more common in people with diabetes when compared with the general population, and major depression is present in approximately 15% of people with diabetes (Canadian Diabetes Association, 2010c). The rate of living with an anxiety disorder is six times higher than in the general population (Diabetes Day-Care Unit-CHUM-Hotel-Dieu, 2005). A hypothesis for the increased risk to mental health is that the patient becomes overwhelmed with the day-to-day management of ongoing tasks, complications and never-ending management, which leads to a sense of hopelessness, which increases low and high blood sugars, which then leads to a higher risk of anxiety and depression (Polonsky, 1999).

With many studies noting the vulnerability of type 1 youth for being at risk for mental health issues, there is also research that reports no substantial risk in comparison to other youth. Helegeson et al. (2007) in their three-year longitudinal study concluded there was no significant difference in the two populations in the following categories: depression, anxiety, self-worth, thinness, bulimia, internalizing of problems, externalizing of problems, adaptive skills, and school maladjustment. The only difference they noted was in the area of social competence. In this category, the researchers noted that the youth living with diabetes had greater difficulty than peers living free of type 1 diabetes in acquiring social competence. They concluded that this might be due to self-care behaviours, the social pressures to engage in activities that contradict diabetes care, and poor peer relationships.
With studies stating there are both increased risk and no significant difference in risk to mental health to this population, the research has begun to focus on the importance of coping as a preventative factor in mental health for diabetics (Grey et al., 1998). The results from Grey et al. (1998) show three important outcomes for adolescents living with type 1 diabetes who received coping skills training (CST) as opposed to youth who did not receive the training. The first was lower haemoglobin AIC and better diabetes self-efficacy. The research stated that youth participating in the CST were less upset about coping with diabetes than adolescents receiving intensive insulin management alone. Finally, researchers noted, “adolescents who received the CST found it easier to cope with diabetes and experienced less of a negative impact of diabetes on quality of life than those who did not receive CST” (p. 902). It is clear that how individuals cope with life stressors will influence their long-term mental health outcomes. A variety of studies have demonstrated that psychosocial factors, such as stressors and coping styles are often associated with neglect of self-monitoring, ignoring dietary recommendations, and not being consistent in insulin injections during adolescences (Charron-Prochowink & Arslanian, 1997; Grey et al., 2001). Good mental health and coping strategies act as an important influence on the effectiveness of management of diabetes (Grey et al., 1998). Coping skills appear to be key elements that influence the long-term health of youth living with type 1 diabetes.

**Family Relationships.**

Another element that appears to be influencing positive health outcomes is the relationships in the lives of youth living with diabetes. Parents and family members are important, as adolescents require different types of support in managing this illness.
Friedrich (2007) reports that management of the illness is complex, demanding, and requires realistic goals for the youth and family. Buchbinder et al. (2005) echo this sentiment in their qualitative study about the youths’ perception of their illness. Among their detailed findings, the authors suggest that diabetes has a substantial impact upon family life, with adolescents aware of the constant concerns of their parents and siblings about diabetes. Silverstein and Bandyopadhyay (1995) report that often these young people feel guilty about the burden they are to their parents and are angered by the day-to-day responsibilities of their illness.

In a parent-youth relationship, chronic illness management adds another dimension for disagreements during a time when conflict in the relationships is already high. Researchers created the Diabetes Control and Complications Trial (DCCT) a diabetes conflict scale in 1993. By designing the DCCT, they established a standardized approach in managing type 1 diabetes in children. The approach consists of intensive insulin therapy as standard management, and subsequently, clinical practice has focused on intensification of diabetes management to promote optimal glycaemic control and prevent complications.

This scale became a standard in diabetes research and Hood et al. (2007) created an updated version of the scale, which included current terminology around diabetes management as well as more questions about blood sugar monitoring and prevention of hypoglycaemia. The conflict scale measures negative emotions around blood sugar monitoring, quality of life, and perceived parental burden from diabetes management (Hood et al., 2007). This research is valuable in understanding how diabetes affects parent-youth relationships.
Although diabetes can be the main source of conflict, other factors of family functioning also need consideration. Hood et al. (2007) highlight the fact that family-specific variables play a key role in diabetes management in children and adolescents. Variables can include poverty, parental stress, family violence, single-parent households, and lower socio-economic status. Thus, it is important to consider these family specific factors in conjunction with the degree of diabetes-specific conflict when one is attempting to provide intervention for diabetes management and control.

Aside from conflict, family can also be a source of support for the youth. Youth may rely on parents to assist with management tasks and to provide support and advocacy. In addition, parents were often present for the original diagnosis. Parents can encourage, motivate and assist their adolescent to manage their health. Hentinen and KyngAx (1993) state that two outcomes happen when the actions of the parents are supportive, accepting, motivating, and the parents taken an interest in the youth’s life. First, improved diabetes management is noted by health care providers. Second, the actions of the parents allow the youth to connect with their parents and ask for help when they are struggling with their illness, and thereby improving their management. These types of supportive characteristics aid in the transition from parent-care of the diabetes to self-care.

All children, over time, begin to take over tasks for self-care. For diabetic children who are transforming into adolescents, self-care tasks have an expanded form. As Schilling et al. (2006) state, by age eleven the transition of parent to youth management has begun. They describe four ages and stages of transformation. In the first transition, preadolescence, age eight to eleven years old where the parent performs much of the required care and low-levels of conflict exist. For eleven to fifteen years olds, youth are
checking their own blood sugars and giving their own injections. The conflict between
the parent and youth is high. In mid-adolescence, fifteen to seventeen years old, the youth
are in charge of almost all of their diabetic care tasks. The least number of conflicts
occurred in the seventeen to nineteen years old category as youth take full responsibility
for their diabetic care. Schilling et al. (2006) states that “although the adolescent was
clearly in charge of diabetes care, parents continued to remind their children to perform
various activities of self-management and to occasionally “pinch-hit” (p.421). Regardless
of the age of their children, parents invest in the care of the adolescents and the entire
process can be complex as diabetes management and puberty challenge the youth and
her/his parents.

**Peer Relationships.**

Aside from family, peer relationships may become the most influential force
during adolescence. Youth spend much of their structured and unstructured time with
friends at school, work, sports, clubs, visiting at each other’s homes, and in other social
situations. Peers may have direct and indirect effects on self-care behaviour and there is
evidence of both the positive and negative aspects of peer relationships on self-
management. Friends are an important influence on youth living with diabetes and self-
management.

In a study of youth living with diabetes, relationships and diabetes care, Greco et
al. (2001) discovered that emotional connecting and companionship with friends was
more significant than emotional support from family members regarding their diabetes.
Youth living with diabetes looked to friends to exercise together, share healthy snacks,
and to accommodate her/him when meal planning. The research also concluded that
friends could provide assistance to the youth living with diabetes about her/his self-care. Examples include; the friend reminding her/him to check her/his blood sugar or take insulin, and giving food when there is a low blood sugar. The study concluded what although friends were not as diligent as parents regarding self-management tasks, they were an important support for the youth.

Emotional support appears to be a key element in the youth’s ability to manage the illness. Greco et al. (2001) suggest that adolescents with few friendships, or who feel uncomfortable telling their friends about diabetes, may miss a valuable support system. Peer relationships can also support adjustment to diabetes. Another important factor to consider is how much power the youth is given by adults to disclose her or his health status. Dovey-Pearce et al. (2007) state when young people are able to decide to whom they want to disclose the diabetes there is a relation to increased acceptance and improved self-management in their diabetes as well as an improved outcome in peer relationships. In addition, the youth feel a sense of empowerment, as they are able to make choices, build confidence, and gain back control about their diabetes. Dovey-Pearce et al. (2007) concluded this process is normal as youth experience a transition from denial to acceptance regarding their condition. Having friends rally around a person who is going through a transition can make that transition smoother.

Research has been conducted to discuss relationships between youth living with diabetes and other youth. Silverstein and Bandyopadhyay (1995) reflect upon a youth camp where each youth living with diabetes brought a friend to camp to experience the day-to-day life of a diabetic. The comments from both groups of youth were quite positive. The youth living with diabetes reported “I like being able to show your friends
that you can do all the things that they can do” (p. 819). Friends who went to youth living with type 1 diabetes camp commented “I learned about what could happen and what to do when it happens” and “I learned that diabetes does not limit what you can do.” (p. 819). The study demonstrated peer acceptance, positive peer pressure, acceptance, and encouragement for diabetic self-care. Although documentation of positive experiences with peers exists, research also indicates that harmful actions occur between persons living with type 1 diabetes and other youth.

Researchers have asked questions about youth living with diabetes experiencing bullying or negative peer interactions because of their illness. Storch et al. (2004) report there is no direct research concluding that peers directly victimize youth with type 1 diabetes because they live with a chronic health condition. Although there is little research that provides a clear link between peer victimization between children or youth living with type 1 diabetes and other children or youth, there are arguments as to why victimization may be occurring and why it is difficult to establish a connection between peer victimization and children and youth living with type 1 diabetes. The literature suggests that the behaviours youth living with diabetes exhibit or the belief systems of the youth regarding their illness may be influenced strongly if the youth has a negative peer experience. For example, youth living with diabetes many require medical attention (hyperglycaemia) and this type of attention separates youth living with diabetes from their peers in two ways. First, the adults in the youth living with diabetes’s life may see her/him as fragile and attempt to protect or look out for the youth. Second, a youth may believe she/he is frail and seeks out attention from adults. These peers may view persons living with type 1 diabetes children as receiving “special treatment” or being the
“teacher’s pet”. In addition, Miller and Wood (1991) have suggested, “that some medically ill children come to expect high levels of attention from others, resulting in peers viewing the child as being too demanding” (p.406). Both results contribute to negative peer interactions.

Aside from behaviour, belief systems about diabetes influence youths’ relationships with their peers. Jacobson et al. (1986) found that 55% of newly diagnosed children did not discuss their diabetes with peers, and 35% believed that their friends would like them better if they did not have diabetes. That initial childhood belief system continues into adolescence and creates a division between the youth living with diabetes and her/his peers. Storch et al. (2004) observed that when youth living with diabetes believe that they are different and lack acceptance by peers, they will isolate from others and often blame peers for their isolation. This behaviour is considered normal, as people do not want to look at their belief systems as a cause of their own difficulties. However, Helegeson et al. (2007) state that when youth with type 1 diabetes feel as if they do not fit in with peers, they may be vulnerable to social pressures to engage in behaviours that conflict with diabetes. A mechanism for shifting the belief structure and behaviour for this population is for youth living with diabetes to connect with other youth living with diabetes. Connections to others who are like themselves may be a powerful aid to understanding themselves and their illness.

**Service Provider Relationships.**

Many researchers speak to the importance of a persons living with type 1 diabetes team for the youth and her/his family. Rubin and Blumer (2005) note that having a diabetes team provides continuous, supportive, and optimal care for people living with
diabetes throughout the course of their disease. Johnston (1973) was one of the first to acknowledge the need for a team approach for treating this illness. The Canadian Diabetes Association recommends that persons with the disease create a diabetes team to assist them with the management of the ailment due to the complexities of the chronic condition (2010g). Given the risk of complication, best care practices for people with diabetes include having a health care team (Bodil et al., 2001; Home, 1989; Mulcahy, 1999).

The team works to answer questions about management and to assist in the long-term care of the person. The team consists of a number of service providers with different roles and responsibilities. The family doctor and paediatrician are concerned with medication management and the general health of the youth. The pharmacist plays a key role in ensuring the administration of medication to the patient is prepared correctly (Johnson & Beach, 1997). Nurse educators and dieticians work to teach persons living with type 1 diabetes about insulin therapy, diabetes day-to-day health care, and food issues (Franz, 1981; Mulcahy, 1999). Specialists like podiatrists, endocrinologists, and ophthalmologists are experts called to deal with problems or to perform regular maintenance or to prevent complications from getting worse. Social workers, psychologists, and psychiatrists have a large role to play in the emotional health of persons living with type 1 diabetes. Psychiatrists are concerned about mental health issues, although psychologists focus on learning and brain development of the youth. Social workers may have the most diversified role on the youth living with type 1 diabetes team as social workers can be found in a variety of jobs and have various responsibilities and roles within those positions.
Jobs in the social work field can include positions in child welfare, mental health, community development, corrections, health care, crisis intervention, immigration, justice, and education. As a result, social workers perform various roles in the community. Roles can include an advocate, mediator, negotiator, speaker, group facilitator, researcher, coordinator, educator, activist, broker, initiator, and enabler (Hick, 2002; Johnson & Beach, 1997). For persons with type 1 diabetes the social worker can appear in any number of circumstances as a valuable member of their team.

Youth living with diabetes are engaging with a number of adults who are trying to assist them with their self-management. A diabetes team member’s goal is to promote good metabolic control for clients. The team acts as a means of promoting and maintaining good physical health and quality of life (Hernandez & Williamson, 2004).

The Dovey-Pearce et al. (2007) qualitative study of youth with type 1 diabetes and health care, found that “health care professionals could usefully emphasize other life areas and understand that diabetes, rather than being a separate set of decisions to make, fits in with other life experiences and outcomes that young people are pursuing” (p.87). This statement cautions service providers against labelling the youth with diabetes as simply a person living with type 1 diabetes. Furthermore, they advise that the diabetes team periodically review an adolescent care plan. The plan, devised in early adolescence or childhood, needs to be in line with a person’s social, psychological, and cognitive development. The plan may include educational and vocational aspirations, social commitments, hobbies, family life and relationships, as well as diabetes knowledge and self-care behaviours. The focus would be on minimizing the impact of diabetes upon these other life-areas.
Research has also focused on what youth want to improve with the services they receive regarding their care. Olson and Sutton’s (1998) discovered that patient empowerment is the core of effective clinical practice for service providers and the key to an improved quality of life for youth living with diabetes. These researchers used Anderson’s (1995) definition of empowerment as “the patient is the centre of goal-setting in diabetes care, the balance between a medically defined regime and having a life worth living are recognized, and relationship where the physician is seen as active and in control, whilst the patient is passive and acquiesce, is challenged” (p. 41). This definition is a key element in designing and effectively implementing services for persons living with type 1 diabetes.

Dovey-Pearce et al. (2005) published a study devoted to developing appropriate services for youth living with diabetes. Their research reported the following needs for this population. Youth want the same person who knows their story, a person who is interested in who they are and is not just concerned about the diabetes. Youth wanted home visits, service providers who are sensitive when they are upset, service providers who interact with them directly (email, text, cell phones), and someone who talks directly to them and not just to their parents. It is clear from the findings that relationships are a key component to the management of type 1 diabetes in adolescence. From this discussion, it is clear that youth living with diabetes want to be viewed beyond being a person living with type 1 diabetes patient and want the incorporation of their life goals into their diabetes care regime.

Community Relationships.
The final group of people involved in the lives of youth with type 1 diabetes are community members. As stated earlier, Hick (2002) commented that community is “a group of people having common ties or interests and/or living in the same locality or district” (p. 275). In this discussion, these people can include minor hockey coaches; youth club leaders, Catholic Church priests, or Highland dance instructors. To date, my literature review has yielded no information on these kinds of social relationships in the lives of youth living with diabetes.

There is a large section of data, however, surrounding teachers and the education system and youth living with diabetes. Outside of home, school is the primary location of children and youth in our society. Teachers play a primary role in the lives of children and youth living with type 1 diabetes during school hours. The roles and responsibilities for teachers when they have a person living with type 1 diabetes will vary according to the age of the person, her/his self-management capabilities, parent involvement, teachers’ union contract, comfort level in assisting with care, and legislation (Nabors et al., 2004). All of these factors will play a part in the relationship between person living with diabetes and teacher.

The literature informs us that teachers can inadvertently victimize persons living with type 1 diabetes in their classroom. Woodrich (2005) noted that this most often arises when teachers are unaware of their students’ health conditions. The teachers may not recognize the link between children’s illness and classroom behaviour problems (Amillategui et al., 2007). For example, a child or youth having a low blood sugar will behave differently than when her blood sugar is in the normal range. The child or youth living with diabetes, if she/he is aware of the low blood sugar may search for sugar, and
create a classroom disturbance, become moody, or may just leave the classroom (Amillategui et al., 2007). Teachers may consider these behaviours disruptive. For example, in 2005, a teacher in Florida forcibly removed an insulin pump from a student’s body because the device was beeping (a warning in the device to notify the user that insulin level is getting low) and he thought it was a cell phone (Bolder, 2005). Aside from not being aware about the condition, teachers may not know what to do to assist a student.

Douthat (2004) describes the parents of a student with type 1 diabetes who sued the school board for violating the Americans with Disabilities Act of 1990, after their son was prevented from checking his blood sugar levels in a classroom setting and administering insulin shots. Although there are situations where teacher victimization of the student has occurred, Peters et al. (2008) state victimization by teachers is relatively low. The authors concluded that the role teachers play is one of the key factors in peer victimization for students with type 1 diabetes.

**Summary.**

There is a vast amount of research about different aspects of the lives of youth with type 1 diabetes. In this study, I asked the question, *What do adults living with type 1 diabetes recall about their relationships with others, during their youth and what was it like living with a chronic health condition?* This examination began to explore this question with a definition of the key terms to provide a basis on which to have this discussion. Second, the literature review identified the incidence and prevalence of type 1 diabetes in the world, in Canada, and British Columbia. This overview provided a basis to discuss the services available for type 1 persons living with type 1 diabetes in the
Prince George area. This overview created a backdrop of the global, national, provincial, and local aspects of type 1 diabetes.

Next, I highlighted common issues associated with youth living with type 1 diabetes. It was pivotal to review this information in order to understand what it may be like to live with a chronic health condition. These included mortality rate, quality of life issues, effective illness management, and mental health. It was revealed that persons living with type 1 diabetes are more vulnerable to other illnesses and death than persons living free of type 1 diabetes.

The focus then shifted to the main aspect of the research question, *What do adults living with type 1 diabetes recall about their relationships during their youth?* A discussion of the literature reviewed family, peers, service providers, and community members as part of the relational experience of adolescents living with type 1 diabetes. Upon review, it appeared that youth living with diabetes face additional challenges because of their illness, which adds a complexity to their relationships. The diabetes and adolescence are influences on the relationships because of the physical aspects of the disease, self-care practices, and illness management.
Chapter Three: Methods and Methodology

This study targets the impact and influence of relationships in the lives of youth with type 1 diabetes. Phenomenology is the research method used to explore the research question. Creswell (1998) states that phenomenology describes the lived experience for several individuals regarding a concept or a phenomenon. This methodology explores the structures of humanity’s consciousness, through interviews with people, about their understanding of a particular incident (Polkinghorne, 1989). The basic purpose of phenomenology, according to van Manen (1990), is to reduce people’s experience of a phenomenon to a description of the underlying universal meaning or essence.

The methodological approach for this study is the process and philosophy of the Vancouver School of Phenomenology developed by Joan M. Anderson, a nursing researcher, at the University of British Columbia. This type of phenomenological research combines a blend of description, interpretation, explication, and construction to describe the phenomenon experience (Anderson, 1991). This paradigm allows for rich description, a clarification and interpretation of the experience though the research process, and manufactures an authentic voice of the phenomenon.

This chapter includes a discussion of phenomenology, a discussion of the phenomenological approach using the Vancouver School of Phenomenology method, and the 12-step process employed in producing and analysing the data.

Phenomenology

Phenomenology is both a qualitative research method and a philosophy (Creswell, 1994). The blending of the two has brought freedom and confusion to the research. The researcher seeks to understand the reality of others although allowing the participants to
guide the process. The process is authentic research as the study participants funnel the information to the researcher. However, the researcher is more than simply a recorder of the experience as she/he immerses her/himself into the phenomena being explored (Creswell et al. 2007).

Although the research process allows for freedom that is essential to this research method, it creates a paradigm that can be confusing and perplexing for researchers as they sort through the data they have gathered. Spiegelberg (1982) reports the main source of confusion is “there are as many styles of phenomenology as there are phenomenologists” (p. 131). This type of inquiry is rooted in the works of Husserl, Heidegger, Merleau-Ponty, Sartre, Spiegelberg, Ricoeur, and van Manen (Creswell, 1994; Dowling, 2007; Halldorsdottir, 2000). Philosophers differ slightly in their phenomenological philosophy and the accompanying research process. Choosing the right methodology can be perplexing as the researcher has many choices in the philosophical approach taken for phenomenological research. The key element for the researcher is to provide a clear outline of the particular philosophy she/he wishes to employ and the research process connected to that branch of phenomenology.

Types of Phenomenology

The essential framework of phenomenology involves the researcher collecting data from the persons who have experienced the phenomenon and developing a description of what is the experience, what did they experience and how did they experience it (Moustakes, 1994). Phenomenology derives its basic philosophical configuration from Edmund Husserl (1859-1938), a German mathematician. Husserl was known to call any project in process a phenomenology study (Natason, 1973). Husserl
emphasized the search for the “essential, invariant structure or essence”. The central underlying meaning of the experience emphasizes the intentionality of consciousness, and contains both the outward appearance and the inward consciousness based memory, image, and meaning of the experience (Creswell, 1998).

Essential to finding the underlying meaning of a phenomenon, Husserl proposed that phenomenological reductionism be employed. Phenomenological reductionism, epoche, or bracketing, requires the researcher set aside her/his preconceived beliefs about the phenomenon and simply be open to understanding the experiences of the participants in the research. Moustakes (1994), a phenomenological researcher believed that this initial step in the data analysis process occurs when the researcher sets aside, as far as humanly possible, all preconceived experiences to understand the experiences of participants in the study. Essentially, phenomenological reductionism, epoche, or bracketing is the practice of pausing one’s own belief system and experience although collecting data from persons who have experienced the phenomenon.

In this study, I had practiced bracketing through identifying my own personal biases, my own experience in living with type 1 diabetes, discussing the research finding with my supervisor and recording my thoughts about research in a reflective journal. It was through this process that I practiced transcendental phenomenological research. Patton (2002) note that transcendental phenomenology or heuristic inquiry places “the phenomenological emphasise on meaning and knowing though persona experience; it exemplifies and places the fore the way in which the researcher is the primary in qualitative inquiry” (p. 109). This type of systematic phenomenological research allows the researcher to analyse the data by reducing the information to significant quotes,
combining the statements into themes, and writing up a description from those themes. A
description of the context of the person’s experiences of the phenomenon combines with
the description of themes and context to illustrate the phenomenon to the audience
(Moustakes, 1994).

Although Husserl and Moustakes have been frequently cited in this type of
research, Martin Heidegger (1889-1976), another German phenomenologist, provides a
different understanding of phenomenology. His view was similar to Husserl’s about the
human experience being a source of knowledge. His work shifted from Husserls’ as he
focused upon how the lived experiences occur; and how the use of hermeneutics can be a
that “hermeneutics is a form of phenomenological inquiry that brings to the fore the
personal experience and insights of the researcher” (p. 107). Hermeneutic
phenomenology has two key elements that separate it from other forms of
phenomenology. First, the researcher must have a powerful personal experience of the
phenomenon being explored and must willingly participate in the research. Second, the
participants involved in the research must have an intense experience with the
phenomenon (Patton, 2002). The participant defines this intense experience and the
researcher documents the information.

This philosophy rejects the notion that bracketing a researcher’s own lived
experience is possible. Theorist van Manen (1990) states, “if we simply try to forget or
ignore what we already “know”, we might find that the presupposition persistently creeps
back into our reflections (p. 47). With this assumption, van Manen proposes that when
conducting research it is important to incorporate the preconceived ideas the researcher
has about the phenomenon. With the documentation of these ideas, the researcher can then reflect upon her/his own impressions, she/he becomes aware of what she already knows, and what biases exist. As the researcher begins to write about the topic, a balancing of the description and the interpretation of the phenomenon occurs (van Manen, 1990).

**Methodology- The Vancouver School of Phenomenology**

The essential goal of phenomenology is to find the meaning of the experience in order to build knowledge. This study will apply a hermeneutic interpretive philosophy using the Vancouver School of Phenomenology developed by J. M. Anderson. Halldorsdottir (2000) describes this method as “a unique blend of description, interpretation, explication and construction…aimed at increasing the greater social good” (p.53). The Vancouver School of Phenomenology assumes that a phenomenological construction transpires through the reality of the individuals who experience the phenomenon. The researcher adopts what Halldorsdottir (2000) states is “moderate realist ontology, believing in one real reality although embracing multiple co-existing realities within the subject domain” (p. 54). These multiple experiences then exist within a single phenomenon, which is the true essence of the phenomena.

Three characteristics set this method of phenomenology apart from others. First, in order to understand the world, the researcher must be able to interpret it. A researcher is able to perform interpretation though experience of conducting research and acknowledging the personal bias in the study in order to discover the essence of the study. Second, the researcher must make sense of the data in a meaningful way in conjunction with the research participants. Halldorsdottir (2000) describes the participants as
“dialogue partners” and “co-researchers” in the process. This collaborative approach is similar to other branches of phenomenology.

Finally, Halldorsdottir (2000) states the researcher “must learn the art of being open and receptive to that which she/he is trying to understand” (p. 53). This is what Ricoeur (1990) asserts that the researcher must do; she/he needs to be willing to be open to understand what is presented to her/him by the participants. Willingness is an important attribute of the researcher as it allows for an open-minded atmosphere, a free flow of information with the researcher open to any outcome. There is no particular importance associated with the outcome of the phenomenon under study other than obtaining the recorded experiences. The co-researcher, who is the expert in her/his lived experience, allows the researcher to discover the essence of the phenomenon.

The Vancouver School of Phenomenology adopts a 12-step methodological process. The steps include: (1) selecting the dialogue partners, (2) silence before entering the dialogue process, (3) participating in the dialogue (data collection), (4) sharpening awareness of words (data analysis), (5) beginning the consideration of essences (coding), (6) constructing the essential structure of the phenomenon (individual cases), (7) verifying the single case construction with the co-researcher, (8) constructing the essential structure of the phenomenon from all the cases (meta-synthesis of all the cases), (9) comparing the essential structure of the data, (10) identifying the over riding themes which describe the phenomenon (interpreting those themes), (11) verifying the essential structure (the findings) with the co-researchers, and (12) writing up the findings (Halldorsdottir, 2000). The next section will outline the procedure undertaken for
Step 1-Participants-Dialogue Partners.

It is essential to this research to choose the appropriate dialogue partners to answer the research question. Two methods of purposeful sampling occurred to gather research participants. The first type of sampling is criterion sampling. In criterion sampling, participants are chosen that meet some specific standard as described by the researcher (Marlow, 2005). The criterion was persons living with type 1 diabetes who were diagnosed with the condition before their nineteenth birthday. Halldorsdottir (2000) recommends that 5-15 cases be examined, with two dialogues occurring with each co-researcher for a total of 20 dialogues. Polkinghorne (1989) states a sample size of 5-25 participants is adequate and does not mention a specific number of dialogues. In this study, I aimed to identify 8-10 persons, ideally fifty percent male and fifty percent female. I was not particular about the person’s location as I felt that I could conduct interviews in person or speaking to her/him on the phone.

The second technique employed in this study was snowball sampling. This type of sampling transpires when some participants who have engaged in the research process then identify others with the same characteristics (Marlow, 2005; Patton, 2002). This type of sampling was unsuccessful in gathering participants. None of the research participants were able to identify another person who met the sample criterion. A further discussion of why this occurred is found in Chapter Four.

Along with the two types of sampling used to gather participants, various methods were used to locate the participants. First, as I am an insider in the type 1 diabetes
community, living with type 1 diabetes myself, I approached people I knew living with type 1 diabetes to participate in the research and/or to direct me to others. One participant was identified through this method. Next, after contacting the local chapter of the Canadian Diabetes Association, I was given permission to speak about the research at a diabetes event. Through this means, three persons chose to participate in the research. The Canadian Diabetes Association referred me to the Juvenile Diabetes Research Foundation walk fundraising event co-ordinator. The event co-ordinator was provided an information package about the study. After receiving approval from the event co-ordinator, I was allowed to set up an information booth about the research and recruit participants. I acquired one participant from this recruitment.

Throughout the Prince George area, flyers about the research study were posted in public places in the city including medical labs, pharmacies, the Diabetes Centre, public bulletin boards, and the YMCA. Two participants were located through this process. The final type of participant recruitment took the form of word of mouth advertising. I accomplished this process by sending out emails to different local list servers and by talking in person to people about my research. Frequently, people would reply stating, “I know someone who might be interested; can you email me your information about the research so I can pass it on to my friend?”

Step 2-Silence.

In order to prepare to understand, I had to sit in silence to think about the process I would be undertaking. To get ready to process and discover meaning from the participants I would be interviewing, I reviewed literature and wrote in my diary about my own experience of being diagnosed with type 1 diabetes. I then reflected upon my
experience with people in my life. Upon meeting the participants, I interviewed them, listened, transcribed, and processed the information they gave. I wrote about my impressions of the time we spent, the thoughts and images that were similar to my own experience, and those that were different. Halldorsdottir (2000) states the use of a reflective journal is part of the learning process. I was able to reflect upon my preconceived notions of the research and become aware of my thoughts about the research as the study occurred. This process allowed me to hear the participants’ story. The process that I engaged in although conducting my research is called reflexivity. Reflexivity happens when a researcher reflects about her/his preconceived ideas, her/his thoughts and then proceeds with the research, more fully aware of the biases in the research study. This process clearly identified and implemented a continuous self-critique of my own experience (Dowling, 2007). The process undertaken by myself allowed for clarity in the research.

Step 3-Data Collection-Participating in a Dialogue.

Participating in a dialogue is one of the key steps in the research process. The researcher needs to be aware, open, and attentive to the participant and her or his story. Participants came from a variety of circumstances. Upon agreement by the participant, a location was determined; and consent forms reviewed; and signed. The interview was audio recorded; and then transcribed by myself. Once a transcription was completed, it was emailed to the participant, who then confirmed the data; the option was given to add any further reflections upon the conversation. This approach was important as the participant is viewed as the expert regarding this experience and the researcher is simply there to guide the process.
Step 4-Data Analysis-Sharpened Awareness of Words.

As interviews were completed, I read and reread the content, sifting through ideas about the experience. Each time I read the interviews, I could visualize the person; and remember the context of the conversation; as well as the before and after comments not on the tape. These images stayed with me as I reflected upon these lives in my reflective journal.

Step 5- Coding-Beginning Considerations of Essences.

Patton (2002) reports that coding of information is a necessary first step in organizing the data from the field. Coding in phenomenology involves identifying the key statement and themes from the participants’ dialogues (Halldorsdottir, 1990). This process was done first systematically, by assembling information from the nine questions asked and categorizing it to the co-responding question. A printed transcript of a participant’s interview used the word for word responses of a participant to answer the questions. I cut and pasted these responses onto large sheets of paper. I then placed those responses under the corresponding research questions. From each question, I chewed out themes and sub themes characterizing the participant’s responses. Each question generated a number of similar themes regarding the question. For example, the first question stated “What was your experience when you found out you had type 1 diabetes?” Themes contained the responses included symptoms prior to diagnosis, what occurred during and after their diagnosis, their experience in the hospital, feelings about the process, and no memory about diagnosis. I noted similarities and then began the coding process in response to my research question.
Step 6- Constructing Initial Case Structure.

The initial coding process began as participants answered questions and their responses were placed under each question. The responses began to form themes and subthemes and thus the beginning of a case structure began. When the completion of coding process ended, all of the themes from the different participants were sorted and grouped (Halldorsdottir, 2000). The meaning of the experience emerged through this process. Through sorting, I began to interpret and understand a lived reality of an individual living with type 1 diabetes. I read and reread each individual’s transcript and then assembled the themes from each question. After I had determined themes from within each question, I then sorted the themes across questions and an authentic description of these lives was constructed. I then placed the themes in context in relation to the original research question. This process produced a description of the phenomenon being explored.

Step 7- Verification of a Single Case with the Participant/Co-researcher.

Once the description of a single participant’s data was compiled, this information along with a transcribed verbatim interview (if not previously verified- step 4), was emailed to each participant. The participant was given the opportunity to review her/his written words and a chance to ponder the themes I had generated to see if there was any other information to be added to the research. Creswell (1998) calls this process member checking. This process is necessary to capture the essence of the phenomenon.

The verification process is vital in phenomenological research and for this study. There were participants whose information was not verified. However, the information was used in the data analysis process. The rationale for doing this was that the unverified participant information was similar to the verified participation information.
It is important to note that the term co-researcher is frequently used to describe participants involved in the phenomenological research process (Moustakes, 1994). Halldorsdottir (2000) tells us that the researcher invites the participant to engage in a dialogue with the researcher and thus becomes the co-researcher in the study. In the study I conducted, the term co-researcher has not been used to describe the participants. The rationale for this decision is that the term can be confusing for the participants and for the readers. I chose the term participant to promote clarity and consistency in the study.

**Step 8- Constructing the Essential Structure of the Phenomenon-Meta-synthesis.**

Halldorsdottir (2000) informs us that, “this process (meta-synthesis) involves comparing all different dialogues in order to find the common threads, as well as differences” (p. 64). This is an essential part of interpretative phenomenology. I combined all of the individual cases into one case that would describe all of the experiences reported by the participants. The rational for this process was to reveal the true essence of the phenomenon being explored. I read and reread the interviews (both verified and unverified), reviewed all the themes listed in relation to the questions asked (step 5) and then experienced the process of being silent in order to assemble the essence.

**Step 9- Comparing the Essential Structure with the Data.**

This step is a verification feature of this phenomenological process. I compared the essential structure of phenomenon with the actual transcripts of the participants. I reread each interview and compared it to the construction of all the other interviews combined. Both interviews that were and were not verified were used in constructing the essential case structure.
After I re-read the interviews and initial meta-synthesis, I wrote notes describing my interpretations of the information gathered from the participants. I did this to further my understanding of the experience of the participants. This procedure allowed me to consider all of the potential outcomes from the data. It is in this step that the true identification of themes surfaced. I printed out on paper each participant’s themes that were generated from the nine questions asked in the interview. I then noted the themes found in relation to each of the nine questions. Next, I cut out the themes from each of the nine questions from the paper with the question number labelled on the back of the paper. After that process, themes were resorted (coded), again to construct the essence of what the participants were saying. This process produced a more definitive essence of both the individual and entire participants’ group experiences.

**Step 10: Identify the Over-riding Themes Describing the Phenomenon.**

After comparing the essential structures with the raw data, I was satisfied with the over-riding themes that I had identified. These final themes became my understanding of the essence of the phenomenon being studied. Denzin (1994) states that “interpretation is an art; it is not formulaic or mechanical” (p. 502). This quote suggests that the researcher needs to takes time to mentally process, understand, and interpret the phenomenon. The Vancouver School of Phenomenology recommends that a route of silence, reflection, selection, identification, interpretation, construction, and verification occur repeatedly until the researcher feels that it is “right” (Halldorsdottir, 2000). In the study I conducted, I reviewed the process of theme analysis through reading and rereading interviews and comparing the essential structure of the data with the interviews. I placed the themes on large pieces of paper to which allowed me to move the data around. I was sorting it and
allowing the comparison that led to my identification of the essence. I did this visual sorting process by placing direct quotes from participants and themes together. The practice used intuitive knowing and experience in my limited research practice to determine the themes. In addition, I referred to my reflective journal to assist me in the coding process.

**Step 11-Verfiying the Essential Structure with the Participant/Co-researcher.**

Once I believed that I had correctly identified the phenomenon from the essential structure that was constructed from all the individual meta-synthesises, it was presented to the participants. The participants then performed a final validity check. I emailed all participants the essential structure, which was the themes and essence. I sent all the participants an email regardless if they had verified their original transcripts and initial case themes. If participants had not previously participated in the validation process, they were given an opportunity to have their original transcription of the interview, the initial case structure, the themes from that initial structure, and a copy of the essential case structure. I conducted this procedure twice to ensure participants had an opportunity to comment on the final validity check.

**Step 12- Writing up the Results.**

This final step is critical in accurately concluding this phenomenological process. Several researchers have stated that this is the key element in conducting any type of study (Creswell, 1998; Denzin, 1994; Patton, 2002). Researchers aim to create the lived reality of others based upon the verification processes previously undertaken. Researchers organize the data in a sequential fluid manner, weaving the themes of the participants’ stories throughout the discussion in relation to the initial research question.
Building on the suggestion of Creswell et al. (2007), I included the significant statements, quotes, and sentences that provided great insight into the phenomenon.

**Relevance, Rigor, and Feasibility of this Study**

Contained within the qualitative research method are three key dimensions according to Guba (1981). They are relevance, rigor, and feasibility. Relevance refers to the potential contribution of the research. How worthy is the research question to the potential contribution of the results to the discipline? Rigor refers to the adequacy and appropriateness of the method to address the questions proposed and solidity of the research design. Feasibility refers to the ability of the researcher to conduct the research, the resources available, and the completion of a study. Within each element, Guba (1981) outlines eleven dimensions in which to evaluate qualitative research. These dimensions include the (1) problem/question, (2) investigative capability, (3) proposed methods, and (4) selection of research context, (5) design, (6) analytic plan, (7) duration of project, (8) budget, (9) human subjects, (10) dissemination, and (11) the fit to existing knowledge.

According to my self-assessment, this present study met many of the dimensions described in Guba’s work. In terms of relevance, this study established that a volume of work about youth with type 1 diabetes exists. While much of the research has focused upon medical aspects of the illness, the impact and influence of relationships with youth that have type 1 diabetes have been a popular topic in diabetes research. Morse (2004) proposes that relevance is measured by the fitness of the method used in the research exploration. Phenomenological research is a viable method to describe the lived experience of a population. The phenomenological method allows for continuous participant participation. The phenomenological method allows for intense verification of
the phenomena. I informed the research participants about the research procedure and consulted on several occasions regarding the phenomenon. I am an insider in the diabetes community as I live with type 1 diabetes community and I have access to the research participants and knowledge of the literature.

Rigor is present within this work. Morse (2004) states the researcher’s experience with conducting research and the method when producing themes are necessary to demonstrate rigor. He notes that the terms *skeletal framework* and *scaffolding* outlines a method to be used and its’ impacts in the research. A skeletal framework occurs when a researcher may be able to identify concepts but needs to do some additional work around the topic to build a theory from the research. This study used phenomenology as a basic methodology to generate a skeletal framework. Scaffolding, as described by Morse (2004) occurs when the researcher cites previous work and uses it as a foundation for the current study. In this study, scaffolding took place in the literature review in chapter two and the discussion about methodology, process, and procedure that occurred in chapter three. These discussions, scaffolded rigor occurred in the study. There is one weakness in this study as I had no previous experience conducting research. To overcome this obstacle, I consulted with my supervisor about the research throughout the process to glean insight and understanding. In addition, the methodology chosen provided several opportunities for participants to ensure that rigor took place during the verification process.

I believe I have also met many of the conditions necessary to meet the criteria for feasibility. First, I had no binding time schedule other than my own. Second, no financial or contractual commitments existed in order to complete this study. Third, I believed that access to participants would be available to me as I am a member in the diabetes
community. I thought that recruitment and connectedness to this population would be a
definite to me as I was conducting the study. I used my connection to the local chapter of
the Canadian Diabetes Foundation, Diabetes Clinic, and Juvenile Diabetes Research
Foundation to gain access to research participants.

**Situating the Writer in the Study**

I contracted type 1 diabetes at the age of 20. I lost 70 pounds in three months. My
hair fell out during that time and has never been quite the same since my youth. I was
chronically thirsty, hungry, tired, and moody. When the doctor diagnosed me, I was in
my third year of university, working part time, and living on my own. The illness
changed my life forever. I had to change many aspects of my life. Eating, sleeping,
drinking (I switched to diet pop), exercise, stress, coping strategies, insulin management,
blood sugar testing, learning about the illness, and how to effectively manage the illness
were part of my huge learning curve. I am still learning today about how to be healthier,
live better and live longer.

Diabetes has affected my relationships. My family and social occasions changed
because of what I could or could not eat. I cannot tell you the number of times I have
been told “not to eat that because I am a person living with type 1 diabetes”, “that this
piece of cake does not have that much sugar and I can eat that” or the other thousands of
assumptions people make about me and do not bother to ask me about. There have also
been times when my blood sugar has become low and I have become an irritable,
obnoxious person. There have been many occasions where I have had to apologize for
how I acted and repair the relationship even though people know my behaviour was due
to a diabetic low. Repairing a relationship and explaining about what diabetes is was
necessary, as children in my life did not know why I was not myself. Other aspects of my life that changed were my introduction to many professionals to assist me with the illness and my need to educate those around me about diabetes.

The illness is part of my life, my daily routine and is a factor in decision making with respect to day-to-day choices. Choosing foods, activities, blood sugar management, and stress management are daily things I need to think about on a continuous basis. There is no vacation from diabetes. However, diabetes does not prevent me from living. I do many things that people who live without diabetes do not do. For example, I participate in mountaineering activities such as ice climbing, rock climbing, and glacier travel to mountain peaks. I am an avid runner and skier. Diabetes is one part of my life. As long as I manage it, I am able to lead my life on my own terms.

In my career as a social worker, my work has primarily focused upon children and youth. I like hearing their stories, listening to how they view the world, and hearing about their lives. The rationale for this study came from my work with youth, my illness and wondering how other adolescents experienced type 1 diabetes in their lives.

It is important to identify assumptions I had about this study before I conducted this research. I believed that the illness would allow me more access to members in the diabetes community than if I did not live with type 1 diabetes. I believed participants would be more likely to trust me, as I am one of them. In fact, the insider’s knowledge that I possessed appeared throughout the interviews, as the participants would say things like “you know what it is like” or “you know diabetes ‘Dr. Smith’, the diabetes physician, right?” There were times when the interview tape stopped, we discussed our current health status, cost of health care, pregnancy and diabetes, blood sugar testing challenges,
fears of complications, and how the relationships in our lives now influence our management of the illness.

In reality, this assumption I made was both true and false in terms of the outcome of the research. The assumptions that I would have access to more members in the diabetes communities is true that I knew the appropriate places to recruit people such as the Canadian Diabetes Associate, the Diabetes Clinic, pharmacists, physician’s offices and labs in Prince George. However, my own personal connections to others living with type 1 diabetes yielded no participants. However, my assumption about being connected to my participants due to my inside knowledge of living with type 1 diabetes was true.

Another assumption I possessed is that I believed that youth with type 1 diabetes have a difficult time in their day-to-day lives because of the illness. Throughout the discussions, various participants noted challenges with blood sugar testing, diet, and blood sugar highs and lows. As a child and youth mental health counselor, I assumed that the environment and family relationships would affect and influence the management of the illness. What participants noted is that relationships in their lives did change, some dramatically, some not so much. Others noted that educating others about diabetes was necessary to create normalcy about their condition. Another assumption I made was that the notion of struggling with the illness would be a central point of discussion throughout the interview. I based this upon my own struggles when I was first diagnosed with type 1 diabetes. Conversely, almost all of the participants believed in living their lives without hesitation and that diabetes was not an obstacle to a good life. For this study, participants were successful in managing their illness and living with a chronic health condition was just part of their lived experience.
The final assumption I made was that certain relationships would be harmful and others would be helpful for adolescents. For example, I believed that all service providers would be helpful. In contrast, all participants noted characteristics of helpful and unhelpful responses from different people regarding their diabetes. A further discussion about all of the assumptions I made in this study can be found in Chapter Six. Regardless of the assumptions and bias I had, I noted them before a dialogue and made a conscious effort not to state an opinion about a discussion topic brought up by a participant.

Summary.

Chapter Three outlined the method (procedure) and methodology (rationale for the method) used in this study. The chapter began by describing the theoretical beginning of phenomenology as a qualitative research method and philosophy. The different types of phenomenology, specifically, the works of Husserl (Natsson, 1973) and Moustakes (1994) were reviewed to provide an understanding of the complexities when conducting a phenomenological study. Next, the 12-step procedure for conducting this phenomenological study, using the Vancouver School of Phenomenology method, was outlined. The procedure described in detail, what steps the researcher employed to gain results. Fourth, the chapter discussed the relevance, the rigor, and the feasibility of this study. Using Guba’s (1981) work as an outline of the eleven dimensions of a good qualitative study, I undertook a self-assessment I believe that I established that this study does meet criteria for relevance, rigor, and feasibility for qualitative research. Finally, the chapter provided insight for the reader as to my assumptions that I brought to this study. These insights contributed to a more transparent relationship between myself and the participants as well as myself and the readers of this report.
Chapter Four- Results

The purpose of this study was to address the question: what do adults living with type 1 diabetes recall about their relationships with others, during their youth? This chapter provides a discussion of the results, proceeded by a demographic overview of the participants in this study.

Step 1-Participants-Dialogue Partners.

In total, ten adults were recruited; six women and four men. One women was disqualified from participating in the study as it was determined she did not meet the criteria. The saturation point occurred when the information generated from participants produced identical or similar themes. When the saturation point occurred, I halted participant recruitment.

As stated earlier, two types of sampling were planned for this study; criterion and snowball sampling. The criterion sampling provided clear definition of inclusion and exclusion criteria. The inclusion criteria were the following; men and women between the ages of 19-40 years, who were diagnosed with type 1 diabetes before their nineteenth birthdays. Exclusionary criteria were all other persons who did not fall within the inclusion criteria. The second type of sampling, snowball sampling, yielded no results in attracting participants to this study and two reasons became apparent. First, the sample size I had to draw upon was small; there are few people who meet the criteria who live in the Prince George area. Second, I assumed that persons living with type 1 diabetes networked with each other and discussed their diabetes frequently. This assumption led me to believe that I would simply find like-minded people who share a common interest,
type 1 diabetes. This assumption proved to be inaccurate as I could not think of anyone I knew who lived with type 1 diabetes and met the criteria for this study.

**Step 2-Silence.**

Halldorsdottir (2000) states the use of a reflective journal is part of the learning process. I was able to reflect upon my pre-conceived notions of the research and become aware of my thoughts about the research as the study occurred. This process allowed me to hear the participant’s stories. I recorded my thoughts and feelings about participants and their stories throughout the research process. On June 17, 2009 after the first three interviews were completed, I recorded this statement in my reflective journal: “It (the interview) made me think that it was a good choice to be a step back emotionally from this issue (diabetes)...I found myself wanting to have a conversation and talk about myself...I put my emotions in check”.

On a different occasion nearing the end of the interview process on October 25, 2009, I wrote in my journal about the themes that were beginning to emerge from the participant interviews: “I am starting to see patterns, thoughts, and ideas of a lived experience”. There were also moments when I questioned the data “I think the data is skewed due to the (sample composition); the education level, belief system, family stability and lack of cognitive impairment of the participants (October 25, 2009)”. The journaling process created a reflective procedure for me as I conducted the study.

**Step 3-Data Collection-Participating in a Dialogue.**

I interviewed ten participants, six female and four male. One interview, participant 003 was excluded from the study, as she did not meet the criteria for the study.
Participant 003 had incorrectly answered the screening questions and it was only determined at the time of the interview that she did not meet criteria. When a potential participant notified me as to having interest in participating in the study, I took the following steps. First, I spoke with the participant to inform her/him of the intent of the research and over the phone completed the pre-screening questionnaire (Appendix C). Once it was determined that the participant was suitable for the study, a time and location were set to conduct a semi-structured interview. The location of the interviews varied, depending upon the request of the participant. Locations included a coffee shop, the UNBC library, a participant’s home and I conducted one interview at my home although talking to a participant over the telephone. At the time of the interview, the participant was given an information sheet (Appendix D) describing the research project in detail. Any questions the participant had were addressed at that time. If the participant continued, she/he signed the informed consent form (Appendix E), completed a demographic questionnaire (Appendix F), and supplied contact information (Appendix G). The contact information form was necessary to verify the interview transcriptions. After completing the interview process, the participants received a $20 gift certificate for their involvement in the study, regardless of whether or not they withdrew prior to the completion of the study. For the one participant where a phone interview was necessary to complete the interview, appendices D, E, F, and G were mailed to the participant with return postage. When the participant received the information, she/he contacted me. This information was reviewed with the participant over the phone. She completed the forms and mailed them back to me. When I received the information, an interview time was determined and the interview occurred.
After the interview was completed, it was transcribed verbatim by me and then emailed to the participant. This occurred within one to two weeks of the interview. The participants were given two weeks to verify the interview, and if verification did not occur, another email was sent requesting verification. If the second verification did not occur, a phone call to the participant requesting verification took place. Finally, if verification had not occurred after two additional weeks after the initial phone call, a second phone call was placed requesting verification. In total, all five female participants verified their interviews and none of the male participants verified their interviews.

**Step 4-Data Analysis-Sharpened Awareness of Words.**

As the interviewing process occurred from June 2009 to November 2009, I believed it was necessary to immerse my thoughts in the data by frequently re-reading the interviews and noting the patterns that emerged. On October 10, 2009, I wrote in my reflective journal, “I think that the themes are…food, family, finding a balance, diabetes being part of them, and the disease (physical part) itself as I read things over”. This process took time. I was continually questioning the data I was analysing.

**Step 5- Coding-Beginning Considerations of Essences.**

Participants gave information about a wide variety of experiences in response to the all the questions. The themes for question one; What was your experience when you found out you had type 1 diabetes? (Karlsson et al., 2008) included; the hospital experience, symptoms of diabetes, and feelings about diagnosis. The themes for question two; What was the same or different in your relationships with your caregivers, friends and people in the community after your diagnosis? (Karlsson et al., 2008) included: knowledge acquired by the participant, friends, and family, sharing knowledge, and the
connection or lack of connection to family, friends and service providers, and thoughts about diagnosis. The themes for question three; What was the role of your caregivers between the ages of 13-18? Describe this relationship (Karlsson et al., 2008) included; blood sugar testing as a source of conflict, transition of care from parent to participant, cost of care, and the physical care of diabetes. The themes of question four; How did diabetes influence your relationships with friends, dating, and doing “typical teen things” like experiments with sports, parties, hanging out, sleep cycle, recreational activities, homework, alcohol, drugs, and sexuality? (Karlsson et al., 2008) included; how diabetes influenced social activities, connection to other youth living with diabetes, activities engaged in by participants, and diabetes influence in daily life. The themes of question five; What attitudes existed from community about your diabetes between the ages of 13-18? (Karlsson, et al., 2008) included; others wanting knowledge, intuitive knowledge, lack of knowledge, and other people telling the participant what to do regarding care. The themes of question six; Did you experience any prejudices, roadblock, or “special treatment” during this period in your life from community members? (Ingadottir & Halldorsdottir, 2008) included; medical roadblocks and special treatment, prejudices experienced by participants, ongoing education for others to reduce prejudices, and the lack of road blocks experienced by participants. The themes of question seven; Describe the relationships you had with different service providers. What things promoted a more connected relationship and what things promoted a lack of connections? (Friedrich, 2007) included; connection to service providers, lack of connection to service provides, how a lack of connection creates a relationship change, and attending diabetes camp. The themes of question eight; How has diabetes changed/created/impacted your identity-now
(Ingadottir & Halldorsdottir, 2008) included; the cost of the illness, teaching others about diabetes, increased self-awareness, empathy towards others, how others see the participants, increased health awareness, how diabetes is just part of me and that this was a hard question to answer. Finally, the themes of question nine; Is there anything else you would like to tell me? included: current struggles with blood sugar testing, thoughts and feelings about change, connection to others living with diabetes, and connection and support in the context of their relationships with others. I then reflected upon the themes in the context of the research question in my reflective journal. On November 20, 2009, I noted, “there appear to be 3-8 themes or codes for each question. I will now take each theme or code to sort out the data again to review”.

**Step 6- Constructing Initial Case Structure.**

As the themes from each question were extracted from each the responses of participants, an authentic reconstruction of her/his experience emerged. These themes were reflected up in context in relation to the original research question. I created a summary of the themes reflected in each participant’s interview in relation to the original research question as extracted from the nine questions asked in the interview. For example, participant 001 theme analysis for question two “What was the same or different in your relationships with your caregivers, friends, and people in the community after your diagnosis?” The words she stated included,

“I talked to the entire class about diabetes. I didn’t feel like I had to keep it a secret. I just knew the point that I was safer if they knew right; My little sibling asking me what my blood (sugar) was- he had no idea what he was asking, but even he was riding me; I was in Girl Guides; it was never anything I was embarrassed about”.
The themes that emerged were educating others about diabetes, keeping oneself safe by telling others, family members putting pressure to complete self-care, and diabetes as part of life.

Step 7- Verification of a Single Case with the Participant/Co-researcher.

Verification procedures have been used throughout this study. Participants were requested to verify the themes the researcher believed constituted their lived experience of being an adolescent living with type 1 diabetes. Participants were emailed a summary of her/his themes based upon the interview and initial case construction. In this study, all five female participants and one male participant responded stating that I had correctly identified those themes. The other three mail participants were emailed once more requesting the verification of the themes. In this study, all female participants participated in the verification process and none of the male participants engaged in this process. Attempts were made to verify the information though two emails with the particular participant’s attached data and phone calls to the participants, requesting her or him to check their email. After two emails and two phone calls, I chose to abandon the verification process with participants who did not respond.

Step 8- Constructing the Essential Structure of the Phenomenon- Meta-synthesis.

Each initial case structure was created by extracting information as gathered from the questions. It was in this process that the phenomenon were constructed and interpreted. Participants’ stories began with their initial experience before, during and after the diagnosis with diabetes, and then the experience shifted to their experiences in their relationships with people in their youth and I concluded with a description of how
diabetes influenced their current identity formation. Four major themes were identified; (1) knowledge, (2) the impacts of diabetes, (3) constructive and deconstructive factors in relationships, and (4) self-awareness and identity. Within each of these themes, several sub-themes existed. I noted this in my reflective journal on December 4, 2009, “There are just too many (themes). How am I going to narrow this down?”

**Step 9- Comparing the Essential Structure with the Data.**

With the completion of the initial structure, I began to compare the themes with the data from the interviews, the initial case constructions from the participants, and the first coding of the data. I did this again due to my limited experience as a researcher. I did not want to make assumptions; I wanted to accurately report on the experiences of the participants. When this process occurred, similar themes and a narrowing of sub-themes emerged.

**Step 10- Identify the Over-riding Themes Describing the Phenomenon.**

As the themes materialized, I wrote in my reflective journal about them. On December 20, 2009, I noted, “there appear to be four major themes with many sub-themes. This is confusing, how do I know what is right? It is all so interconnected. Perhaps that is the point of a lived experience”. Upon further reflection and sorting, I did categorize the four major themes and sub-themes.

**Step 11-Verifying the Essential Structure with the Participant/Co-researcher.**

This step was the final validity check. Six participants responded to the first email. All six validated the themes as presented. A second email was sent to the remainder of participants who did not respond to the first email. There was no response from these participants. This was the final step before writing up the results.
Step 12- Writing up the Results.

In this final process, I identified the themes and sub-themes and verification occurred by the participants. In this study, four major themes existed; (1) knowledge, (2) the impacts of diabetes, (3) constructive and deconstructive factors in relationships and (4) self-awareness and identity. In the knowledge theme, three sub-themes emerged (1) acquiring knowledge (2) sharing knowledge, and (3) knowing and intuitive knowledge. The second theme, the impacts of diabetes, presented four sub-themes: (1) impacts of food, (2) impacts of medicine, (3) financial impacts, and (4) social impacts of diabetes. Constructive and deconstructive factors in relationships, the third theme, consisted of two sub-themes; (1) connection and support, and (2) knowledge. Three sub-themes appeared in the self-awareness and identity theme. They are (1) initial formation, (2) adolescent formation, and (3) adult formation. These themes were then analysed and a complete analysis is found in Chapter Five.

Along with participant interviews, I utilized a demographic questionnaire to gather information about past and present circumstances from all participants regarding their diabetes care, family of origin, insulin management, service provider utilization, location, education, and marital status. This information and nine questions examining the experience of a diagnosis of diabetes, relationships with family, friends, community and service providers, roadblocks, special treatment, and identity informed the results of this study. In both the demographic and thematic presentation of the data in Chapter Five, participants are referred to by number. For example, the first participant interviewed is participant 001. The researcher chose numbers instead of pseudonyms because numbers
seemed more appropriate to describe a disease where numbers are a significant aspect of a person’s living with type 1 diabetes person’s health.

**Demographic Analysis.**

In total, there were nine participants in the study, five female and four male. Participants were asked a variety of demographic questions in relation to their diabetes, community, family composition, and service providers. Six participants in this study stated that they were Caucasian, although three did not categorize themselves with any ethno-cultural group. All but one participant stated that they were currently living in the Prince George area. One stated that she lived in Northern British Columbia.

The age at which the participants contracted type 1 diabetes ranged from one year to sixteen years old. Five participants informed the writer that they lived in Prince George at the time of their diagnosis; one lived in another part of Northern British Columbia, two in the Lower Mainland of British Columbia, and one in Toronto, Ontario. All participants reported that they lived with at least one biological parent. Five commented that they lived with both parents and siblings, one lived with parents only, one lived with single parent, and two lived with a single parent and sibling(s). Table 1.0 provides a composite overview of this information. What is important to note is that six out of 9 participants lived with both parents; and the remaining participants who lived with one reported contact with the parent they did not live with periodically or regularly during their youth. One person reported that his father passed away during his youth from complications from living with type 1 diabetes. Regardless of the type of family composition, all participants reported an intact, supportive family structure.
<table>
<thead>
<tr>
<th>Participant Identification Number</th>
<th>001</th>
<th>002</th>
<th>004</th>
<th>005</th>
<th>006</th>
<th>007</th>
<th>008</th>
<th>009</th>
<th>010</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age at Diagnosis</td>
<td>9</td>
<td>13</td>
<td>12</td>
<td>16</td>
<td>12</td>
<td>1</td>
<td>12</td>
<td>11</td>
<td>11</td>
</tr>
<tr>
<td>Family Composition:</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Two parents</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>and siblings</td>
<td>Y</td>
<td>Y</td>
<td>Y</td>
<td>Y</td>
<td>Y</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Family Composition:</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Single Parent</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>and sibling(s)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Y</td>
<td>Y</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Family Composition:</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Single Parent</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>no sibling</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Y</td>
</tr>
</tbody>
</table>
I constructed a table listing the participant’s current age, marital status, and the number of children for the participants. However, due to the small size of the sample and the location of the participants, I concluded in consultation with a committee member that possible identification of the participants in my study might occur. Therefore, I made the decision to remove the table and present the data in a written format. The date noted that the participants’ ages ranged from 20 years to 39 years, with a mean age of 28.2 years. Four people stated that they were married, three were single, and two were cohabitating with a partner. Three people stated that they had one or more children: one participant reported that she was currently pregnant and the remainder commented that they did not have any children.
Table 2.0 refers to participants’ responses for employment status and education level. All but one participant is working full or part-time and/or attending post secondary education. This person is choosing to be a work at home parent and stated that she plans to return to paid employment when her children all older. All participants report completing high school and eight out of nine reported a completion or are currently enrolled in a college, university, or doctoral program. Five out of eight participants reported that they were also employed part or full time in the work force.

What can be concluded from the participants in this study is a population that is highly motivated, organized, capable, cognitively intact and functional within the realities of daily life. In addition, these people live with a chronic health condition where to be effective in the management of this condition they must perform many daily self-care tasks. This particular population is atypical of persons living with type 1 diabetes. The literature review in Chapter 2, noted significantly poorer health care outcomes for persons living with type 1 diabetes in comparison to persons not living with this chronic health condition. What can be concluded from this study is that persons who are highly motivated, educated, employed, cognitively intact, competent will structure their environment more effectively, thereby being more effective in managing their chronic health condition.
<table>
<thead>
<tr>
<th>Participant Identification Number</th>
<th>001</th>
<th>002</th>
<th>004</th>
<th>005</th>
<th>006</th>
<th>007</th>
<th>008</th>
<th>009</th>
<th>010</th>
</tr>
</thead>
<tbody>
<tr>
<td>Employment Status</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Full Time</td>
<td>Y</td>
<td>Y</td>
<td>Y</td>
<td>Y</td>
<td>Y</td>
<td>Y</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Part Time</td>
<td>Y</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Student</td>
<td>Y</td>
<td>Y</td>
<td>Y</td>
<td>Y</td>
<td>Y</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

As a result of being a

Work at home parent

Education Level

High School

Some College or University

College Diploma

Undergraduate Degree

Graduate Degree in Process

Graduate Degree

Y
Table 3.0 provides information regarding insulin administration. Participants disclosed a wide variety of insulin administration methods. All but one participant began administering insulin from a needle. Three commented that they switched methods from insulin pen to pump or from needles to pen during their youth. Table 3.0 notes that six people used needles, four insulin pens, and one an insulin pump. Over time, many participants changed insulin administration methods because of improved technology. Currently, five participants stated they are using an insulin pump, three are using an insulin pen, and one uses needles. One participant stated the following about the insulin pump.

I have an insulin pump which I feel so lucky for my insulin pump everyday because I did, I did do injections for my first ten years with diabetes.…and I don’t think people understand that it is not really a choice for me to not have an insulin pump because if I don’t have it, my health will be awful (004).

Another commented on the improvement of her daily life because of having an insulin pump.

Also, living with diabetes using an insulin pump has been really flexible in terms of my eating schedule with a busy family and gives me precise control of my blood sugar now. Which, is really helpful and makes diabetes not too much a big burden (009).
TABLE 3.0
Participant Youth and Current Insulin Administration

<table>
<thead>
<tr>
<th>Participant Identification Number</th>
<th>001</th>
<th>002</th>
<th>004</th>
<th>005</th>
<th>006</th>
<th>007</th>
<th>008</th>
<th>009</th>
<th>010</th>
</tr>
</thead>
<tbody>
<tr>
<td>Youth Insulin Administration;</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Needle</td>
<td>Y</td>
<td>Y</td>
<td>Y</td>
<td>Y</td>
<td>Y</td>
<td>Y</td>
<td>Y</td>
<td>Y</td>
<td>Y</td>
</tr>
<tr>
<td>Insulin Pen</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Insulin Pump</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Current Insulin Administration;</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Needle</td>
<td>Y</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Insulin Pen</td>
<td>Y</td>
<td>Y</td>
<td>Y</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Insulin Pump</td>
<td>Y</td>
<td>Y</td>
<td>Y</td>
<td>Y</td>
<td>Y</td>
<td>Y</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Table 4.0 offers detailed description types of services providers that had contact with participants in their youth. In this table, it is important to note that no participants had any contact with 911 services, child protection, or a podiatrist. All but two participants reported any admission to an emergency department outside of their initial diagnosis. What can be revealed is that participants in this study and their families were highly functional in their ability to manage this chronic illness. As, the service providers that were accessed were primarily used for assisting in the management of type 1 diabetes, it becomes clear that the participants in this study and their families were capable, accessed support from their diabetes team when needed and were effective in managing the disease.
TABLE 4.0

Types of Service Providers used between the ages of 13-18 Years

<table>
<thead>
<tr>
<th>Participant Identification Number</th>
<th>001</th>
<th>002</th>
<th>004</th>
<th>005</th>
<th>006</th>
<th>007</th>
<th>008</th>
<th>009</th>
<th>010</th>
</tr>
</thead>
<tbody>
<tr>
<td>Paediatrician</td>
<td>Y</td>
<td>Y</td>
<td>Y</td>
<td>Y</td>
<td>Y</td>
<td>Y</td>
<td>Y</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Family Doctor</td>
<td>Y</td>
<td>Y</td>
<td>Y</td>
<td>Y</td>
<td>Y</td>
<td>Y</td>
<td>Y</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Psychologist</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Y</td>
<td></td>
</tr>
<tr>
<td>Ophthalmologist</td>
<td>Y</td>
<td>Y</td>
<td>Y</td>
<td>Y</td>
<td>Y</td>
<td>Y</td>
<td>Y</td>
<td>Y</td>
<td></td>
</tr>
<tr>
<td>Diabetes Clinic</td>
<td>Y</td>
<td>Y</td>
<td>Y</td>
<td>Y</td>
<td>Y</td>
<td>Y</td>
<td>Y</td>
<td></td>
<td></td>
</tr>
<tr>
<td>911</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Y</td>
</tr>
<tr>
<td>Canadian Diabetes Association</td>
<td>Y</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Hospital Emergency</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Y</td>
</tr>
<tr>
<td>Hospital Paediatric Ward</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Y</td>
<td></td>
</tr>
<tr>
<td>Child Protection</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Podiatrist</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Y</td>
</tr>
<tr>
<td>Child and Youth Mental Health</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Psychiatrist</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Y</td>
</tr>
<tr>
<td>Dietician</td>
<td>Y</td>
<td>Y</td>
<td>Y</td>
<td>Y</td>
<td>Y</td>
<td>Y</td>
<td>Y</td>
<td>Y</td>
<td>Y</td>
</tr>
<tr>
<td>Pharmacist</td>
<td>Y</td>
<td>Y</td>
<td>Y</td>
<td>Y</td>
<td>Y</td>
<td>Y</td>
<td>Y</td>
<td>Y</td>
<td></td>
</tr>
<tr>
<td>Endocrinologist</td>
<td>Y</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Social Worker</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Y</td>
</tr>
<tr>
<td>School Counsellor</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Y</td>
<td></td>
</tr>
<tr>
<td>Nurse</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Y</td>
</tr>
<tr>
<td>Other</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
In addition, all participants noted that a family doctor, diabetes clinic, dietician, and pharmacist were service providers in their lives. One person remarked how these individuals were a part of her diabetes care team as a child and this group of people assisted her with her care.

"Cause I had a good team of, of (diabetes) educators. That gave me what I needed. It wasn’t perfect management... The people I saw regularly in my diabetes care team. I was overwhelmed and sad at the diagnosis, which would be for the rest of my life, um, but soon I was assured and confident by the diabetes team at BC’s Children’s Hospital (009).

Another participant made this comment about her experience with service providers, the level of expertise within her diabetes team, and the approach taken by service providers to assist her in managing her health.

"It was Sick Kids, Toronto, which is you know one of the foremost diabetes centres...So they had they had really good set up for that sort of thing...They read me right and they said, listen, you are capable of doing this, we’ll support you, we’ll teach you, we’ll help you, you can come in every month and will re-establish anything that you need to ask, if you need to visit with the dietician or the endocrinologist or what ever it is. But um, I think there was probably a lot of individual, tailor made approach, there was not one standard thing (008).

Rubin and Blumer (2005) reinforce the notion of the importance of a diabetes team. They state that a diabetes team will meet all of the areas of concern regarding self-care by persons living with type 1 diabetes. Their book outlines that the youth living with type 1 diabetes is the team captain and different service providers’ roles assist the captain in making things impacts in an effective manner.

**Summary.**

This chapter began with a description of how the results were obtained by completing the procedure as outlined in Chapter Three. A systematic account of conducting the procedure gave detailed information as to how the results were obtained.
Next, I provided an overview of demographic information provided by the participants. Each of the five demographic tables outlines the types of persons who participated in this study. Table 1.0 stated the participants’ ages and family composition at the time of diagnosis. Table 2.0 outlined the current ages, marital status, and number of children reported by participants. These two tables provided a brief overview of age and family composition. Table 3.0 summarized the current employment status and education level for participants. In this discussion, it was pointed out that all of the participants are high school educated or higher, with three persons either completing or in the process of completing graduate degrees. All persons except one who is choosing to be a work at home parent are working full or part-time and/or attending post-secondary institutions. It evident from this sample is that this group of people are educated, highly motivated, and hard working.

Table 4.0 then shifted our focus to the method of insulin administration during participants’ youth and their current administration practices. What was evident is that over time, many people shift from needles or insulin pens to insulin pumps. The rationale for the switch was for more effective management and convenience. In their interviews, one factor that held people back from getting an insulin pump was cost. Table 5.0 charted the different types of service providers utilized by participants. The demographic examination has provided background information and context to the thematic analysis of this study.
Chapter Five - Discussion

Thematic Analysis

Four themes emerged from the analysis of how adults living with type 1 diabetes recall relationships in their youth. The major themes and sub-themes are discussed in this chapter by using key statements from the participants regarding their experience. Table 5.0 provides a list of the major themes and sub-themes in this study.

TABLE 5.0

List of Themes and Sub-themes

<table>
<thead>
<tr>
<th>List of Themes</th>
<th>List of Sub-Themes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Knowledge</td>
<td>Acquiring Knowledge</td>
</tr>
<tr>
<td></td>
<td>Sharing knowledge</td>
</tr>
<tr>
<td></td>
<td>Knowing and Intuitive Knowledge</td>
</tr>
<tr>
<td>Impacts of Diabetes</td>
<td>Impacts of Food</td>
</tr>
<tr>
<td></td>
<td>Impacts of Medicine</td>
</tr>
<tr>
<td></td>
<td>Financial Impacts</td>
</tr>
<tr>
<td></td>
<td>Social Impacts</td>
</tr>
<tr>
<td>Constructive and Deconstructive</td>
<td>Constructive Factors: Connection and</td>
</tr>
<tr>
<td>Factors in Relationships</td>
<td>Support</td>
</tr>
<tr>
<td></td>
<td>Deconstructive Factors: Connection and</td>
</tr>
<tr>
<td></td>
<td>Support</td>
</tr>
<tr>
<td></td>
<td>Constructive Factor: Knowledge</td>
</tr>
<tr>
<td></td>
<td>Deconstructive Factor: Knowledge</td>
</tr>
<tr>
<td>Self-Awareness and Identity</td>
<td>Initial Formation</td>
</tr>
<tr>
<td></td>
<td>Adolescent Formation</td>
</tr>
<tr>
<td></td>
<td>Adult Formation</td>
</tr>
</tbody>
</table>
The first theme identified by the participants is knowledge about diabetes. Three sub-themes are found within this theme. The sub-themes are (1) acquiring knowledge, (2) sharing knowledge, and (3) knowing and intuitive knowledge. All three sub-themes discuss the progression of knowledge the participant and she/he obtained as they learn about diabetes and how to care for the condition.

The second theme is the impacts of diabetes. This theme describes the life experiences that occur when a person lives with type 1 diabetes. The impacts of diabetes contain four sub-themes regarding how a person with diabetes lives. These are: (1) the impacts of food, (2) the impacts of medicine, (3) the financial impacts, and (4) the social impacts. The impacts of food and the impacts of medicine describe the experience participants in this study had regarding food and medicine in relationship to their diabetes. The financial and social impacts of this theme outline the financial and social implications of living with this illness.

The third theme examines constructive and deconstructive factors in relationships for youth living with type 1 diabetes. This theme contains two sub-themes that either further enhance a relationship between the participant and another person or causes that relationship to deteriorate. These sub-themes include: (1) connection and support, and (2) knowledge. This discussion focuses on the constructive and deconstructive factors in different relationships in the participants’ lives.

The final and most complex theme in this analysis is self-awareness and identity for youth and adults living with type 1 diabetes. A dialogue occurs through three sub-themes that are connected through a time line of the participants’ development: (1) at diagnosis (initial formation), (2) during adolescence (adolescent formation), and (3)
current age (adult formation). First, the participants reflect upon thoughts, feelings, and beliefs about diabetes and self at diagnosis. Next, the participants reveal their thoughts, feelings and beliefs about diabetes and self between the ages of 13 and 18 years. Finally, the participants divulge their thoughts, feelings, and beliefs about diabetes and self in relation to who they are now. Through the review of all four themes, responses to the original research question will occur.

**Knowledge.**

Knowledge is the first theme discussed by the participants in this study. Knowledge is a fundamental building block in the human experience. When faced with day-to-day or new learning experience, knowledge becomes a mechanism that people use to be successful. For the participants who received a diagnosis of and currently live with type 1 diabetes, knowledge about diabetes was and is pivotal to managing their condition. All the participants noted the initial learning they and their families received was from a diabetes care team in the hospital. Nurses, doctors, a dietician, and in some cases an endocrinologist each met with youth living with type 1 diabetes and her/his family to provide preliminary education. This initial education by a persons living with type 1 diabetes team is a standard practice when a person receives a diagnosis (Franz, 1981; Mulcahy, 1999). This initial experience after diagnosis becomes a vital step in the knowledge building process for persons living with type 1 diabetes and their families.

**Acquiring knowledge.**

The first sub-theme, which I named, acquiring knowledge, describes the initial learning for the participant and her/his family about what to do regarding this chronic health condition. Participants stated the following regarding their first experiences when
learning they had type 1 diabetes: “I remember sitting in the nurse’s station and they were teaching us how to do injections with oranges and syringes…and then….you’re thinking this is going to be me next, I better get this right” (008).

They spent time with me calculating the food I had to eat, the food I could not eat, the insulin I had to do, the exercise they wanted me to do. And so we talked about this for ten... I was in the hospital for ten days (002).

They, there gave me some books to read and there were kind of like um... They weren’t text books or comic books; they were something in the middle. It had pictures of kids doing different aspects of persons living with type 1 diabetes care. Like a blood test or a needle (002).

They were obviously doing a number of things, stabilizing blood sugars, um, but also, um, teaching me and teaching my parents, my mom in particular how to manage this, so. So, um, so, initially, it probably was purely a like a stabilizing thing, a clinical thing but then it moved in to we need to teach you how to manage, manage this over time (008).

One participant commented that his care was in the hands of his parent as his diagnoses of type 1 diabetes occurred at age one. This experience was different from the other eight participants in this study. Because the participant had no memories of his diagnosis, he commented on the experience of always living with the illness.

They basically um, did everything for my diabetes from 1 till they let me take full control when I was about ah, 14, I guess, so, basically they did all my tests, …what a brutal way to raise your child up until my teens (007).

For all participants, receiving care and knowledge about their illness was essential in order to begin to manage the condition. Olson and Sutton’s (1998) work states that initial education is vital for children living with diabetes and their families as it can establish good preliminary care and relationships for long-term effective management of the illness. For caregivers and children or youth, the first contact with educators and the process of receiving education is the starting point for treatment.

*Sharing knowledge.*
Although acquiring knowledge about diabetes was the original goal for the youth living with diabetes and their family, this quickly changed. Sharing knowledge about diabetes with others emerged as another sub-theme within the discussion of knowledge. Once leaving the hospital, participants and parents then needed to share with others what they learned about diabetes. Participants reported the following experiences after they left the hospital and began sharing knowledge about diabetes others:

I remember going to school and having my uh… I remember being the kid who sat with the class room. I talked to my whole entire class we sat and like I talked and we and talked about it. I didn’t… I didn’t feel the need to like keep it a secret. Or keep it from anybody. I just knew the point that I was safer if they knew right, so. I was very open with them (001).

I brought um, my um blood glucose monitor to school with me. Showed everybody how I use it. Tested some kids blood sugars for them and then everybody kind of just went back to normal. Um, that was the kids from school (004).

After I got out of the hospital I had to go back to school and all the kids in my class thought I got diabetes from eating too much candy. So I had to explain to them everything about diabetes and how you don’t get it from eating too much candy. And they all thought they were going to get it from eating too much candy (004).

I do remember when you went to birthday parties or that sort of thing their parents were actually more wigged out in making sure oh well are you allowed to have ice cream or that kind of thing (008).

When I went, when I came back to school, my dad and my mom talked to the principal, who was fantastic and after that, I never ever talked to any of my teachers again. I am not sure if they knew or if they just did not say anything (002).

Basically what would happen is my mom would come in and make an appointment with my teacher and go over ah, a hand, not quite a 200 page handbook but ah, maybe around 75-80 pages and ah, and sit down and give the teacher a tube of um, fast acting glucose or something like that (007).

Participants reported that they believed those around them needed to know how to care for or assist them in their diabetes care. Both parents and children engaged in the
sharing and teaching process with siblings, other children, teachers, friends’ parents, coaches, and instructors, anyone who may need to come to the aid of a child with diabetes. Silverstein and Bandyopadhyay’s (1995) article described how youth living with diabetes attending a camp with friends without the illness was beneficial both groups of adolescents. When the sharing of knowledge about diabetes occurred, both types of youth reported increased peer acceptance, positive peer pressure, and understanding of diabetes care.

Although most participants reported acceptance from peers regarding their new condition, one of the participants believed that some peers did not understand some of her new challenges she had. Participant 005 voiced her experience of how she perceived peers’ lack of knowledge of diabetes as a disconnection in their relationship:

> But they were, oh I heard you got diabetes a lot of them, you know they would just say like, at least it is not cancer; I mean you will be fine. It’s just like you have to check your blood sugar or something? Like that’s how they say. They made it sound very, like it was easy. And I knew very much that it wasn’t (005).

Storch et al. (2004) acknowledge how this type of response can be harmful for a youth living with diabetes. The article states that if youth living with diabetes do not believe they fit in, or if they perceive themselves as different, they may become less compliant in completing diabetes self-care tasks. Helegeson et al. (2007) echo this by noting how isolation can widen the gap between persons living with type 1 diabetes and persons living free of type 1 diabetes.

The initial education process for the youth living with diabetes, his/her family, and community members is a steep learning curve. Participants stated that the responses they received from others were both positive and negative when they provided others with information about their illness. Many of the participants noted that informing others
about their diabetes is an ongoing process. A few participants commented on this informing process in adulthood. Participant 006 stated, “Anytime I get employed, I just let them know I have diabetes. A lot of them understand what diabetes is”. Another respondent, participant 004 remarked, “I always told my boyfriends that I had diabetes. So, it was not really a problem. They knew, they knew what to do if I had a low blood sugar”. Another participant made this comment about a relationship he had with someone for a significant amount of time and how hidden an illness such as diabetes can be.

But generally for the people I hung out with I basically tell them as a passing by comment in case anything did happen….I have had one acquaintance for 10 or 15 years who I would expect to know that I had diabetes and I’ve been told as recently as March that they had no idea and they have known me since I was about 15 or 16 (007).

For many of the participants, the information sharing about diabetes in certain circumstances is vital to their care. Depending upon employment, education, travel, peers, and relationships it is necessary to provide information about diabetes including: what diabetes is and how to care for someone who is hypoglycaemic and what dietary needs exist. This discussion was a persistent theme expressed by the adults living with type 1 diabetes in this study. The literature suggests that this ongoing information sharing is important for persons living with type 1 diabetes for two main reasons. First, the information sharing allows others to provide care for a person living with type 1 diabetes if she/he cannot provide care for him/herself (Dovey-Pearce et al., 2007). An example would be a hypoglycaemic situation where a person living with type 1 diabetes is disorientated, delusional, exhibits slurred speech, and may even become unconscious. Second, by informing others, youth living with type 1 diabetes gain control over their lives by releasing personal information at her/his comfort level (Dovey-Pearce et al.,
This course of action reduces stress experienced by youths living with type 1 diabetes if any self-care concerns arise. Whether this process occurred during a person’s youth or continues in their adulthood, participants identified this process as part of their lived experience.

*Knowing and intuitive knowledge.*

The final sub theme to emerge from the data concerning knowledge was knowing and intuitive knowledge. Participants reported that as they grew towards adulthood and grew in their knowledge about their illness, they took more responsibility for their care. A few participants made these comments regarding the transfer of their care from their parents. One person stated:

> I think I started doing both shots probably around cause I was home less, and I had a part-time (job) so I was at work so I had to do shots at work. If I stayed at friend’s houses I had to do my own injections at friend’s houses (004).

Schilling et al. (2006) reported that the transfer of care occurs in stages. This transfer typically begins at 11 years with full transfer occurring between the ages of 17-19 years. This transfer of knowledge from adults (caregivers and service providers) suggests that the youth demonstrated the knowledge and expertise to administer their own diabetes care and can advise others about their care.

From this basis of knowing, intuitive knowing materializes. This process, as described by participants occurred when the participant and caregivers simply knew what to do regarding the diabetes care. Participant 006 remarked, “After although it comes into a routine, it is basically my every day routine, going to school or that same stuff after a although or whatever, yeah, and ready to go”.
Another respondent commented extensively on this progression from knowledge to intuitive knowing.

I think out of the starting gate, my mom was fairly, very concerned that meds was on time and portions were done in such a way. We actually had scales; I remember we had scales on the kitchen counter. And I can remember she was measuring things. And that sort of stuff and I think for both of us, things started to become more intuitive. Like you knew, what needed to be done… And what, what, what limits you could push if dinner wasn’t at 6 of course it was at 6:30. Well that was okay and that sort of thing (008).

The intuitive knowledge participants experienced came from two sources of information. The physical sensations of hypoglycaemia or hyperglycaemia created a memory of what to do when those situations occur. Second, the repetition of the memory of the hypoglycaemia or hyperglycaemia experience shaped a behavioural response to the situation, thereby constructing intuitive knowledge to a situation. From these sensations and repetitive behaviours persons living with type 1 diabetes commented that self-care decisions were based on those experiences they had from the sensations and repetitive behaviours. Participants reported that living with diabetes became part of their daily routine. Normalization of diabetes practices occurred within the lives and homes of these persons living with type 1 diabetes. As a result, each participant created an intuitive practice for her/his care. Ingadottir and Halldorsdottir (2008) noted that this process is “trial and error…through combining the basic knowledge with real experience, understanding is gained” (p. 611). One person commented on just knowing if his body needed more insulin to impacts.

Now I am back on long acting and short acting, so. I was not taking the long acting. I was keeping my short acting in my back pocket and when ever my body felt like it needed a shot…..Then I would wait a ½ hour, 45, see if my body felt high then take one more unit (006).
This comment is realistic given that the physical sensations of hypoglycaemia or hyperglycaemia are common in many persons living with type 1 diabetes. Rubin and Blumer (2005) noted that the physical symptoms of both conditions provide biofeedback to a person that something is not quite right. This altered state then activates diabetes self-care by a persons living with type 1 diabetes. The physical sensations are then treated and a regulated blood sugar is the result. Ingadottir and Halldorsdottir (2008) conducted a phenomenological study revealed that this “body listening” behaviour guides persons living with type 1 diabetes in self-care decisions.

The knowing and intuitive knowledge about diabetes as described by participants in this study is a process that has occurred over time and continues to evolve. It is a process learned and tested by persons living with type 1 diabetes and their families. This evolutionary process is frequently used to assist persons living with type 1 diabetes in their illness management. Knowing what to do was essential in each youth’s learning curve. Replication occurred many times and then became a part of their intuitive knowing. This final sub-theme, along with the two previous sub-themes: (1) acquiring knowledge, and (2) sharing knowledge, all describe a fluid learning process for youth living with type 1 diabetes, her/his family, and the community. This theme outlined the experience for persons living with type 1 diabetes in this study as they acquired, shared, and built intuitive knowledge about their illness. The discussion now shifts to understanding the impacts of diabetes within youth living with type 1 diabetes.

**Impacts of Diabetes.**

The second theme found in this study is the impacts of diabetes. The impacts of diabetes refer to aspects of a person’s life that result from living with diabetes. The study
revealed four sub-themes regarding care and the ability to manage health for the participants. The sub themes include: (1) the impacts of food, (2) the impacts of medicine, (3) financial impacts, and (4) social impacts. Each sub-theme describes part of the meaning of what it means to live with type 1 diabetes.

**Impacts of food.**

At the time of diagnosis, food is one aspect of life that changes because of the diabetes. Participants in this study made various comments about food once they were diagnosed with diabetes. One person made this comment about food, diabetes, and the help he received from a dietician, “And I had a dietician to help me and my mom and what I can eat and what I can’t eat and how to adjust everything. And what to eat out, like McDonalds or something” (006). Another participant reported the following regarding the changes regarding diet after diagnosis.

> My parents did change some stuff, they changed the menu a little bit. There was no more ah, treats sort of thing. I mean there was treats but not like no cake, no pie, ah. All the pop in the house, we did not have a whole lot. But every time we bought pop it was always diet pop. Ah. We never really did go to McDonalds, so we just kept cooking at home. We ate lasagne, steak, and corn on the cob or whatever. Same like we did before, desserts were curtailed and I kinda missed that (002).

Some participants reported that food was a difficult discussion in their home with their parents. In this present study, one participant stated that she sneaked food. She remarked, “There was no way you could sneak a few chips into your diet without somebody finding out. And I would always have a little bit. I’d only have a couple” (001). Another declared that discussing food choices at times resulted in arguments with parents “If I was out to dinner or something, my mom would be like, should you have that? Like if we are getting dessert” (005).
Schilling et al. (2006) reported that argument over food choice, blood sugar testing, and sneaking food were typical occurrences in many homes. Although conflict is normal, the consequences can be more severe for youth living with diabetes. The consequences can influence both short-term and long-term health outcomes for a persons living with type 1 diabetes.

However, food was not a source of conflict or discussion in every participant’s home. Participant 004 made this comment, “I definitely didn’t battle with food like with my parents, like it was never an argument”. Another stated that her life did not change significantly because of being a person living with type 1 diabetes.

We had a fairly good diet anyways, I wasn’t really much given over to eating a lot of sweets and junk food and all that kind of stuff. So it wasn’t a big, it wasn’t a big adjustment for me (009).

What I gathered from this discussion is that food was a topic that was heavily discussed with caregivers and the youth. Some youth found little stress transitioning to a firmer, restrictive diet, although others struggled. Youth living with type 1 diabetes often had to change their diet, learn the composition of food, portion sizes, and caregivers adjusted meals for the youth and family. At diagnosis, families met with a dietician who explained to the caregivers and youth how to balance insulin intake and food consumption. Stability between insulin intake and food consumption is paramount in persons living with type 1 diabetes care. When this balance occurred, the result would be normal blood sugars and better long-term health outcomes. Rubin and Bulmer (2005) note that dieticians should attempt to create a nutrition plan that is flexible, fits with the lifestyle of the person, and takes into consideration any cultural or ethnic food needs.
This type of approach will lessen the stress when diagnosis is recent, as food may become a source of conflict between youth living with diabetes and their caregivers.

Food and the struggles with food are often a source of conflict for many youth living with type 1 diabetes and their parents. Food disagreements include: food choices, whether the youth should eat if their blood sugars were high, what to eat if blood sugars were low, and sneaking foods by the youth (Schilling et al., 2006). A participant noted that she snuck food that she wanted and another participant noted conflict with a parent when being questioned about a food choice. At times, food choices may be a mechanism by which youth assert their independence and their identity. Karlsson et al. (2008) report that adolescents living with type 1 diabetes make food choices that can be linked to their autonomy or individuality, and participate in food choices that are related to peer pressure.

**Impacts of medicine.**

Although food is an important consideration in the impacts of diabetes, the impacts of medicine are equally important. As a chronic health condition, type 1 diabetes requires medicine and physical care to sustain a person and when the illness is undiagnosed or uncared for, the condition produces physical symptoms. The initial onset of symptoms of the illness is physical in nature. The physical symptoms include: frequent urination, increased thirst, weight loss, increased hunger and fatigue, fruity breath, and blurred vision (Rubin and Blumer, 2005). These numerous physical symptoms only exist because a person contracted type 1 diabetes and therefore, these symptoms become a impacts of the illness. All participants reported on the physical symptoms they suffered before their diagnosis of type 1 diabetes. Participants commonly reported frequent urination and thirst, “I was just extra thirsty and urinating more frequently” (009), “I had
no idea of what was wrong. And I could not stop drinking water. And on other days, I would just be normal” (005), “I had symptoms for about three months, I think. I was peeing all the time. I was thirsty. I couldn’t, couldn’t stop drinking or peeing. I lost about sixty pounds” (002). Participant 004 noted that she was just sick and could not understand what was happening to her “When I found out I had type 1 diabetes, um, it was because my parents were wondering why I was sick all the time”.

After the initial onset of symptoms, in this study, the most frequent discussion about the medical aspects of care that resulted from diagnosis with diabetes was blood sugar testing. All of the participants reported past and current struggles with blood sugar testing. Many stated that they were not sure why they had a mental block about doing the testing. Participants shared their reflections of blood sugar testing as a youth and now.

I remember being resentful about having to write down my blood sugar three or four times a day. I didn’t mind the needles. I have never minded giving myself an injection. I hate testing though. I hate it. For years I have not tested (002).

I cared about school; I cared about like personal hygiene. I care about everything but diabetes. Because that was one thing that was not going to take my life, or take over my life (005).

So it’s been, it’s been even into adulthood, testing is something that has been my nemesis, it is not something that I have um, that I’ve, until actually the pregnancy then I kind of like 8 times a day. So, but it is not about me, it’s about the baby (008).

I have always had a really until recently a hard time with testing, an extremely hard time. Now I test all the time. I have done it for almost a year now, I guess, but ah, it was so hard for me to test myself (002).

Participants also discussed other physical aspects of a person’s body in reaction to hypoglycaemia, where to place an insulin shot on her/his body, and blood sugar testing. Participant 002 mentioned, “I ran a fairly high blood sugar because I did not want to get low. You act like a fool and everyone makes fun of you and you feel like crap”.
Discussions about blood sugar testing regularly occurred in the interviews with all of the participants. One person made this observation about her testing “At one point I had bruises on all of my fingers from doing the blood glucose testing because my skin is very sensitive” (004). Others made these comments.

I noticed when you constantly do it in one spot and it gets tough. The skin gets tough so I would get my mom to stick it in the back of my arms for a change up and ah, after a although I actually learned to do it myself in my arms (006).

I always hated taking my blood sugar with the end of my finger it just hurt so much. Right? And it ended up if you take it a lot, the end of your fingers get all chewed up, right. So, I started faking my blood sugars; just writing down random blood sugars in my book (010).

Along with the physical tasks associated with diabetes, participants reported on other medical aspects of their life. Participants reported on having to complete haemoglobin A1C testing, a blood test performed every three months to measure a person’s overall blood glucose level.

I had to I think I was poked about 5 times in my left arm, I and they did not get any blood, 3 or 4 times in my right one…. I was dead set against having to do anything with haemoglobin A1Cs because I hated, detested the lab with a passion (007).

Um, as common and a regular thing, obviously, when you went on this monthly or however frequently it was, you would have full blood work done and every three months an HBA1C. But, um, I remember that, that being a point of conflict (009).

Coffen and Dahlquist (2009) noted there are 25 tasks that a person’s living with type 1 diabetes needs to perform daily. These include; administration of insulin (needle, pen, or pump), taking blood glucose, understanding and the physical sensations of hypoglycaemia and hyperglycaemia in order to treat these conditions, going to a lab for haemoglobin A1C testing, and ongoing worry of long term health complications. The medical impacts of diabetes clearly affected the daily lives of the participants. From the
initial symptoms of frequent urination, extreme thirst, being sick, and weight loss to the daily progression of physical self-care task regime, youth living with type 1 diabetes had a different experience of adolescence than those without the illness.

Participants reported on the necessity of and the struggle with physical and medical impacts of the illness. All reported struggles with glucose testing, experiencing hyperglycaemia or hypoglycaemia, and physical change in their bodies because of the administration of insulin. Many medical aspects of diabetes were and are ongoing issues for participants. These necessary medical processes become a impacts of the illness and a daily experience for the participants in this study. The medical aspects of living with diabetes are now complete; the financial impacts will further describe the experience of living with this illness.

Financial impacts.

The third impact of diabetes is the financial feature of the illness. The financial impacts of diabetes as described in this study refers to how finances may or may not influence self-care and long-term health outcomes of people who live with type 1 diabetes. A few participants, particularly students, commented on the current and the past financial burden of diabetes and the impact on self-care decisions.

And I am not going to lie I buy the cheap like white bread if it is cheaper than whole wheat or something, it is little but you know I don’t make a lot of money and I am going to school, so (005).

It was always a struggle for them (parents) because... And it still is a struggle for the coverage because diabetes supplies are really expensive. And I know that there was lots of times where it was really financially hard for my parents to pay for my supplies for my diabetes (004).

I am still constantly struggling with my extended health care plan to help me with paying for my supplies and pump supplies are so expensive. And I don’t think
that people understand that it is not really a choice for me to not have an insulin pump because if I don’t have it, my health will be awful (004).

And I remember too that when I was first diagnosed strips were free. And all the diabetes supplies were free. And then they changed that. I don’t remember when... but I was still living with my parents and my dad had medical so they were still free enough. But after I was not covered by my parents medical and did not have my own medical I could not afford the strips (002).

Although only three participants commented on the impact of finances on their care, it was clear that financial well-being could determine physical well-being.

Helegeson et al. (2007) stated that financial security for a family or individual could be one aspect in positively influencing long-term health outcomes. The Canadian Diabetes Association (2010a) reported the cost of diabetes supplies varies across Canada and access to supplies is dependent on the income of youths living with type 1 diabetes and their families. Hood et al. (2007) echo that belief, reporting that low socio-economic status influences the health of youth with type 1 diabetes by access to medical supplies, mechanisms to administer insulin, and food choice availability.

**Social impacts.**

The social impacts of diabetes are the final theme in this discussion of the impacts of diabetes. The social impact of diabetes as described in this study consists of two parts. First, there is the perception of what diabetes is by other people who are in the lives of a person living with type 1 diabetes. These people can include; family, friends, acquaintances, service providers, and community members who reacted in some manner when they learned a person was living with type 1 diabetes. The second part is the social aspect of a persons living with type 1 diabetes, which includes interactions with peers and activities engaged in by participants. These two areas influenced participants and only occurred because they had type 1 diabetes. The social areas where respondents described
incidents related to their condition included: use of syringes for insulin administration, friendships with peers and persons living with type 1 diabetes care, education, sleep pattern, and driving.

A few respondents reported one of the social impacts of their diabetes was the administration of insulin using a syringe. When using a syringe or needle, participants commented that people who did not know that they were a persons living with type 1 diabetes, thought that they were an IV drug user, which created an occasional social stigma.

And then on top of that, if you see somebody in their teens pulling out needles and doing injections on the table not knowing what it was, um back 10 years ago or 15 years some people might say something (007).

And they (the police) asked me to hop out of the car, they were being pretty cool until they opened up the glove box and saw all those needles. And then they threw me up against the wall and then they were being really rough with me. And I said I’m a diabetic. They took my insulin and then they handcuffed me and put me back into the car and they were yelling at me (010).

Many participants described their diabetes care as a private occurrence, partly because of the perception that the person using a syringe may be a drug user. Participants reported that they did not want to be associated with IV drug usage. To avoid this judgement, participants used their syringes in privacy to avoid the risk of possible judgment. Participant 009 remarked, “And I usually went to do my blood tests in the washroom or somewhere private to give myself injections or whatever”. Another participant commented on the placed in which he administers insulin now as an adult.

Well, if I had to do any tests or anything I would go to the washroom instead of pulling out my poker and stuff like that instead doing it out in front of people. Where as now I am more outgoing about it and it is just it is something that I know a lot of other people have now and just. It is always better to test and stuff like that now then it was back then, when I was younger (007).
Although a few participants took a cautious attitude about their diabetes when it came to outsiders not knowing them or their condition, as they feared social stigma, other participants in this study seemed to find the appropriate times to disclose that they lived with diabetes. Many participants found that they could be open and honest with their peers. In this present study, some participants felt that there was no stigma about their condition and shared the experience of living with their illness with others.

There is probably 3 or 4 (people I am) comfortable talking to about my diabetes and explaining to them what to do if I was having a low blood sugar and describing to them the symptoms of a low blood sugar. Um, I had one friend and one boyfriend who I would have let given me an insulin injection (004).

Even back then when I was 15 or 16 years old. Every one was always interested in what I had to say. They would always ask me questions about, about the soreness of testing, about what I can or can’t eat. The most common one I get is, you can’t have any sugar right? (002).

I think because I was so open I was kinda, I mean if people did find out they thought it was very, oh cool and what’s this and that and would ah, show them. I was, I was very open I didn’t care, this is my needle, this is my tester, test my blood kind of thing (001).

This observation suggests that youth living with type 1 diabetes, as the majority of youth find connection with peers as they share personal information about themselves through friendship. Greco et al. (2001) comment on how peer relationships can be a positive influence on adherence to self-care tasks. Friendships develop from common interests, similar belief systems, and values. Living with diabetes becomes an added dimension to the relationship as trust and sharing occur. For many participants, peers were part of their lives and then became part of their self-care. Participant 006 stated, “They knew what to do if an emergency situation occurred and something happened in my diabetes that I could not take care of myself”. Other participants mentioned the following.
But he would go hey, you look tired, are you okay? Go check, go take your blood sugar, you know. He'd kind of watch out for me. Sometimes I'd tell him to shut up, but um. He's still my best friend, so (010).

And I usually went to do my blood tests in the washroom or somewhere private to give myself injections or whatever. But most of my friends were pretty supportive and they wanted to know a little bit about it, about diabetes (007).

La Greca et al. (1995) report friendship as an important supportive factor in the lifestyle and activities of youth living with diabetes. The present study noted that when youth have friends that can share some of the activities in their life and (exercise, health snacks, accommodations for meal planning), a type of emotional support is gained. This type of support is different compared to one found in a family system. La Greca et al. (1995) note that family provides more tangible support for tasks associated with daily management and although friendship provides companionship and emotional support.

Once friends became educated about diabetes, they were able to act as allies to assist their friend with management. Silverstein and Bandyopadhyay (1995) echo the importance of friendship at a diabetes camp, where friends learn about diabetes along with those who have diagnosed. This process strengthened friendships and provided support for the youth living with diabetes.

All of the participants reported about the typical features of adolescent life such as playing sports, being part of clubs, working, driving, being with friends, drug and alcohol use, sleep cycle, and homework. Participant 009 stated, “I played sports and I was on student counsel and um, choir and things like that”. Another person commented on working in the community, “…I did work at McDonalds as a teenager” (004).

Participants made remarks about activities they were part of during their adolescence.

I use to go on 10 day canoe trips out in um, Northern Ontario and um, or I was a lifeguard for the city of Toronto parks and recreation my mid to late teens and
there were guard bashes till 3 am at sorority or fraternity houses and whatever and
that. I don’t ever remember thinking I can’t do that or I can’t have half a beer
something like that (009).

I had we, a group of friends, we went skiing; either water skiing or downhill
skiing all the time. They all knew. I mean I have never been afraid to tell anyone
that I was a persons living with type 1 diabetes. Ever, so all my friends knew. So
if I had to eat something after a run of skiing, and whatever meet up with them
after the next run or they would wait for me (002).

My coaches or instructors, um, they knew I would, I would sometimes go out and
take care of a low blood sugar or whatever. But, I usually just let them know at
the beginning of the term or the season. And they respected that (009).

These activities are typical for many adolescents. Many participants commented
on drug and alcohol use during their youth. The responses varied. Participants 002 stated
that he, “…never had a drink until I was 20 years old. I never, never tried drugs”.

Although others made comments about different levels of experimentation with
substances.

I stayed away from the sugary drinks cause they made me really, really sick. And
I always tested my blood sugars before I was going to bed. Just to make sure that I
had that balance because I did not want to wake up in the middle of the night with
a high blood sugar cause it didn’t, it doesn’t feel good (004).

I experimented with lots of different drugs and I drank. Um, and you know
sometimes I could drink a case of beer by myself and be fine and other days I
would be throwing up all over the place. And it was probably because my blood
sugars weren’t being managed properly (010).

But otherwise I um, I guess just being um, self aware and being careful I did not
really have a lot of alcohol, maybe a couple times at parties. But I noticed that
staying up really late would really affect my diabetes (009).

I went through this stage when I was like 19. Where it lasted for about 3 weeks,
so it was not like a huge big party stage. It was just like I had never been drunk
before (005).
A few participants discussed how living with type 1 diabetes was part of their education in high school. One person stated how a low blood sugar affected school performance. Another stated how he used his diabetes to avoid going to high school.

There were times actually in schools where I would have a low blood sugar during tests and got really, really bad grades but I was able to discuss that with my teachers and then rewrite. Because when you are having a low blood sugar, you can’t focus and all I could focus on is that on the fact that you have a low blood sugar and what was I going to do to make my blood sugar balance out again (004).

I remember in high school I would use it to my advantage, I would get there in the morning and I would not feel like going to class so I would go to the principal office instead, and I forgot to take my insulin this morning, I need to go home...And of course um, they can’t take the chance that I am lying to them and risk a medical emergency and they’d have to send me home. Um, and then I just would not come back (010).

Sleep cycle were another aspect of adolescent life that participants described in their interviews. Some reflected on how living with type 1 diabetes affected their blood sugars and insulin administration. One person observed that living with type 1 diabetes did not affect his/her sleep cycle.

I always liked sleeping. And it is funny to look back now, cause I wonder how much was actually caused by growing and getting through the teenage years. And how much was actually caused by my crappy blood sugars (001).

I remember the ah, youth living with type 1 diabetes nurses that I saw would always say you have to get up by 9 o’clock in the morning, take your insulin, if you want to go back to bed, then go back to bed. You got to get up, five minutes, take your insulin. And I wouldn’t do it, I would sleep till 4 o’clock in the afternoon and then I would get up and take my insulin (010).
Three participants commented on having their driver’s licence. All stated that there were complications with living with type 1 diabetes at the same time. One person told the story of having her licence taken from her due to a medical reason.

Like my family doctor constantly nagged at me to test my blood sugars and then one day when I was like 16 or 17 I got a letter in the mail from my doctor declaring me medically incompetent and I was no longer able to drive...So, they took my licence away. My driver’s licence away because I did not test my blood sugars (004).

Two others noted that parents were concerned and cautious about their teen driving because of the diabetes.

I was driving my own car. As a teen, I know it was a big worry for my mom when I was driving...I was not always as free to do those things without careful consideration, or extra planning or make sure um, that it was a smart thing to do. My diabetes was in good control so that I wouldn’t put others at danger (009).

Well I remember being when I went to get my driver’s licence my mom said to them, the people at the motor vehicle branch, oh, he is person living with type 1 diabetes. And I turned and looked at her and I wanted to smack her. Why would you tell them that right? And then, they came out with this big huge medical forms that I had to go get filled out. And um, it cost like $185 bucks back then to get it filled out. And my mom ended paying for that for me, but um. You know it seemed kind of unfair but I guess it is in the interest of public safety to make sure that people on the road... (010).

From this discussion, it appears that the participants in this study experienced many typical adolescent experiences. It is clear that youth with diabetes do not differ from other youth in terms of activities, choices, and peer interaction, and development. Participants had varying experiences with drugs and alcohol, school, work, sports, clubs or groups, recreational activities, sleep cycles, and driving. The key elements that distinguish these adolescents from youth living free of diabetes in this discussion are the self-care activities and four impacts of diabetes.
Throughout the examination of this theme, the impacts of diabetes, there are many things that have influenced the lives of youth living with diabetes. The four sub-themes in the impacts of diabetes are, (1) the impacts of food, (2) the impacts of medicine, (3) the financial impacts, and (4) the social impacts. Each sub-theme described the range of typical experiences to a person when she/he lives with type 1 diabetes. The persons in this study have this experience because they live with type 1 diabetes. In essence, the disease created this experience and resulted in a different adolescence than youth living free of type 1 diabetes.

**Constructive and Deconstructive Factors in Relationships.**

The third theme that emerged from this study is constructive and deconstructive factors in relationships. Two sub-themes were contained within the third theme: (1) connection and support, and (2) knowledge. In the context of this discussion, connection and support refers to the bond or union between two people and youth living with type 1 diabetes actions associated with that bond or union (La Greca et al., 1995). This definition implies that when connection occurs in relationships, actions are described as help, assistance, and understanding. La Greca’s et al. (1995) work referred to this concept as how people who are friends with a diagnosed person “make them feel good about diabetes” (p. 453). The final sub-theme, knowledge, was previously discussed but appears in this discussion as a factor that enhances or demolishes relationships. Knowledge in relation to diabetes, according to Ingadottir and Halldorsdottir (2008) means “learning about diabetes, insulin, and youth living with type 1 diabetes’s body, blood sugar testing and understanding the social context of diabetes” (p. 610). For
persons living with type 1 diabetes in this study, other people having knowledge about their diabetes was an important aspect in their relationships.

Within each of the two sub-themes, participants reported positive (constructive) and negative (deconstructive) factors. This discussion will outline the constructive and deconstructive factors for each of the two sub-themes. Participants provided information about different types of relationships. They described family relationships and informal relationships with friends, community members, teachers, and coaches in a variety of environments. One question directly asked participants about their experiences with professional service providers who assisted them with their persons living with type 1 diabetes care.

**Constructive factors: connectedness and support.**

The first sub-theme that surfaced was connectedness. As stated previously, connection to a person is the basis for the formation of a relationship. Participants in this study frequently commented on their family relationships in association to their diabetes. Participant 006 commented, “My family has been really supportive and everything and helped me out when I needed help. They’re a shoulder to cry on when I am going through hard times”. Other participants reflected similar sentiments.

Christmas one year, my brother and my dad made me a box with different compartments to store my diabetes stuff. My meter and my needle and...my two insulins that I have. That was an unusual Christmas present I guess not everybody would get (002).

So, it was a supportive environment for dealing with diabetes as well. I think my mother was more ah, concerned with my numbers and making sure my haemoglobin A1C’s were within the best range possible. So, my dad was more generally supportive but um, mom would help me with changing insulin ratios or whatever. And making sure I was writing everything down so we would have it when we would go for check ups and stuff like that (006).
Participants revealed constructive factors in their family relationships. They described family members as having concern and understanding for their condition and providing emotional, physical and financial support. Karlsson et al. (2008) reported that connection occurs in relationships with family through their actions and words. Along with constructive factors for family relationships, each participant was able to comment on the characteristics that enhanced their relationships with different service providers.

One person made this comment about a service provider, a nurse who tested products on her own body before she informed her patients.

She did everything she could possibly do to help me. Um, that includes giving me insulin when I didn’t have any and I could not get any help from anybody else. She helped me set up my insulin pump. She um, she gave me her home number. We yeah, we just had an amazing connection that was very supportive, very non-judgemental. She tested everything out on herself and I always really appreciated that about her. So if she had a new type of syringe that she wanted to show me, she actually, and she did not have diabetes she would actually use it on her own body (004).

One mentioned the care he received from his family doctor when he was first diagnosed with diabetes, “and ah, I think he came to see me probably a few times a day for the first week I was in the hospital”(002). Participant 001 described a physician who combined caring with a matter of fact attitude.

He was just, he was very real, he would call me on my... you know. If he knew I was lying or anything, he would say, I know you are lying, I see people like you everyday and he was very real he didn’t try to ah. He wasn’t babying you, he wasn’t (001).

Many participants recalled service providers from their childhood or adolescence by name, recounting specific incidents that made the participants take note of their health in association with their diabetes care. They described characteristics of service providers as people who were genuine, non-judgemental, who saw them as a person beyond the
diabetes, and who were flexible in their style of the delivery of education. Schiffrin (2001) outlined flexibility as a key factor when working adolescents living with type 1 diabetes adolescents and their families.

**Deconstructive factors: connection and support.**

Aside from support and connection, participants noted that conflict with their family, specifically their parents, was a source of disconnection. Although participants stated that typical adolescent sources of conflict (friends, homework, rules) occurred, some participants reported that diabetes care was a basis for conflict in their homes. For participants in the present study, blood sugar testing was a large source of conflict. Participant 002 remarked, “We never had any conflicts. Well that is not true. I would get in trouble; you know if, I did not test. Or if I did not want to”. Another person stated.

> Like my mom constantly nagged me to test my blood sugars because that was... I never didn’t give myself insulin but I hated testing my blood sugar. And I think being at that age I was searching for control and I could control that. So, other than nagging me they couldn’t really, they couldn’t really do anything (004).

These comments are consistent with the literature that reports parent/youth conflict and the lack of adherence to type 1 diabetes care by youth (Hood et al., 2007; Schilling et al., 2006). Hood et al. (2007) designed the diabetes control and complications trial (DCCT) as a standardized tool to measure the conflict level between caregivers and youth and determine the adherence to diabetic care. Revealed through the conflict scale was that typical disagreements between parents and youth living with diabetes occurred over food choices or consumption and blood sugar testing. Although the conflict scale was not used in my research, it is important to note that participants in my study reported conflict in their youth with their parents regarding their diabetes care. It is interesting to point out that upon reflection, the adult persons living with type 1 diabetes in this study
acknowledged the difficult position that their parents were in and wished they had listened to them in regards to their care. One person commented that she feels bad because of the way she treated her mom.

I didn’t get along with my mom, she was you know trying to you know make sure meals were like you know prepared or whatever. And trying to make sure I had like juice and like sugar tablets… she was like incredibly like just helpful…just being a mom, being really, really awesome. Accept I didn’t appreciate that. What a jerky kid (005).

This comment may be typical for some youth living with diabetes and was true for one person in this study. Silverstein and Bandyopadhyay (1995) state that, “young people feel guilty about the burden upon their parents and family” (p. 817). Often youth may feel that their care is overwhelming to their parents. The “burden” as described by Silverstein and Bandyopadhhyay (1995) may lead to depression, withdrawing from others, or a youth may attempt to take over her/his care without the proper skills, knowledge, or ability in place.

Aside from parental disconnection, all participants reported on sources of disconnection between themselves and their service providers. In this study, many reported that when service providers appeared judgemental, did not listen to them, and faked understanding and focused on medical aspect of the illness and not the person, the participant soon lost interest in maintaining that relationship.

So the relationship is like a block. If you can’t talk to somebody about diabetes, if they don’t have diabetes then they are strictly speaking to you from a medical basis. Like yeah, I know you’ve read probably a text book on diabetes but that does not actually help me, because I have it (005).

Although participants acknowledged that service providers were attempting to motivate them for improved care, it had the opposite outcome.
He (my doctor) was like trying to help and ah, I just feel a bit of guilt because of that. Because I know people are trying to help you and I just, I don’t know, I just could not accept it. Right then, I just couldn’t I was just to wrapped up in my own drama (005).

Even at that early age, I remember thinking, why are you, I don’t mind you telling me a piece of information or teaching me something or whatever. But don’t pretend, you have a deep understanding of this, because you don’t you are not a person living with type 1 diabetes (008).

Participants noted the experience of disconnection between service providers and themselves as influencing their care. Karlsson et al. (2008) state “if professionals were not familiar with a teenagers’ every day activities, it was sometimes hard (for the youth) to adhere to the health regimen because the professional did not confirm with the teenager’s life situation” (p. 568). This statement applied to a few participants who reported that they did just not go back to a service provider if there was no connection with that person.

From this dialogue, the participants gave an account of a number of characteristics that constructed positive relationships or negative relationships with their parents and service providers. Participants in this present study revealed that the characteristics of understanding, being genuine, non-judgmental, viewed the patient being seen as a person, offering support and being honest as characteristics they desired in a positive relationship with a service provider or parent. Dovey-Pearce et al. (2005) echo this discussion and offer a comprehensive list of attributes that enhance relationships when being part of the life of a youth living with diabetes. These include consistency of contact, civility and rapport, listening, involving the person in the consultation and giving them choices, a non-judgemental and encouraging approach, giving positive as well as negative feedback, facilitating coping skills and access to specialist information, whole-
person care facilitated by multidisciplinary teams, and age-appropriate shifts in consultation style. These characteristics, as described by the participants and literature, reveal that when the relationship between youth living with type 1 diabetes, family, and service providers is strong and functional, there is a higher rate of cooperation in diabetes management because of harmonious relationships.

Deconstructive factors in relationships as described by participants in this present study included lack of connection and support that occurred when family members and service providers were judgemental about their care choices, when they were not being treated as a person, and were misunderstood. Dovey-Pearce et al. (2005) states that these types of characteristics in service providers and parents alienates youth and deter youth from adhering to a successful type 1 diabetes management regime.

**Constructive factor: knowledge.**

Knowledge was discussed earlier in this chapter as a major theme and appears here as a sub-theme as a constructive and deconstructive factor in relationships. In this current study, participants commented on how knowledge enhanced and strengthened their relationships or how the lack of knowledge weakened those relationships. One person mentioned her friend and her friend’s parents.

She, the whole family knew exactly what to do. It was no big deal. And she would help me with my insulin, and like she would help me with my food and they took me on all kinds of vacations (004).

Silverstein and Bandyopadhyay (1995) illustrate the impact knowledge can have on adolescents living with type 1 diabetes when their friends receive the information.
Many participants echoed this same opinion. They remarked that management and day-to-day impacts became easier and their relationships became stronger.

The participants in my study did not report many disconnections with their family members regarding their lack knowledge about the diabetes. There was only one person who stated that her father did not have knowledge about diabetes. She stated that their relationship had changed since he left the community and his involvement in her care was minimal. She made this remark about visits she would have with him “But I remember him saying when he would take us out to restaurants I remember saying I can’t have um, um I shouldn’t have sugar and stuff. And I remember him saying, just have what you want” (005). It is unclear if this parent made these parenting choices out of lack of knowledge about diabetes and care for someone with the condition, out of love, a parent wanting to make a child happy, a parent who had minimal contact with his child or had another rationale for that particular parenting choice. Regardless, the participant reporting this incident felt that his ability to assist her with her condition was minimal.

A few persons reported that disconnections occurred between themselves and peers, acquaintances, or other adults in their lives who did not have knowledge about diabetes. Participant 007 recalled this situation about food choices and his diabetes: “They have not ever really pressured me into like saying you can’t have this or you can’t have that because then I would basically stop hanging out with them”. Another person made this comment:

I remember one girl saying to me, why were you away from school for a week? And I was like oh, well, I got diabetes, I had to say there. And she was like that was not a very good excuse; all of (us) had to go to school (005).
Most participants stated that knowledge was provided to them and their parents from diabetes educators with information to understand and manage their illness. From that platform, they were able to educate others and build allies within their existing relationships. Schiffrin (2001) echoes this belief system as the reorganization and redistribution of family activities occurs at the onset of diagnosis. The education process for all begins and continues to build over time as the family is learning together, with parents or caregivers taking the lead position of care. However, when there is a lack of knowledge, disharmony and frustration was the consequence for many families (Schiffrin, 2001). Although knowledge transfer was vital in the relationships between the youth and her/his caregivers, friends, and community members, it was even more important in the relationship with service providers.

Service providers, parents, and youth all need to work together to assist the youth in effective diabetes management. All nine participants observed the importance of knowledge in the relationships they had with service providers. When the service providers conveyed knowledge respectfully, the participants in this study reported an increase in compliance in their treatment. Participants made these remarks about the connection they had with their service providers and knowledge. Participant 006 remembered this about one diabetes educator, “Basically any question I had she was there and able to answer anything… like I said was awarded by the CDA (Canadian Diabetes Association) for her knowledge in ah, youth education and all that. And I believe she deserved the award”. Another person spoke about his connection to a physician. And if I tried to ask him a question, which I tried to do this all the time, he would answer it the best he could. He is probably the doctor that had the most influence on me on trying to get my blood sugars under control (002).
From these experiences, it is apparent that knowledge about diabetes is an important factor in building a relationship for youth living with diabetes. The manner in which service providers delivered knowledge to participants was vital in building the relationship between the two persons involved in the management of diabetes. Mulcahy (1999) note the ideal characteristics possessed by a service providers are when she/he has a “variety of knowledge and skills from each discipline (which) provides a comprehensive learning experience” (p. 161). This comprehensive learning coupled with a respectful attitude was an effective combination for many of the participants in my study.

Deconstructive factor: knowledge.

Lack of knowledge in relationships can lead to disharmony and possibly end a relationship. In this study, none of the participants reported on lack of knowledge from family. Earlier in this chapter, in the knowledge theme, participants reported that if someone lacked knowledge, education rectified the situation.

However, there were some comments regarding service providers and their lack of knowledge. For the participants in this study, any lack of knowledge from service providers pushed them away from medical care. A few participants were able to report on how a lack of knowledge from a service provider produced a disconnection in their relationship. One participant made this comment.

I decided that my family doctor did not know enough about diabetes to be helpful. So, I actually told her that I would not be talking to her about my diabetes anymore I would be talking to “Sally” at the diabetes education clinic. Um, my doctor never really kept up with the times, she did not know about pumps, she did not ever push me to get a pump, and she never got me to try anything new. And never asked me how I was doing. At one point I had bruises on all of my fingers from doing the blood glucose testing cause my skin is very sensitive. And, she was kind of like; suck it up (004).
Knowledge about diabetes is crucial to youth living with type 1 diabetes, those around her/him and service providers in creating, and/or maintaining a relationship. When knowledge is conveyed in a respectful manner, a connection increases between two people. Participants recounted many instances where the relationships they had been in were created, improved, or were maintained once information was shared. However, when there is a lack of knowledge, relationships deteriorate.

Through this discussion of connection and support and knowledge, it has been easy to see how fragile relationships can be for youth living with diabetes. The participants have described several situations where the relationships they have with persons in their lives can be changed by the attitudes and knowledge shown by caregivers, peers, and service providers in their lives. It is through reviewing connecting and disconnecting factors in relationships that it becomes easy to understand the influence of these elements on the self-awareness and identity development of an adolescent.

**Self-Awareness and Identity.**

Self-awareness and identity is the final theme in this present study. Frequently described and discussed by participants in relation to themselves and living with type 1 diabetes were two concepts, self-awareness and identity. Hernandez (1995) described the lived experience of type 1 diabetes as an “integration of the personal and youth living with type 1 diabetes self” (p. 35). Within my research study, participants were able to reveal how diabetes is part of their thoughts, feelings, and beliefs about who they are and how they see the world at different developmental stages in their lifetime. This discussion examines three different developmental stages for the participant: (1) self-awareness and identity at diagnosis, (2) self-awareness and identity during adolescence after diagnosis,
and (3) self-awareness and identity, now as an adult. Their account of their construction of their self-awareness and identity occurs through the thoughts, feelings, and beliefs about themselves and their condition at the three developmental stages as outlined.

**Initial formation.**

To examine self-awareness and identity, participants were first asked the question “what was your experience when you found out you had type 1 diabetes?” This question revealed emotions, thoughts and belief systems about that experience. Participants disclosed the symptoms prior to diagnosis, their hospital experience, and what emotions they felt during that time. Participant 009 revealed, “I was overwhelmed and sad at the diagnosis which would be for the rest of my life, um, but soon I was assured and confident by the diabetes team at BC’s Children’s Hospital”. Other participants made these observations of the experience.

The onset of puberty and I was starting to lose a lot of weight and at that time I was ah, very ah, very athletic, I was doing ballet…rapid weight loss and all of the thirst and all of the regular, you know signs of ah, that diabetes on set…And I know um, I, I remember thinking on the one hand, I should be really upset about this but on the other hand nobody made a really big deal out of it so. So the initial sort of thing was upsetting being in hospital was a bit upsetting… It wasn’t really, it wasn’t until I got home that everything sort of hit. Like oh, we’re now dealing with a chronic illness that I am going to be with for the rest of my life (008).

I remember we were just driving home one day and I was like drinking like 3 one litre water bottles and I just could not like stop and I was like mom, something is wrong. And we both kind of thought, yeah, you might have diabetes. So we went to the hospital and they confirmed that. So, um, I was not surprised but um, I was also kind of, when he told me, when the doctor told me... But, um when he told me that, I was like no I can’t have that because like I am not suppose to have something like that. Huh, it is supposed to be a cold or something (005).

I was there for a week and I was miserable. And I felt really, really alone because it was just me and a girl and a girl who had her tonsils removed. And yah, it was not a pleasant experience at the hospital at all (004).
When I was first when I was 10 or 11 and I remember thinking, just horrified, “Oh my God I am a diabetic, who would ever want to date me”. And I don’t know where that came from and I don’t know what that was about. But I was horrified for like, at least a year, for a long time (001).

It was overwhelming I ah, I did not know how I was going to deal with it. I did not realize all the things that I would have to cut out or change or do extra. I did not know even what questions to ask. I think (that) was the first intelligent question I asked (002).

Participants articulated emotions of shock, feeling overwhelmed, sad, disbelief, fear, puzzlement and relief when diagnosed. Schiffrin’s (2001) research about the experience of receiving a diagnosis of diabetes is similar to the reports of the participants in my study. Schiffrin notes the psychosocial impact of the diagnosis. Schiffrin describes how families and the person being diagnosed experience a wide variety of feelings including anxiety, fear, grief, helplessness, and anger. It is these emotions, coupled with symptoms before diagnosis and hospital experience, which creates the self-awareness and identity formation process. The participants I interviewed reported this experience.

Participants described the symptoms of diabetes prior to diagnosis and the hospitalization experience as part of their self-awareness and identity formation. All respondents reported that as part of their hospitalization, they received education from a variety of professionals regarding their new condition. The length of stay in hospital varied from 3 days to 3 weeks depending upon health and circumstance of the participants. Aside from a common diagnosis experience, a few participants commented on how the initial education shaped their beliefs about diabetes in their life. Participant 004 noted, “It’s like unless you tell people you are a person living with type 1 diabetes, they don’t know. You’re just the same person”. Two other participants made these remarks about diabetes.
I hate needles I don’t want to have needles. Nurses started giving me needles obviously with insulin…they started teaching you how to give, you know injecting an orange and your thinking this is going to be me next, I better get this right. And then thinking, after the first few times that you have given yourself an injection, I really prefer that someone else wasn’t doing this, thank you very much (008).

One thing that was ever taught by my educator and that was don’t let the diabetes control your life in any way. You should be able to live a perfectly normal life, same ways as anybody else would. So throughout my life that’s what I based everything on (006).

It is interesting to review the feelings, thoughts, and beliefs participants had as they reflected upon their memories at the time of diagnosis. The information gathered from these participants suggests that when these youth developed diabetes they had common experiences. They had physical symptoms, their caregivers sought medical attention, a diagnosis transpired, and a hospital stay occurred to stabilize the condition and provide initial education. During this period, youths experience a wide variety of emotions and thoughts, which can influence their beliefs about who they are because of this life-changing event. Through the participants’ observations, this process of acquiring a chronic health condition is complex and affects a person’s identity. The thoughts, belief systems, emotions, and new information about the diagnosis are intermingled, influencing, and affecting the development of a person.

However, this situation was not cannot be true of all the participants in this study. One person was unable to articulate his experience when he found out he was diagnosed with diabetes. Participant 007 was diagnosed at 1 year of age and has no memory of the event. He stated, “My experience really wasn’t, and I did not have any experiences because ah, I was diagnosed at such a young age”.


This respondent also commented that he and his parents have never talked about what that experience was like for them. He stated that they just assisted him in his care and then transferred his care to him when he got older. The participant shared none of the same experiences as the other participants simply because of his developmental stage at the time of diagnosis. For him, the diabetes has always been there in his life and memory and he cannot remember not having the illness. He made this comment.

I learned to deal with it (diabetes) at such a young age that it. Like of course I can question it and stuff like that of course during some arguments it might come up. But, ah overall it was something that wasn’t, that I questioned really. It is just an unfortunate circumstance (007).

These two different perspectives revealed a difference in self-awareness and identity in the participants in this study. One person did not have the same experience as the remainder of the participants due to a developmental factor. I concluded that those respondents who did recall their diagnosis are that the emotions, beliefs and thoughts they had about themselves changed because they contracted type 1 diabetes. Each of the participants spoke about their lives being different because of living with diabetes as a new reality was placed upon them. One participant made this comment, “Well, I, it was always something I had to kind a think about and not run out with my friends I just had to make sure I had my equipment with me (009). Another participant noted this about her experience and not knowing what would have been different if she was living free of the illness. “I can’t step outside of what my experience was and think well this is what it would have been like if I had not had diabetes. I, I can only like. Does that make sense” (008).
Although it is simple to conclude that living with diabetes made the persons in this study different, it is difficult to determine if living with the condition made their lives better or worse than someone who does not live with the condition. One participant concluded that individual personalities play a large role in how an individual manages her or his diabetes. She states.

I’m probably blessed with having a fairly cautious personality to being with. It might have been different. ....When I started working, I worked for the ministry of natural resources and worked as a park naturalist so you were in dorm housing, .......(and I had an) interaction with another diabetic, ...she was a recreational drug user, she drank whenever, she did not eat particularly well, and she was not particularly hygienic about her.....needles (008).

From this discussion, the experience of receiving a diagnosis of and living with type 1 diabetes for the individuals in this study concluded that the lives of these participants changed in some manner because of the diagnosis. It is difficult to determine how the lives of the participants may have been different if the diagnosis with the condition had not occurred. What can be concluded is that when a person lives with type 1 diabetes it is different than when you do not live with the condition.

**Adolescence formation.**

In this next discussion, I asked participants to reflect upon their emotions, thoughts and beliefs about themselves and the world as an adolescent, after diagnosis. Participants shared feelings of frustration and annoyance with type 1 diabetes care, conflict with others in their lives about the care, and the pressure to complete the care. In addition, this group reflected upon how their belief system about their care enabled better management of their diabetes. The participants also discussed how normal their lives were, aside from the diabetes and its self-care practices.
All participants informed the researcher about the complexities of managing diabetes. Some discussed blood glucose management, conflict with their caregivers about testing, and haemoglobin AIC testing.

Thinking back about it, I don’t know how I did that because you eat more one day and less one day. There is no way of controlling. You are expected to eat the exact same thing every day...When we went out for dinner and I ate a little bit extra, I would have had high blood sugar for the next couple of days I think...I remember there was a period of time where I hated, I always hated taking my blood sugar with the end of my finger it just hurt so much (010).

I would be high and then come home and do an A1C and my doctor would yell at me for it being too high...And I mean, I remember, I remember thinking, about what this is going to do to my A1C results. All the time I would think about that. Every day I would think about my lows and my highs and how it was going to bring me up or down on my 3 month test. It was a bit of pressure... And actually to be honest with you sometimes I would at home in a kind of controlled situation I would try to be low to try to bring down my A1C number (002).

I was nagged a lot. That was pretty much it. From 13 to 18 that was like pretty much the whole thing... the nagging turned into anger and then I got angry about it too and then I refused It wasn’t nice. It was pretty bad actually. And then I started actually lying about my numbers. I would figures out ways to make them lower on the machine so she couldn’t find out obviously...it was a fight between me and my mom I guess (001).

Aside from day to day management, one person stated that doing typical adolescent things was more complicated because of diabetes.

As a teen, I know it was a big worry for my mom when I was driving... I was not always as free to do those things without careful consideration, or extra planning or make sure um, that it was a smart thing to do. ...my diabetes was in good control so that I wouldn’t put others at danger (009).

Aside from the complexities of daily living, many people disclosed that diabetes simply became part of their routine. Diabetes self-care activities were necessary for their long-term health. These practices were something they had to do to be alive and one person stated.
Just like having to take 5 minutes out of your day, couple times a day to monitor, to make sure your bodies in check, in the right working order and that. Um, as long as it is in working order, there shouldn’t be nothing you can’t do (006).

To ensure good self-care practices, one person commented that it was her attitude and belief about the diabetes that made a difference in her life "I don’t remember ever stopping and thinking wow, I got diabetes that really cramps my style. Don’t ever remember doing that. I use to go on 10-day canoe trips" (008).

Another participant stated that her diabetes educators allowed her to feel confident in her management. She believed her diabetes management would not be perfect, but it was possible. She gave this account of her experience.

Cause I had a good team of, of educators. That gave me what I needed. It wasn’t perfect management, throwing in the hormones when you are growing up, there’s lots of um, issues to deal with about in different environments and things. Overall it went fairly well (009).

Participants in this study noted frustrations with their daily routines and care responsibilities. However, a positive attitude towards self-care enabled participants to experience normal adolescent development. All of the participants stated that living with type 1 diabetes did not prevent them from having typical teenage experiences like dating, working, playing sports, joining interest groups, experimenting with alcohol and drugs, hanging out with friends, driving, and attending school. All stated that they were no different from their peers and made these comments.

Living with type 1 diabetes didn’t effect it (my life), being a teenager yeah, I slept all over the place, all kinds of odd ball hours but and different times and that. Going out to hang out at friends places like when I was younger I ran away from home and wherever I could sleep I’d be fine (006).

I kept it fairly well controlled um, so it wasn’t really a major concern when I did normal things. I really enjoyed lots of sports, throughout high school. And um other extra curricular things, I just made sure I had what I needed (009).
This discussion suggests that although youth living with diabetes had many of the same experiences as other teens, their lives differed because of living with diabetes. Silverstein and Bandyopadhyay (1995) noted that in one discussion session in their study with female youth living with type 1 diabetes, the conversation topics ranged from diabetes care, to telling others about their diabetes, to boys. In this study, the participants’ experience of adolescence in identity formation and self-awareness is similar to their peers living free of type 1 diabetes. What differentiates youth living with diabetes from youth living free of diabetes is the increased risk of hypoglycaemia, hyperglycaemia, self-care activities, and long-term health outcomes. It is these health related concerns that influence and affect identity formation and self-awareness. One person commented on having a “low” (hypoglycaemia) and that experience affecting peer relationships.

I played baseball, we went on road trips. Ah, I think I played it safe on the road trips. I ran a fairly high blood sugar because I did not want to get low. You act like a fool and everyone makes fun or you and you feel like crap (002).

One participant reflected upon her past self-care practices related to her past identity and belief system about her diabetes.

I did not do a whole lot of blood sugar testing… Ah, yeah, looking back now, it is kind of silly but I think that for me in my mind. It was like nobody else is doing it so as long as I give my insulin to myself, I will be okay (004).

Identity formation and self-awareness construction occur out of feelings, thoughts and beliefs about oneself. Karlsson et al. (2008) points out “…that acquiring experiential knowledge is an essential process in building self-determination (p. 568)”. For the adults in this study who reflected on their youth, the experience of living with diabetes formulated part of their self-awareness and identity. Although participants did not feel that their diabetes was their identity, they acknowledged its influence in their lives.
Moving forward from the discussion of how participants viewed their identity formation and self-awareness as youth, the dialogue shifts to the final sub-theme, the adult perspective regarding current identity and self-awareness. The participants were asked this question directly, “How has diabetes changed/created/impacted your identity-now?” During the interview process, each participant reacted in one or more of the following ways; they asked for clarification of the question, requested a definition of identity, paused, made facial movements that implied confusion, had no reply, or stated that they simply had no idea. This reaction surprised me as the participants easily answered all of the other questions as they had openly shared feeling, thoughts, and beliefs about their lives. Upon further probing, participants did reveal how diabetes influences their self-awareness and identity. They reported self-awareness includes self-care, health, finances, family, and diabetes. A few respondents commented on how living with type 1 diabetes has increased their awareness of their health. This increased awareness then created a healthier person. Participant 002 observed, “I mean if I had not gotten diabetes I don’t think I would be as healthy as I am today”. Participant 010 made this reflective comment about health and diabetes “I would say that, um, being persons living with type 1 diabetes makes you more conscious about your health. It’s almost like a healthy disease. I know that is an oxymoron”.

Many participants noted being healthier and having self-awareness of one’s health as a benefit of living with a chronic health condition. These comments are similar to the description of Patterson et al. (1999) about self-awareness as a transformation process for persons living with type 1 diabetes. Their research noted the following:
transformation...is an ongoing process of preserving and renegotiating the balance between themselves and their diseased bodies (p. 792). This self-awareness process influences the identity formation of the individuals in my study.

Although health was frequently mentioned in the dialogue about self-awareness, family and friends were rarely mentioned. In the interviews, participants named or referred to their children or spouse. Many respondents did not comment on how diabetes affects their spouse or children. However, one person, participant 002 disclosed the fears he has about hypoglycaemia, a possibility for any persons living with type 1 diabetes.

That is my biggest fear is going low. And all the trouble I have had with diabetes is being low, hypoglycaemic, everything. Not to say I have never been high, but I have never had any trouble from being high. And it seems to happen quite often for me. And it’s happened from the time probably I was 16 years old, I would get low (002).

In his interview, participant 002 went on to describe a time he was hypoglycaemic and it influenced his ability to parent.

When my wife was working nights, and I was at home alone with my son and I got low... I either get really affectionate when I am low a lot or really angry. This time I got angry... I told him to go to sleep, a few extra words. And so he started to cry and so I went back into his room, I told him to go back to sleep again and I yelled at him some more and...my wife tried to call me and I wouldn’t answer the phone, cause I did not hear it. And she finally got a buddy to come on over see how I was doing and feed me some juice or whatever it was. And I came out of it. But for an hour and a half I was at home but I wasn’t there, and I wasn’t looking after my son and it scared, it terrified me...And so now before bedtime he’s like don’t yell at me daddy...it bothers the hell out of me (002).

His story demonstrated how diabetes influences parenting and the dynamics within a spousal relationship. It is unfortunate that more information about how living with type 1 diabetes affects one’s family was not gathered. It would have been interesting to examine the participants’ comments about how their illness has an effect on others.
The lack of information points out how total self-awareness in all areas of a person’s life is not always possible.

However, although only one participant commented on living with type 1 diabetes and its impact on others, two people described how diabetes resulted in an increase in empathy towards others.

I think I have a greater appreciation for, um, infirmity. Although being a persons living with type 1 diabetes does not make you an infirm. Like, I guess … I have more compassion or a greater appreciation for that I think. Certainly on the occasions where I have a, a profound low blood sugar, where your head starts, you just get into a mental state that you can’t snap out of. Um, it gives me an appreciation of, people to a certain extent struggle with mental illness…but you get a tiny glimpse into what does it feel like when your brain is acting on it’s own, when it is heading out into space (008).

Like I always know, if there is something you have gone though chances are there somebody who has it ten times as worse…but, I don’t know, I have a lot empathy, I think it also made me have a lot of empathy for people (005).

Diabetes, it appears, can be a mechanism to creating self-awareness in the individuals that I interviewed. Each person described how diabetes influenced her/his health, finances, their parenting, or built empathy within them. It is this day-to-day living with diabetes where self-awareness emerged as a theme for adult persons living with type 1 diabetes.

In terms of living with diabetes as an identity marker, participants struggled to answer this query. Nevertheless, participants noted simply that diabetes was just part of them. Ingadottir and Halldorsdottir (2008) echo this finding in their phenomenological study. Their research makes this point, “knowing oneself and respecting the disease without letting it dominate one’s life is the key for successfully integrating what constitutes quality of life” (p. 610). Respondents in my study commented that their diabetes was only as big a part of their identity as they chose it to be. Participant 010
observed, “That is a tough question to answer. I don’t identify as a person living with type 1 diabetes. Um, you can’t look at anyone and say oh look that person is a person living with type 1 diabetes. Um, it is something that you need to live with”. Two other people commented.

For my identity, I just think that, um, although it is very much a part of me, like because, I, I, I choose not to make it like, I don’t chose to make it like, I don’t know, this huge like deal. It is just, an autoimmune disease and where my beta cells don’t work anymore, okay (005).

I can not really say that diabetes shaped who I am because diabetes is just everyday (event). It is a way of life for me. Just something I take of and it is not something I do. Like shape me cause I keep it in shape (006).

Aside from diabetes just being one part of a person, another participant challenged others’ notions of what it means to be a person living with type 1 diabetes in relation to the health care she receives. She found it necessary to confront others about their beliefs about her identity as a person living with type 1 diabetes.

People were quite surprised that I don’t see a doctor...I don’t regularly go to the diabetes centre here, as a normal course of, of business. I don’t go to my ah, general practitioner unless I need something...People um seem surprised often when I say to them that I don’t regularly see a doctor when I want. But you are persons living with type 1 diabetes, aren’t you? Yeah but yeah, if everything is going okay, then, why do I need to take up time and space in the health care system?...That started with messaging that was given to me at the age of 12. This is something that you need to manage and you need to deal with and you will have help if you need it and ask for it (008).

From this dialogue on self-awareness and identity as an adult living with diabetes, the participants gingerly revealed their feelings, thoughts, and beliefs about how diabetes influenced and affected their lives. The respondents noted that diabetes was simply a part of their identity, not their only identity. This final theme concluded how respondents reflected upon living with type 1 diabetes, their self-awareness, and identity.
The original discussion of self-awareness and identity began when participants discussed their experience when diagnosis of diabetes occurred. All but one participant were able to comment on their feelings, thoughts, and beliefs at that point in their life. The remarks they made during the interviews were candid, insightful, and thorough.

Next, information described the adolescent years of the participants once they had lived with the disease for an undetermined amount of time. All respondents were able to comment on the challenges, the conflicts, and relationships with others in relation to living with their diabetes and adolescence. Participants noted that they saw themselves as typical adolescents. However, they lived with one not so noticeable difference. The diabetes, the participants noted, was just a part of their identity. This constructed belief about identity carried forward to the final discussion.

In this dialogue, participants were directly asked how diabetes influenced their identity now. All persons involved in the study were initially stuck by this question. When nudged on, participants did reveal how diabetes is part of their self-awareness and identity. They identified a connection between self-awareness and living with type 1 diabetes through health, self-care beliefs, finances, family, and empathy towards others.

What was evident from this discussion was self-awareness changes over time as maturity and responsibility emerge. The initial discussion focused upon self-awareness and identity at diagnosis. Participants revealed their thoughts, beliefs, and feelings about this experience. The discussion then shifted to what was the experience during adolescence after living with the illness. In this study, participants remarked that living with type 1 diabetes influenced their identity and self-awareness but did not prevent them from being like other youth. In the final discussion surrounding self-awareness and
identity, participants struggled to formulate how diabetes integrates into their identity formation. Upon further reflection, participants noted that living with type 1 diabetes is part of who they are and their identity was not determined because of living with diabetes. It is easy to conclude that the initial belief system about diabetes and oneself started in adolescence, and then became cemented in adulthood.

Summary.

In this discussion, four major themes emerged from the interviews with adults living with type 1 diabetes when they reflected upon their experiences as youth: (1) knowledge, (2) impacts of diabetes, (3) constructive and deconstructive factors in relationships, and (4) self-awareness and identity. Each of these themes described what it means to have diabetes. Diagnosis of diabetes was a turning point, after which changed occurred in all areas of the youths’ lives. Knowledge, the first theme consisted of three sub themes; (1) acquiring , (2) sharing and (3) knowing and intuitive knowledge. From that examination, it was discovered that learning about diabetes is a process for the person who was diagnosed, the family, friends, and other community member. Knowledge acquisition, sharing and teaching others and then developing intuitive knowing was a course of action that developed over time and continues today for adult persons living with type 1 diabetes. When service providers passed knowledge on to their patients, often a new life long relationship with health care providers was created. This relationship changed throughout the developmental process for the participants. Although living with type 1 diabetes played a significant role in the lives of people living with the illness, participants in this study reported that it was not the only focus in their lives. Knowledge transmission from service providers becomes a vital process as youth living
with type 1 diabetes learns processes and then uses the knowledge for illness management.

The second theme, the impacts of diabetes, offered information about some of their experiences when living with diabetes. This theme is comprised of four sub-themes: (1) the impacts of food, (2) the impacts of medicine, (3) financial impacts, and (4) social impacts of the illness. From the moment the youth contracted diabetes, their relationships and health changed. As their health changed, the functional reality of diabetes became apparent though food, medicine, financial and social aspects of the condition. Here, we learned primarily that these experiences only transpired because the youth contracted diabetes.

The discussion shifted to the constructive and deconstructive factors in relationships. Both constructive and deconstructive factors examined two sub-themes: (1) connection and support, and (2) knowledge. The participants revealed the fragility of relationships in their lives. The respondents disclosed incidents that connected or disconnected them to their caregivers, friends and service providers. For participants, the relationships shifted with caregivers, friends, and community members when they contracted diabetes. Positive and negative aspects of these relationships occurred through connection, support, and knowledge within these relationships.

The understanding of relationships then navigated the discussion towards the final theme of self-awareness and identity. This theme was analysed though examining the feelings, thoughts, and beliefs of participants through three sub-themes that are categorized into different developmental levels: (1) at diagnosis, (2) during their adolescence, and (3) current views of themselves. In this section, it was ascertained that
feelings, thoughts and beliefs about self-awareness and identity shift over developmental periods. This shift began at diagnoses with the realization that a person’s life will now be different. In that moment, all participants, except one person due to his age, recalled the experience of getting ill, receiving a diagnosis, acquiring knowledge, and managing the illness. Living with diabetes is a process that follows along developmental guidelines from childhood to adulthood. The relationships in a youth living with diabetes’s life also follow developmental milestones. Patterson et al. (1999) suggest that this initial transformation process is “...the most dramatic and significant in the participants’ experience in living with diabetes (p. 792)”.

Although in adolescence, a person’s self-awareness begins to excel and identity formation begins to solidify. The transitions a youth living with diabetes faces during this developmental phase occur on a physical and emotional level, in addition to a health and illness level (Karlsson et al., 2008). Finally, in adulthood a person’s identity within himself or herself is formed.

Throughout the research process, reflections of the participants were gathered about their lived experiences in their youth. What is evident is that persons living with type 1 diabetes when reflecting upon their youth and who they are now, view themselves within the context of their illness and are not bound by the assumptions that living with a chronic illness implies. Persons living with diabetes want to be view as a whole person, not simply as a person living with type 1 diabetes. These relationships can be fragile or strong depending upon a multitude of factors including connection, support, and knowledge. Participants stated throughout that aspects of living with type 1 diabetes care were difficult and many viewed diabetes as an insightful illness providing self-awareness into themselves and others.
Chapter Six: Conclusions

The final chapter of this study contains five sections that explain the remaining aspects of this study. First, an examination of the limitations of this study occurs. Within this examination, three limitations are reviewed. Next, I examine the ethical considerations in completing this study. Third, an exploration of areas for future research in type 1 diabetes research occurs. Fourth, a discussion of implications for social work, as I am a social worker, and practice issues were a factor in my decision to pursue this research. Fifth, the participants in this study reveal the seven life lessons they would want others to know if they ever meet someone living with type 1 diabetes. To conclude this study, my final thoughts are shared.

Limitations of the Study.

Within this study, there are six limitations noted. First, as previously stated in Chapter 3, my own experience was an influence in the study. Although I am an insider in the diabetes community, I took the necessary precautions to ensure the research is value free. First, I kept a reflective journal to record thoughts during the entire research process. The journal entries were reread to internally reflect upon previous interviews and thoughts about the direction of the research. Second, I spoke monthly with my thesis supervisor to discuss the direction of the research. The supervisor read the transcripts of the interviews, offered feedback as to the direction of the interviews, and commented on the research process that I was experiencing.

The second limitation of this study is that it focuses on adults’ recollection of their experience of their youth rather than speaking directly to adolescents. The decision to speak with adults occurred because of increased access to a population and obtaining
consent for participation in the study. The reluctance and vulnerability of youth to speak about relationships, was an additional factor. Youth may be less apt to provide critical feedback about relational experiences as they are currently participating in those relationships. In addition, youth may have fewer resources than adults to cope with emotions that arise with the interview.

Next, although adults in this study appeared to have the skills to cope with the stressors that arose from the study, the information they provided may be limited. Often people’s memories can be skewed as they recall events from their past. The memories are factual and due to time, specific details may be forgotten or added. This was noted by a number of participants as they struggled remembering years, medication changes, and even stated that, “I just don’t recall” or that “my memory is poor, but the impression I have is…” However, the essence of people’s belief of those relationships was captured in my study.

Another limitation of the research was the scope of the relationships discussed in the interview questions. The study focuses on family, peer, service provider, and community member relationships. Of the nine research questions I asked, only four asked specifically about relationships. The study was attempting a broad examination of relationships. As a result, the complexities for youth living with type 1 diabetes and the specific details of a particular relationship may be lost. Different participants focused upon different relationships in accordance to their importance to that person. One participant noted that she was a loner, and another disclosed a large circle of friends. In regards to service providers, one person reported a close relationship with a nurse, and another reported no significant relationships with any service providers.
In connection to the questions I asked, my original focus of the research was recollections of relational experiences of youth who with type 1 diabetes. However, five out nine questions I asked were not related to relationships the participants I dialogued with, rather, the questions focused upon the participants lived experience. My choice in question selection was broad and did not gather the specific information I was inquiring about. The questions I asked provided me with information related to relationships and the lived experience of living with a chronic health condition during adolescence.

A final constraint of this study is the small size and composition. The sample size is small due to the slim population of people on which draw from. Adults living with type 1 diabetes account for only 10% of youth living with type 1 diabetes population (Canadian Diabetes Association, 2010b). As a result, generalizing the results to the entire persons living with type 1 diabetes population or to persons with type 1 diabetes would be a misinterpretation of the data.

The composition of participants was almost homogenous. Most of the participants originated from Prince George. There was one from Ontario and two from the Lower Mainland of British Columbia. The recollection of experiences was similar. However, when participants were from other parts of the country or province, the experiences reported were remarkably similar in the three cases.

Furthermore, the composition of the participants was not typical that a general population of persons living with type 1 diabetes. The participants were highly educated, employed, and had intact family structures and positive relationships with their parents. All the participants accept one were either enrolled in post-secondary institutions or had completed a college, bachelor, or masters degree. Four participants reported being
employed and enrolled in post-secondary studies. All participants accept one who by choice was a work at home parent were all employed outside of the home. When discussing family composition, six out of nine people lived with both of their biological parents, the three other lives with one of their biological parent. None of the persons in this study reported living in foster care, experiencing physical, emotional or sexual abuse or were involved with child protection. Participants in this study are highly motivated, capable person who had intact and positive family relationships that provided support, and encouragement. As a result of this sample size, what can be stated is that people who have these characteristic are more effective in managing their diabetes care.

**Ethical Considerations.**

The purpose of this study was to explore how adults living with type 1 diabetes recall their relationships with others, during their youth. The intent was to gather information from adults about what it was like to live with a chronic health condition, be an adolescent at the same time, and manage their relationships with other people. Two ethical considerations existed in the completion of this study. The first ethical consideration rested in the ability of the participants to cope with emotional distress that arose during the interview process. I noted that a few participants shed a few tears during the interviews when they spoke of struggles they had during their youth. I offered comfort after the interview, asking if they needed some time to process what had just occurred during the interview, directing them to the community resources, and then encouraging them to access their personal supports.

A second ethical consideration is the connection between the participants and me when the study concluded. I have seen the various participants in the community. I have
not openly discussed the research with the participant unless prompted to do so by a participant who has asked; “how’s it going?” “do you have all your people?” or “when will I see the results”?

Although the ethical considerations were few in this study, they were important considerations. I am a person who lives with diabetes and I am connected to participants in various ways; I am required to be transparent in my relationships with the participants I interviewed. This was necessary as participants and I access the same service providers, attend diabetes related events, and our lives overlap within the Prince George community.

There are a number of areas to consider for future research. The first would be to replicate this current study and increase the number of participants in the study. This study sample was small with limited participation from the potential adult diabetes population. A larger sample size with different participants may yield different or similar results.

Another consideration would be documenting the experience of living with type 1 diabetes from the perspective of a person who got the illness as an adult. This perspective would examine if the lives of adults who live with type 1 diabetes are different because of the age at which they received the diagnosis of the illness. It would be interesting to examine the similarities and differences between the two groups in terms of experience at the time of diagnoses, change in relationships, relationships with service providers, and the impact or influence of type 1 diabetes on their lives now.

A final consideration is what this particular composition of participants can provide information in relation to living successful with diabetes and other chronic health
conditions. The participants who had supportive families during adolescence are moti-
vated individuals in their personal lives as well as in managing their health. The characteristics that these participants represent can be something that can be further studied to reveal what motivates people to care for themselves when living with a chronic health condition and the lack of involvement in social work services such as child protection, addictions and mental health. This type of research has many practical applications for health care and social work practice.

**Implications for Social Work.**

I am a social worker and practice within the community in which I live. I have practiced social work for over 10 years. When telling people I was returning to complete my Master of Social Work degree, I was asked, “How is your thesis related to social work practice”. I informed them that social work is the buffet of human services and that it occurred in a wide variety of government, non-profit, clinical, and medical settings. Within these settings, social workers are performing a wide variety of tasks. Hick (2002) states that social work practice is “work consisting of a series or process of intervention actions, that is of benefit to those in need…it may consist of social work with individuals, group work or community work. Social work is an action orientated field in which individuals and social change play key parts” (p. 284). For youth living with type 1 diabetes, social workers may become involved in their lives in a variety of capacities. These roles can include child and youth mental health clinician, social worker at the hospital, child protection worker, school counsellor or other social services positions within health, education, and social welfare fields.
As stated earlier, the participants in this study were highly motivated individuals with a supportive intact family structure. The participants had minimal contact with social workers. One reported connecting with a social worker and a child and youth mental health counsellor, and another person a school counsellor. There were no reports of child protection or other social worker involvement. This information is important in social work practice by learning what characteristics within individuals or families are protective factors for youth who live with a chronic health condition, like type 1 diabetes.

When looking to understand the lives of youth living with type 1 diabetes, social work becomes the ideal discipline from which to conduct research. The aim of social practice strives to help others and to advocate for change and there may also be implications for other social workers and care providers from which it practices many disciplinary lenses. These disciplinary lenses include and are not limited to gender studies, sociology, psychology, health, education, political studies, and history. Conducting social work research is important to both the practice of social work and social change. Although researching this topic, I continually reviewed “why social work needed to tell the stories of youth living with type 1 diabetes”. My answer was always the same. Social work is about people, stories, and understanding why things are the way they are and why they are not something else. It is through social work that society learns about others and, in many cases changes to make society a better place.

**Participant Life Lessons Drawn from Participant Dialogues.**

The participants in this study provided their thoughts and emotions regarding their experiences living with type 1 diabetes. These thoughts provide those who do not live with the condition with insight into their lives. The participants in this study have given
seven life lessons as generated by the researcher by reviewing the interview transcripts and themes and organizing them. I believe that these life lessons provide an understanding of what works when living with a chronic health condition like type 1 diabetes by having insight into a motivating attitude.

Life Lesson One.

People living with diabetes see themselves as people first, persons living with type 1 diabetes second. In this study, participants noted that diabetes was simply a part of them, not their entire personality or purpose in life. Diabetes simply impacts as a piece of their identity.

Life Lesson Two.

Diabetes management is not perfect and people living with diabetes are doing the best they can. All the participants described times when their diabetes was not manageable and how they overcame this to get back on track. This non-judgmental attitude towards themselves can be seen as inspiring to others.

Life Lesson Three.

Living with diabetes is a learning process. For participants in this study, a transition from childhood and adolescence into adulthood, living with a chronic health condition becomes an ongoing process of learning, sharing, and acquiring knowledge about yourself and your health.

Life Lesson Four.

Attitude is everything. Throughout this study, participants shared their moment of triumph and hope with a simple belief that living a fulfilling life with diabetes is possible. Acceptance of self and diabetes were contributing factors for living life to the fullest.
Life Lesson Five.

Knowledge about diabetes is powerful. Throughout this study, knowledge transmission was a reoccurring theme for participants. Participants discussed the knowledge they received at diagnosis, the ongoing process of learning, the sharing of knowledge with others, and the creation of intuitive knowledge within oneself. The participants also noted that when lack of knowledge did transpire, relationship breakdowns sometimes occurred.

Life Lesson Six.

Type 1 diabetes does not stop you from living, but it is a little bit different. Participants shared that diabetes did not stop them from living their lives but did influence their life choices. The aspects of living with diabetes that make life different for persons living with type 1 diabetes than persons living free of type 1 diabetes were reviewed in the discussion regarding the impacts of diabetes.

Life Lesson Seven.

When meeting someone with type 1 diabetes, there are things to do to develop a positive relationship with that person. The participants revealed characteristics regarding the different relationships they experienced in their youth that enhanced their relationships with others. These include people are supportive, willing to learn, accepting, honesty, genuine, understanding, knowledgeable, and people who saw them as who they were first and a person living with type 1 diabetes second. These characteristics were consistently positively described by participants in this study in their relationships that they viewed with family, friends, community members, and service providers as positive.
Final Thoughts.

This research has been both an academic and personal quest. My aim was to seek out information on a topic that combined my passion for understanding the lives of youth, their relationships with other, and the disease that I live with daily. The research has provided insight into diabetes from the participants’ viewpoint through interviewing adults and asking their reflections of their youth. This information, I believe will affect and influence the practice of service providers, and has told a valuable story of understanding relationships in the context of adolescents’ lives.
References


adolescents with type 1 diabetes and their best friends. *Journal of Pediatric Psychology*, 26 (8), 485-490


Halldorsdottir, S (2000) Vancouver School of Doing Phenomenology. In B Fridlund & C Hildmgh (Eds), *Qualitative research methods in the service of health* (pp 47-81) Studentitet, Sweden


sensitive pedagogy. Ontario, Canada: University of Western Ontario.


VOLUNTARY PARTICIPANTS NEEDED FOR RESEARCH WITH ADULTS LIVING WITH TYPE 1 DIABETES REFLECTION THEIR YOUTH

As a voluntary participant in this study, you would take part in a semi-structured interview about your experience of living with type 1 diabetes between the ages of 13-18 years in the context of four relationships: your family, your peers, service providers and community members.

To be involved in the study, you need be between the ages of 19-40 years.
YOUR participation would involve 2-4 hours.

In appreciation for your time, you will receive a honorarium.

For more information or to be volunteer,
Please contact:

Laura Nordin, B.A. B.S.W. R.S.W.
School of Social Work, University of Northern British Columbia
nordin@unbc.ca

Appendix B

Advertisement

RESEARCH PARTICIPANTS NEEDED FOR RESEARCH STUDY AT UNBC! I am looking for adults between the ages of 19-40 years who have contracted type 1 diabetes before the age of 18. As a voluntary participant in this study, you would take part in a semi-structured interview about what it was like for you being an adolescent with type 1 diabetes; what were your relationships like with family, peers, service providers and community members in the context of your illness.

Your participation would require approximately 2-4 hours and in appreciation of your time, you will receive an honorarium. For more information or to volunteer please contact Laura Nordin at nordin@unbc.ca.
Appendix C

Participant Pre-Screening Questions

Name: ____________________________

Current Age: _________________

Age when contracted Type 1 Diabetes: _______________

Types of Service Providers:

Pediatrician: __________
Family Doctor: ____________
Psychologist: ____________
Ophthalmologist: __________
Diabetes Clinic: ____________
Canadian Diabetes Association: _________
Hospital Emergency Department: _______
Hospital Pediatric Ward: _________
911: _______
Child Protection: ________
Child and Youth Mental Health Counselor: ________
Psychiatrist: __________
Dietician: __________
Pharmacist: __________
Podiatrist: __________
Endocrinologist: ________
Social Worker: __________
Nurse: ________________
Appendix D
Information Sheet

Researcher: Laura Nordin, BA BSW RSW

Email: nordin@unbc.ca

Thesis Supervisor: Dr. Si Transken

Thesis Title: **Adults with Type1 Diabetes Reflections of their Youth: A Phenomenological Study.**

You are invited to participate in a research study entitled *Adults living with type 1 diabetes Reflection of their Youth: A Phenomenological Study.* The research is being conducted by Laura Nordin in partial fulfillment of the requirements for the degree of Master of Social Work from the University of Northern British Columbia and is supervised by Dr. Si Transken.

**Purpose of my research:** The purpose of this research is to explore young adults’ experience of type 1 diabetes when they reflect upon their youth. This question explores four social relationships when living with this condition. The young adults will recall their understanding of their lives as teens interacting with family, peers, community members, and service providers. It is expected that this study will yield information on the importance, and complexities of relationship building for this population. This data will be valuable in informing service providers, community members, family, and researchers of improved practice for service providers, effective programming, empathy, and awareness for those having relationships with someone with type 1 diabetes.

**Voluntary Participation:** Your participation in this study is completely voluntary. There is no obligation on your part to participate. You may withdraw from the study at any time without consequence.

**Potential Benefits and risks:** If you choose to be a participant in the study, you will be asked in an interview a series of questions, which are primarily aimed at obtaining your
description of your experience of living with type 1 diabetes as an adolescent in the context of four social relationships. The only potential risk anticipated by the researcher is that some participants may feel slightly uncomfortable speaking about the complexities of their social relationships and their chronic health condition. Counseling support is available through the Native Friendship Centre (250-562-4738), Mental Health Services (250-565-2668), Crisis Centre phone line (250-563-1214), or through a referral by your family doctor to a suitable mental health professional. Additional resources are listed at the end of this information package. Potential benefits from participating may include a feeling of validation from telling their story of living with a life long health condition, and its impact on their adolescence. The research could offer a sense of contribution to research of type 1 diabetes.

Why you were chosen: I was diagnosed with type 1 diabetes at the age of 20. Like all people with a chronic health condition, I have my good days, my fabulous days, bad days, and those days that are just horrible. I have worked in the field of social work for over 10 years. I have focused my practice on the care of children and youth in the communities, I have lived in. I wondered, what would it be like to be 14, going through all those things a teen goes through, and manage a chronic health condition? I thought that this was a story that needed to be told to give others the understanding of this unique complex experience.

What you will be asked to do: The interviews are expected to take 1-2 hours each. Interviews will be audio tape-recorded in order that the material can be later analyzed by the researcher.

Individuals that will have access to your responses: Your interview will be transcribed and typed verbatim. Transcription will occur either by the researcher or by a transcriber. If transcription occurs through a transcriber, that person will sign a confidentiality form. Transcriptions will be identified by pseudonym and not your name. Transcripts and tapes will be stored in a locked filing cabinet. The transcription will also be filed electronically in a computerized format and will be protected by a password. Only the researcher, supervisory committee, and transcriber will have access to the tapes and transcriptions.

Anonymity will be maintained: Names and contact information of participants will be kept strictly confidential. Only Laura Nordin will have access to names and contact information. The names and contact information will be kept in separate files from transcripts. They will also be stored in a locked filing cabinet. After the interviews from all the participants have been analyzed, you will be asked to help confirm the research results. This step will involve meeting with the researcher, receiving a copy of your transcripts, and reading it to verify the authenticity.

It is expected that your experience will contribute to the body of knowledge related to type 1 diabetes, adolescents, chronic disease management, and the complexities of relationships for this population. In an effort to inform counselors and researchers of the findings, the researchers plans to publish the results in professional journals or reports and/or findings at conferences. In order to illustrate the results, it is anticipated that some
direct quotations from some interviews will be published. However, names of participants or other identifying information will not be revealed.

**Storage of Data:** Tape recordings will be kept for two years after the study is completed and then the cassette tapes will be destroyed. Interview transcripts, names, and contact information will be kept for three years after the completion of the study at which time the documents will be shredded and the electronic file deleted.

**Confidentiality:** The researcher, Laura Nordin is a member of the BCASW- British Columbia Association of Social Workers. I am a registered social worker bound by the Code of Ethics of the Association. If you have concerns, please contact the BCASW at 604-730-9111 or 1-800-664-4747 in British Columbia. Confidentiality will be kept in the strictest of confidence.

**Remuneration for Participating:** I will be providing a $20.00 honorarium for the time you have given in this research project.

**Research Results:** You may obtain a summary of the research results by contacting the researcher, Laura Nordin at nordin@unbc.ca. I will mail a summary of the results and thesis defense date to you. A summary of the research will be mailed to the participants. Upon completion of a successful thesis defense, a copy of the successful defended thesis will be posted at the UNBC archives.

**Complaints:** Please let the researcher know if you have any questions before proceeding with the study. If you have any question about the study, please contact the researcher, Laura Nordin at nordin@unbc.ca. Any complaints about the study can be directed to the Office of Research, UNBC at 250-960-5820 or [www.unbc.ca/research/](http://www.unbc.ca/research/).

*Thank you for you time*, Laura Nordin
Counseling and Support Resources in Prince George

Community Services

Mental Health Community Services
Community Response Unit
250-565-2668

Adult Community Addiction Services
250-565-7200

Native Friendship Centre
250-562-4738

Elizabeth Fry Society
250-563-1113

Private Counseling Services

Brazonni & Associates
250-614-2261

Walmsley & Associates
564-1000

Crisis Intervention and Counseling referral services

Crisis Centre
250-563-1214

Alcohol and Drug Referral Services
1-800-663-1441
Appendix E

Research Ethics Board
Informed Consent Form

**Purpose of my research:** The purpose of this research is to explore young adults’ experience of type 1 diabetes when they reflect upon their youth. This question explores four social relationships when living with this condition. The young adults will recall their understanding of their lives as teens interacting with family, peers, community members, and service providers. It is expected that this study will yield information on the importance, and complexities of relationship building for this population. This data will be valuable in informing service providers, community members, family, and researchers of improved practice for service providers, effective programming, empathy, and awareness for those having relationships with someone with type 1 diabetes.

**Voluntary Participation:** Your participation in this study is completely voluntary. There is no obligation on your part to participate. You may withdraw from the study at any time without consequence.

**Potential Benefits and risks:** If you choose to be a participant in the study, you will be asked in an interview a series of questions, which are primarily aimed at obtaining your description of your experience of living with type 1 diabetes as an adolescent in the context of four social relationships. The only potential risk anticipated by the researcher is that some participants may feel slightly uncomfortable speaking about the complexities of their social relationships and their chronic health condition. Counseling support is available through the Native Friendship Centre (250-562-4738), Mental Health Services (250-565-2668), Crisis Centre phone line (250-563-1214), or through a referral by your family doctor to a suitable mental health professional. Additional resources are listed at the end of this information package. Potential benefits from participating may include a feeling of validation from telling their story of living with a life long health condition, and its impact on their adolescence. The research could offer a sense of contribution to research of type 1 diabetes.
Why you were chosen: I was diagnosed with type 1 diabetes at the age of 20. Like all people with a chronic health condition, I have my good days, my fabulous days, bad days, and those days that are just horrible. I have worked in the field of social work for over 10 years. I have focused my practice on the care of children and youth in the communities, I have lived in. I wondered, what would it be like to be 14, going through all those things a teen goes through, and manage a chronic health condition? I thought that this was a story that needed to be told to give others the understanding of this unique complex experience.

What you will be asked to do: The interviews are expected to take 1-2 hours each. Interviews will be audio tape-recorded in order that the material can be later analyzed by the researcher.

Voluntary Participation: Your participation in this study is completely voluntary. There is no obligation on your part to participate. You may withdraw from the study at any time without consequence.

Individuals that will have access to your responses: Your interview will be transcribed and typed verbatim. Transcription will occur either by the researcher or by a transcriber. If transcription occurs through a transcriber, that person will sign a confidentiality form. Transcriptions will be identified by pseudonym and not your name. Transcripts and tapes will be stored in a locked filing cabinet. The transcription will also be filed electronically in a computerized format and will be protected by a password. Only the researcher, supervisory committee, and transcriber will have access to the tapes and transcriptions.

Anonymity will be maintained: Names and contact information of participants will be kept strictly confidential. Only Laura Nordin will have access to names and contact information. The names and contact information will be kept in separate files from transcripts. They will also be stored in a locked filing cabinet. After the interviews from all the participants have been analyzed, you will be asked to help confirm the research results. This step will involve meeting with the researcher, receiving a copy of your transcripts, and reading it to verify the authenticity.

It is expected that your experience will contribute to the body of knowledge related to type 1 diabetes, adolescents, chronic disease management, and the complexities of relationships for this population. In an effort to inform counselors and researchers of the findings, the researchers plans to publish the results in professional journals or reports and/or findings at conferences. In order to illustrate the results, it is anticipated that some direct quotations from some interviews will be published. However, names of participants or other identifying information will not be revealed.

Storage of Data: Tape recordings will be kept for two years after the study is completed and then the cassette tapes will be destroyed. Interview transcripts, names, and contact information will be kept for three years after the completion of the study at which time the documents will be shredded and the electronic file deleted.
Confidentiality: The researcher, Laura Nordin is a member of the BCASW- British Columbia Association of Social Workers. I am a registered social worker bound by the Code of Ethics of the Association. If you have concerns, please contact the BCASW at 604-730-9111 or 1-800-664-4747 in British Columbia. Confidentiality will be kept in the strictest of confidence.

Remuneration for Participating: I will be providing a $20.00 honorarium for the time you have given in this research project.

Research Results: You may obtain a summary of the research results by contacting the researcher, Laura Nordin at nordin@unbc.ca. I will mail a summary of the results to you.

Complaints: Please let the researcher know if you have any questions before proceeding with the study. If you have any question about the study, please contact the researcher, Laura Nordin at nordin@unbc.ca. Any complaints about the study can be directed to the Office of Research, UNBC at 250-960-5820 or www.unbc.ca/research/

To be completed by the Research Participant
(Circle either YES or NO)

Do you understand that you have been asked to be in a research study? YES NO

Have you read and received a copy of the attached information sheet? YES NO

Do you understand that some of you actual words may be published in a written form? YES NO

Do you understand the benefits and risks of the study? YES NO

Do you know what resources you can access for supportive counseling? YES NO

Have you had the opportunity to ask questions and discuss this study? YES NO

Do you understand that you are free to refuse to participate or to withdraw from the study at any time? You do not have to give a reason and it will not affect any medical or other kind of care you are receiving. YES NO

Has the issue of confidentiality been explained to you? YES NO
Do you understand who will have access to the information you provide? YES NO
Do you have any further questions? YES  NO

This study was explained to me by: ____________________________
Print Name

I agree to take part in this study:

_________________________  ______________________
Signature of Research Participant  Date

Printed Name of Research Participant

I believe that the person signing this form understands what is involved in the study and voluntarily agrees to participate.

_________________________  ______________________
Signature of Researcher  Date

The Information Sheet must be attached to the Consent form and a copy given to the Research Participant.
Appendix F
Demographic Questionnaire

Please circle the applicable choice or answer the question on the line provided.

Current Age: __________

Age when diagnosed with Type 1 Diabetes: __________

Gender:       Male       Female       Transgender

Which Ethno-cultural group(s) do you belong to:

What Community/Communities did you live in between 13-18 years:

Person/People you lived with between 13-18 years:

Type of insulin delivery system between 13-18 years:
Insulin Pen  Insulin Pump  Needles  Other

Current type of Insulin delivery system
Insulin Pen  Insulin Pump  Needles  Other

Number of incidents when you required 911/Ambulance services/Hospital stays/Emergency Room services due to diabetes between the ages of 13-18 years.

0  1-3  4-6  7-9  10-12  13-15  16-18  19-21  22-24  25+
Types of service providers you saw between the ages of 13-18 years (check all that apply):

Pediatrician: ______ Family Doctor: ______ Psychologist: ______

Ophthalmologist: ______ Diabetes Clinic: ______ 911: _________

Canadian Diabetes Association: ______ Hospital Emergency Department: ______

Hospital Pediatric Ward: ______ Child Protection: ______ Podiatrist: ______

Child and Youth Mental Health Counselor: ______ Psychiatrist: ______

Dietician: ______ Pharmacist: ______ Endocrinologist: ______

Social Worker: ______ School Counselor: ______ Nurse: ______

Other: ______ Other: ______

Current Marital Status:

Single  Married  Co-Habiting  Divorced  Widowed  Separated

Children:

Number:  0  1  2  3  4  5  6+

Ages: __________________________

Employment Status: Full-time  Part-time  Unemployed  Student

Employed Seasonally  Permanently out of the workforce due to disability

Permanently out of workforce due to being a work at home parent

Occupation: __________________________

Level of Education Achieved:

Elementary School  Some High School  High School  Some University/College

College Diploma  Undergraduate Degree  Graduate Degree  Other
Appendix G
Participant Contact Form

Name: ____________________________________________

Mailing Address:

____________________________________________________

Phone Number:

Day Contact: ________________________

Evening Contact: ________________________

Contact Comments (if applicable):

_________________________________________________________________

_________________________________________________________________

_________________________________________________________________
Appendix H
List of Questions

1. What was your experience when you found out you had type 1 diabetes? (Karlsson et al., 2008).

2. What was the same or different in your relationships with your caregivers, friends, and people in the community after your diagnosis? (Karlsson et al., 2008, Ingadottir & Halldorsdottir, 2008).

3. What was the role of your caregivers between the ages of 13-18? Describe this relationship. (Karlsson et al., 2008).

4. How did diabetes influence your relationships with friends, dating, and doing “typical teen things” like experimenting with sports, parties, hanging out, sleep cycle, recreational activities, homework, alcohol, drugs, and sexuality? (Karlsson et al., 2008)

5. What attitudes existed from community about your diabetes between the ages of 13-18? (Karlsson et al, 2008) equip

6. Did you experience any prejudices, roadblocks, or “special treatment” during this period in your life from community members? (Ingadottir & Halldorsdottir, 2008).
7. Describe the relationships you had with different service providers. What things promoted a more connected relationship, what things promoted a lack of connection? (Friedrich, 2007).


9. Is there anything else you would like to tell me?

Appendix I
Transcriber Confidentiality Form

Transcriber Confidentiality Agreement

This study is being undertaken by Laura Nordin for the University of Northern British Columbia.

The purpose of the research is to explore young adults’ experience of type 1 diabetes when they reflect upon their youth. This question explores four social relationships when living with this condition. The young adults will recall their understanding of their lives as teens interacting with family, peers, community members, and service providers. It is expected that this study will yield information on the importance, and complexities of relationship building for this population. This data will be valuable in informing service providers, community members, family, and researchers of improved practice for service providers, effective programming, empathy, and awareness for those having relationships with someone with type 1 diabetes. A final report on the research will be presented to the University of Northern British Columbia, and the results may be written up for publication or conference presentations.

Thesis Title: Adults with Type 1 Diabetes Reflections of their Youth: A Phenomenological Study.

I, ____________________________, the Research Transcriber, agree to:

1. keep all the research information shared with me confidential by not discussing or sharing the research information in any form or format (e.g., disks, tapes, transcripts) with anyone other than the Researcher.
2. keep all research information in any form or format (e.g., disks, tapes, transcripts) secure although it is in my possession.
3. return all research information in any form or format (e.g., disks, tapes, transcripts) to the Researcher when I have completed the research tasks.
4. after consulting with the Researcher, erase or destroy all research information in any
form or format regarding this research project that is not returnable to the Researcher) (e.g., information stored on computer hard drive).

Research Transcriber

(print name) (signature) (date)

Researcher

(print name) (signature) (date)

If you have any questions or concerns about this study please contact:
Laura Nordin, BA BSW RSW
Email: nordin@unbc.ca

This study has been reviewed and approved by the Research Ethics Board of the University of Northern British Columbia. Any complaints about the study can be directed to the Office of Research, UNBC at 250-960-5820 or www.unbc.ca/research/.