SELF-CONCEPT AND JUVENILE DIABETES IN YOUNG ADULTHOOD

by

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Abstract

The aim of this study was to gain an understanding of self-concept and living with juvenile diabetes in young adulthood. The incidence of juvenile diabetes is rapidly increasing worldwide. The intensive management regimen required to treat juvenile diabetes often disrupts an individual's usual activities and requires disease-focused behaviours. Few studies have examined the lived experience of juvenile diabetes and self-concept. Researchers have often overlooked the unique aspects of having diabetes in young adulthood. Research is needed to develop counselling interventions that improve young adults' care and quality of life. This study took place in Western Canada. Eight young adults ages 19-29 who self-identified as having juvenile diabetes participated in one to two-hour semi-structured interviews. Interviews were analyzed using the descriptive phenomenological approach, as outlined by Giorgi and Giorgi (2003a). Being shaped but not defined by juvenile diabetes emerged as the essence of the young adults' experiences. Self-concept was shaped by diabetes in three main ways: (1) becoming more responsible, mature and resilient, (2) planning ahead and thinking critically, and (3) gaining empathy. The journeys shared by participants fit into 18 themes. Underlying seven of these themes was the choice that participants made to stay positive and maintain hope. Rather than becoming inwardly focused on disease management, participants often turned their focus outward to becoming diabetes advocates and educators. As much as possible, participants separated symptoms from self and did not let diabetes limit them. Paradoxically, their limitations forced them to gain skills that put them ahead in other areas of their lives. These findings may be particularly relevant for mental health professionals working with young adults living with chronic illness.

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Acknowledgments

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Chapter 1: Introduction

Research Focus

This study explores self-concept and living with juvenile diabetes in young adulthood. It examines the sometimes overlooked psychological aspect of life with diabetes: how people make sense of their "self" in this altered social, physical, and existential reality, how they perceive self-concept as they live between social categories of health and illness, how self-concept develops, and how "self" finds meaning in the midst of chronic illness. Using descriptive phenomenology, self-concept and juvenile diabetes were explored from the perspective of the experts who lived with it every day. This study built on previous findings in order to provide a more in-depth analysis of this topic than studies previously conducted.

(Mis)Understanding Juvenile Diabetes

Statistics. The incidence of juvenile diabetes is rapidly increasing worldwide (Wennick & Hallstrom, 2007) and is a significant health problem in Canada. Over three million Canadians have diabetes. Approximately 10% of people with diabetes have juvenile diabetes (Canadian Diabetes Association, 2013). Canada has the sixth highest occurrence rate of juvenile diabetes in children 14 years or younger in the world. For reasons yet unclear, the occurrence rate is rising by three to five percent per year, with the greatest rise occurring in five to nine year olds (Juvenile Diabetes Research Foundation International, 2009).

Types of diabetes. Many people are unaware that there are different types of diabetes: Juvenile diabetes, also called type 1 diabetes or insulin-dependent diabetes, adult onset, also called type 2 diabetes or non-insulin-dependent diabetes, and gestational diabetes. In addition to these types, the consulting group for the World Health Organization has proposed another subgroup of diabetes, a slow progressive autoimmune type 1 diabetes, most commonly referred to as type 1.5 diabetes (McInnes, 2008). Due to the complexity of the topic, it is not uncommon for juvenile diabetes to be misunderstood. A study by Wennick and Hallström (2007) found that mothers of children with juvenile diabetes expressed frustration that their friends often confused juvenile and adult onset diabetes and thought their child's diabetes was due to diet.

Adult onset diabetes is the most common form of diabetes. It usually develops after age 40, although it can develop earlier and has more recently begun to appear more frequently in children. In this form of diabetes the pancreas still produces insulin, but the body does not produce enough or is unable to use it effectively. It is treated with diet control, exercise, self-monitoring of blood glucose and, in some cases, oral drugs or insulin. Adult onset diabetes is caused by genetics and lifestyle factors such as being overweight (Juvenile Diabetes Research Foundation International, 2009).

Gestational diabetes is a condition that affects about two to five percent of pregnant women, in which they develop high blood sugar during pregnancy. Gestational diabetes typically disappears after the baby is born. However, women who have had this condition are at risk of developing adult onset diabetes later in life (Juvenile Diabetes Research Foundation International, 2009).

Type 1.5 diabetes is defined by adult age at diagnosis, presence of diabetes-associated auto-antibodies, and a delay in insulin therapy to manage hyperglycemia. It is possible that 50% of all non-obese adults with adult onset diabetes actually have type 1.5 diabetes. This type can masquerade as adult onset diabetes because beta cell destruction is slower than in children, and the classic symptoms of juvenile diabetes are often not present. Although there are immunological and genetic similarities between type 1.5 diabetes and juvenile diabetes, there are underlying differences between the disease processes. Some of these differences could be due to age-related effects on the immune system. Researchers have yet to reach consensus on the diagnosis and treatment of type 1.5 diabetes (McInnes, 2008).

This study focuses on the experience of young adults living with juvenile diabetes. Juvenile diabetes can occur at any age, but is most commonly diagnosed from infancy to the late 30's. Juvenile diabetes is not caused by being overweight or by eating too much sugar. Most people with juvenile diabetes have a healthy body weight (Betchart & Patten, 1998). Juvenile diabetes is believed to be an autoimmune condition. The immune system creates antibodies against itself, which destroy the insulin producing cells of the pancreas. As a result, the body requires multiple injections of insulin daily or a continuous infusion of insulin through a pump to make up for the insulin that the body is no longer able to produce (Juvenile Diabetes Research Foundation International, 2009; National Diabetes Education Program, 2014). Juvenile diabetes is typically not hereditary. Ninety percent of children who develop juvenile diabetes have no family history. Research findings to date suggest that genetics account for less than half of the risk of developing juvenile diabetes. However, genetics and environmental triggers are being studied as potential causes of the condition (Juvenile Diabetes Research Foundation International, 2009).

Managing juvenile diabetes. The most effective strategy to achieve and maintain tight control of blood sugar levels is strict adherence to a specific diet and exercise plan, and multiple insulin injections or infusions each day based on careful monitoring of blood sugar levels. Optimal blood sugar control can be very difficult to obtain. Many factors, including illness, stress, hormone changes, and periods of growth can easily cause blood sugars to become out of control. Some people find that even though they strive for tight control and follow their meal plan and insulin schedule, they still experience rapid fluctuations in their blood sugars (Juvenile Diabetes Research Foundation International, 2009). Living healthfully with juvenile diabetes involves behaviours such as maintaining a healthy diet, adjusting insulin, treating and preventing high and low blood sugars, and testing blood sugar levels (Betchart & Patten, 1998). Taking insulin is a treatment for diabetes, but it is not a cure. Although progress toward finding a cure has been substantial, there is currently no cure for juvenile diabetes (Marschilok, 2013).

Insulin can be taken by injections. The number of daily injections varies depending on type of insulin and lifestyle factors. An alternative to injections is insulin pump therapy. People on insulin pump therapy wear an insulin pump, a small portable medical device that injects insulin at programmed intervals in order to regulate blood sugar levels. Programmed values have to be determined by the person using the insulin pump and/or her or his health team, as the insulin pump cannot self-regulate blood sugar values. The advantages of using an insulin pump include greater flexibility with meals, exercise, and daily schedule; improved physical and psychological wellbeing; and smoother control of blood glucose levels. Disadvantages of the pump include: risk of infection, risk of very high blood sugars if something goes wrong with the delivery system, more required testing of blood sugar levels, and a constant physical reminder of diabetes (Juvenile Diabetes Research Foundation International, 2009). The type of insulin therapy that young adults choose to use likely affects how they experience their condition.

Complications. The goal of therapy is to keep blood glucose levels within normal limits in order to reduce the risk of short and long-term complications. Short-term complications include hypoglycemia (low blood sugar), hyperglycemia (high blood sugar), and ketoacidosis, a serious life-threatening condition resulting from the body's inability to break down glucose, the body's main energy source (The Nemours Foundation, 2013). Potentially devastating long-term complications that may result from high blood sugar levels over a number of years include heart disease, stroke, kidney failure, blindness, and amputation (Juvenile Diabetes Research Foundation International, 2009; Schur, Gamsu, & Barley, 1999). However, careful monitoring and control of blood sugar levels greatly reduces the threat of long-term complications. According to a 2009 longitudinal study published in the Archives of Internal Medicine, the rate of serious complications in people with juvenile diabetes, especially when treated intensively, is lower than reported historically (Diabetes Control and Complications Trial/Epidemiology of Diabetes Interventions and Complications Research Group, 2009). Despite challenges, people with juvenile diabetes are able to lead active and productive lives (Juvenile Diabetes Research Foundation International, 2009).

Illness intrusiveness is a term in diabetes research that refers to the extent that a chronic illness disrupts an individual's life by interfering with valued activities and interests and reducing perceptions of self-esteem, self-efficacy, and personal control (Devins, Hunsley, Mandin, Taub, & Paul, 1997). Recent studies seem to indicate that people with diabetes today have improved quality of life and reduced illness intrusiveness, compared to 20 or 30 years ago. This is likely due to advancements in treatment such as insulin pump therapy and intensive glucose monitoring.

A unique counselling psychology perspective. Research from a counselling psychology perspective is needed to address the concerns of the growing number of Canadians with juvenile diabetes. Juvenile diabetes, alongside other chronic conditions, creates an existential dilemma that extends merely beyond viewing it as a medical problem (Encandela, 1997). Chronic illness pervades every aspect of a person's life–physical, social, and existential (Bernstein, 2004)–and can be threatening on both psychological and psychosocial levels (Schur, Gamsu, & Barley, 1999). The demands of treatment regimens create an altered social, existential, and physical reality that may seem foreign to those who are well (Charmaz, 1999a).

In the search for better medical treatment and ultimately a cure, researchers have historically paid less attention to the psychological aspects of diabetes. Little research has been directed at understanding how people with juvenile diabetes conceptualize and experience life (Gillbrand & Flynn, 2001). How chronic illness affects self-concept has often been overlooked. Diabetes research typically focuses on medical aspects of the condition such as diabetes management and patient compliance. Diabetes education for patients typically focuses on medication, diet and exercise, while paying minimal attention to the dynamic interaction between the individual and the social context of the illness, which is fundamental to the formation of identity (Tilden, Charman, Sharples, & Fosbury, 2005). Research from a counselling psychology perspective can help address this gap.

Self-concept is an important variable to research further because of its important connection with diabetes management and therefore general health and wellbeing. One study found a correlation between poor self-concept and deteriorating control of diabetes during mid-to-late adolescence (Luyckx & Seiffge-Krenke, 2009). Their findings compliment previous research and suggest that self-concept variables are related to longitudinal trajectories of blood sugar control in juvenile diabetes. Their results suggest that strengthening adolescents' self-concepts may help them gain improved long-term glycemic control. Self-concept appears to be an important aspect of diabetes care that needs to be explored further.

Background to the Research Question

When researchers began exploring the impact of illness on identity development, they did not differentiate between chronic and acute illness. In the 1950s Parsons (1951) introduced the notion of the "sick role," a concept he used in his attempt to delineate the social implications of illness. As researchers began to analyze Parson's definition of the "sick role," many found that the construct failed to adequately address the significance of chronicity in establishing the degree of influence an illness has on an individual's sense of self (Charmaz, 1999a; Davis, 1972; Murphy, 1990). Contemporary research takes into account the distinction between short-term illness and chronic health conditions and opens up the possibility of wellness in the midst of chronic conditions.

Current researchers often explore how participants have found and created meaning in their circumstances. A number of relevant studies have come out of the United Kingdom. There is a push for holistic care that incorporates psychological aspects of treatment. Researchers are advocating for better care for young adults who often "fall between the cracks" of pediatric and adult care (Doherty & Dovey-Pearce, 2005; Narayanasamy, 2004).

Due to the interdisciplinary nature of this topic, relevant studies have come from a number of areas including medical, psychological, and sociological literature. From a health psychology perspective, Dovey-Pearce, Doherty, and May (2007) wrote a relevant article on the influence of diabetes upon adolescent and young adult development and on understanding the psychological needs of young adults with diabetes. From a clinical psychology perspective, Schur, Gamsu, and Barley (1999) researched the young person's perspective on living and coping with diabetes. From a sociological perspective, Charmaz published several works that explore self-concept and chronic illness. Two of her more relevant works are highlighted (1983, 1991). From a psychological perspective, Bernstein (2004) examined the impact of early onset juvenile diabetes on the development of self and identity. These important contributions are discussed in the following chapter.

Conceptual Framework and Key Constructs

Interviews are understood through a symbolic interactionism conceptual framework; emphasis is placed on the way individuals make sense of social interactions and the meanings that they attach to social symbols such as language (Polit & Hungler, 1997). According to this framework, individuals act on the basis of the meaning they give to a specific situation, and on how they anticipate others to view their actions (Smith, 1996). Meanings can also be derived and changed through social interaction (Bryman, 1988; Smith, 1996).

In this thesis, self, self-concept, sense of self, and identity are used largely as synonymous. Each term has nuanced meanings that help explore what self-concept is. With phenomenology, a single definition of self-concept is not required. The term self-concept is predominantly used in this thesis because Charmaz' definition and use of the term fits closest with the exploratory aim of this thesis.

Self. The self refers to all those qualities, attributes, values, and sentiments, that a person assumes to be his or her own. Events and, often, elusive experiences that hold significance accumulate over time and form self (Charmaz, 1999a). Under ordinary circumstances the self is relatively enduring (Charmaz, 1999b). Self has consistent qualities and yet can change over time as life experiences unfold (Charmaz, 2002). Self can be understood as object or process. Self as process assumes the dynamic nature of self as emerging, developing, and unfolding (Charmaz, 1999b). An assumption is made that self is fundamentally social in nature and is developed and maintained through social relationships over the course of a lifetime (Charmaz, 1983). Self can be viewed as a kind of narrative, or perhaps an interlocking set of narratives, told to self and others, about where one came from, what one is doing now, and where one is headed in the future (Kihlstrom & Kihlstrom, 1999).

Self-concept. Self-concept has been studied from a broad range of theoretical frameworks. It can be approached from a one dimensional or multi-dimensional perspective. Early researchers often treated self-concept as a single entity and focused their research efforts on examining self-esteem (Wylie, 1979, as cited in Campbell, Assanand, & De Paula, 2000). A wealth of evidence substantiates the multi-dimensional nature of self-concept (Byrne, 1996). In this thesis, self-concept is understood from a multi-dimensional perspective.

Campbell, Assanand, and De Paula (2000) define self-concept as a global and multi-dimensional framework that incorporates the beliefs, feelings, and memories a person has of oneself. Self-concept is related to the behaviours, traits, abilities, roles, and characteristics that are considered representative of oneself.

There have been a number of qualitative approaches to studying self-concept. Marsh and Shavelson (Marsh, 1989, as cited in Byrne, 1996) developed a multidimensional hierarchical model of self-concept, which divided self-concept into several facets: social, emotional, physical, and academic. A questionnaire was developed based on this model, which has been backed up by substantial construct validity research (Byrne, 1996). Others have used predetermined lists of traits and attributes that participants then rate and group, or have had participants come up with their own list of traits and attributes, which they then rate and group. Campbell, Assanand, and De Paula (2000) suggest using a standard set of probes to generate self-aspect groups in order to make findings across studies more comparable. As a starting point, they suggest having participants consider the roles they occupy, the activities in which they engage, and the groups to which they belong.

In keeping with Charmaz' (1981,1991, 1999b, 2002) research model, self-concept is defined in this thesis as the relatively stable, coherent organization of sentiments, attitudes, values, judgments, characteristics, and personal attributes that a person holds about him or herself that have become consistent over time. It is based on taken-for-granted ways of thinking, feeling, and acting that become defining characteristics that distinguish an individual from others. Self-concept can be understood as an organized set of definitions of self through which a person describes him or herself. Self-concept tends to change slowly because it is made up of organized feelings and beliefs. Over time, self-images that are consistent or inconsistent with existing self-images are evaluated. Thoughts and feelings about images of self that arise from interactions with others cumulatively form self-concept.

Identity. Identity is often understood as the way participants view themselves and also the way they see themselves in relation to others (Schur, Gamsu, & Barley, 1999). Identity is a public and shared aspect of an individual, whereas self is typically characterized as a private, internal construct (Kelly & Field, 1996).

According to Erikson (1968), identity is a subjective sense of sameness and continuity in the self that is perceived and recognized by others. Erickson's model emphasizes ways that identity develops over time. Erikson's theory of identity development provides insight into how young adults with diabetes may experience their identity development. Based on his observations of "healthy" individuals, Erikson hypothesized that identity development occurs in sequential, psychosocial stages that occur over the course of the lifespan. Each stage may have specific challenges that relate to living with diabetes.

The basic conflict for adolescents, ages 12 to 18, is identity vs. role confusion. In this stage adolescents develop a sense of self and personal identity. Social relationships are of utmost importance. Successfully negotiating this stage leads to an ability to stay true to oneself, while failure results in feelings of inferiority.

Adolescents have a tendency to exclude those who are different and often ostracize those with chronic illnesses, making them even more susceptible to feeling like outsiders (Gliedman & Roth, 1980). In an effort to gain social acceptance from peers and avoid being excluded, adolescents with diabetes may feel more inclined to keep their condition hidden (Bernstein, 2004).

The basic conflict during the early 20's is intimacy vs. isolation. Relationships are central, as young adults strive to form intimate, loving relationships with others. Successfully negotiating this stage leads to strong relationships, whereas failure leads to isolation and loneliness. If a person's identity is established at this point, sexual and mutual interpersonal intimacy are sought. When young adults do not feel secure to seek intimacy, they become consumed with self-absorption, or distantiation, which Erikson (1980) defines as, "the readiness to repudiate, to isolate, and, if necessary, to destroy those forces and people whose essence seems dangerous to one's own" (p. 101).

In their search for intimacy, young adults with juvenile diabetes may feel inclined to be more open about their diabetes and may suffer if they hold back this aspect of their lives (Bernstein, 2004). People with chronic illness who use protective strategies such as lying, concealing, or manipulating in an attempt to gain more social acceptance, may find it difficult to discern when and how to open up with others in order to attain intimacy (Gliedman & Roth, 1980). This can be a barrier to developing intimacy.

The next phase of adulthood, late 20's into the 50's, involves a crisis of "generativity versus stagnation." In this stage people seek to create or nurture things that will outlast them, often by having children or creating positive change that benefits others. Success in this stage leads to feelings of accomplishment and usefulness, whereas failure results in stagnation and lack of satisfying interpersonal relationships (Erikson, 1980).

Balancing the rigors of diabetes management with pregnancy and the expectations that come with being a good parent creates some additional challenges for people with diabetes (Juvenile Diabetes Research Foundation International, 2009). For some, early complications may lead to feelings of stagnation and personal impoverishment. However, people with diabetes who have successfully coped with their condition may desire to act as role models for other people with diabetes or become more involved with fundraising and other efforts to find a cure during this phase of life as a way of providing for future generations (Bernstein, 2004).

Young adulthood. Arnett (2000, 2001a) has proposed "emerging adulthood" as a developmental phase in Western developed societies, between late adolescence and young adulthood (late teens through to the early 20's). This is a time when young adults are continuing to explore and to develop their personal identity. It is a transition time before fully taking on the responsibilities associated with adult life. A greater proportion of young adults are pursuing college and university education, and career choices, marriage, and having a family are occurring later in life. Those in their late teens through early 20's are delaying enduring decisions and experimenting with and exploring roles. This period of life is characterized by feelings of oscillation, as self-identity is still developing due to the multiple opportunities for change and different experiences (Arnett, 2001b).

For the purposes of this study, age 19 was chosen as the lower age limit for young adulthood based on Erikson's (1968) stages of identity development. According to

Erikson (1968), identity continues to evolve throughout the life span. However, by the time people have reached their 20's, identity has culminated into a reasonable "coherent whole" (p. 161). By age 19 participants were well on their way to developing a coherent identity and could reflect on how their experience of living with juvenile diabetes had or had not been formative in their identity development. The upper age limit of young adulthood was defined as 29 in order to reflect the extended period of identity exploration in western society that allows young people a prolonged period of independence (Arnett, 2000).

Chapter 2: Literature Review

Diabetes is an extensively researched condition. However, relatively little attention has been given to the lived experience of chronic illness (Gillibrand & Flynn, 2001). This chapter provides a detailed, critical review of the literature on the lived experience of juvenile diabetes in childhood, adolescence, and young adulthood with a focus on self-concept and life with diabetes in young adulthood. Gaps in the literature and ways that this study contributes to the field of counselling psychology are outlined. We begin by reviewing four key studies that examine the research question. This is followed by detailed findings that fall under three major headings: Intrapsychic Aspects, Psychosocial Aspects, and Experience and Personal Formation. We conclude by tying these three main areas together and looking at where the research needs to go from here.

Four Key Studies

In searching for relevant literature I had look broadly because there were not many studies that related to this specific topic. The following studies are key because they are the best of what is available out there. The big picture question of this thesis is, "how does juvenile diabetes affect self-concept in young adulthood?" There have been four major studies that have specifically addressed this question to date. The first two of these studies were conducted in the UK and the last two were conducted in the USA. To this point, there has not been a Canadian perspective on this issue. Due to the lack of pre-existing research in the topic area, each of these studies took a qualitative interview approach. Accordingly, one of the constraints of each of these studies was a smaller sample size. However, these are helpful preliminary studies. The details of how self-concept was affected in these studies and others are covered thematically under the other major headings in this chapter.

Schur, Gamsu, and Barley (1999), approached the question from a clinical psychology perspective. They looked at the young person's perspective on living and coping with diabetes. Eight young people with juvenile diabetes, ages 16 to 22 were interviewed. Men and women were equally represented. The mean age of the sample was 19.6 years and the mean duration of diabetes was 12.3 years. Interpretative phenomenological analysis was used to analyze the results. They found that participants seemed to feel that living with diabetes had not impacted their overall identity. However, they expressed that having diabetes may have influenced aspects of their selves, interestingly, in ways that could be deemed as socially acceptable and positive.

Limitations of the study were that the sample was small and may have been unique because participants self-selected for the interview and all seemed to be coping well. Participants were all in higher education, and were Caucasian, perpetuating a problem in diabetes research that little is known about other ethnic groups and lower socioeconomic status groups. This thesis aimed to include participants from various cultural and socioeconomic groups. At times, the study seemed distant from participant's voices, possibly due to their grounded theory approach. This thesis aimed to keep the voice of participants as much as possible.

Dovey-Pearce, Doherty, and May (2007) approached the question from a developmental, health psychology perspective. They examined the influence of diabetes upon adolescent and young adult development. Participants were between the ages of 16 to 25 years old. The mean age of the sample was 19.9 years. There were 19 participants (eight male and 11 female). Interviews were analyzed using a Framework Approach. They found that, in young adulthood, juvenile diabetes added an additional challenge that could impact personal identity and self-concept from diagnosis and onwards. It appeared that a sense of being labeled as "not normal," "different," and "unwell" caused adolescents and young adults to rapidly redefine themselves in relation to others and in relation to their future.

Participants were from both rural and urban areas. No comment was made about ethnicity, socioeconomic background, or level of coping with diabetes, so it is not known how well various groups were represented.

The third key study is from an American perspective. Over a number of years, Charmaz has researched self-concept and chronic illness. Her 1983 study on "loss of self" in chronic illness, and her 1991 book on the self in chronic illness are particularly relevant to this thesis. Charmaz' research provides a foundation for understanding self-concept and juvenile diabetes in young adulthood. Her findings are based on longitudinal data from qualitative formal in-depth interviews, informal conversations, unpublished personal accounts of illness, and published autobiographical works. Her data set expanded over the years. Adults with various serious chronic conditions, including multiple sclerosis, cardiovascular disease, cancer, lupus erythematosus, arthritis, and diabetes, were interviewed. Participants resided in Northern California. The 1983 study included 57 respondents with chronic conditions that were believed to be severely debilitating. The sample from the 1991 book involved 90 individuals with chronic illness and 20 caregivers and providers. Her theoretical framework, data collection and analysis were informed by symbolic interactionism, grounded theory, social psychology, and sociology.

Charmaz (1995) found that chronic illness disrupted the sense of wholeness of body and self. It intruded upon daily life and undermined identity and self. Receiving a diagnosis suddenly and unexpectedly, particularly at a younger age typically associated with health and vitality, could rapidly forces changes in identity. Diagnosis shook former assumptions about having a smoothly functioning body and notions about the relationship between body and self. This relationship between body and self was particularly problematic for people with chronic illness who realized that they had suffered permanent losses. Charmaz' findings on body, self-concept, and adapting to illness influenced several of the interview questions in this thesis.

Charmaz covered a lot of material on self-concept and chronic illness. Her research focus was broad, covering a number of chronic conditions. The findings were not specifically geared for counselors working with young adults with chronic conditions. It is not known how findings would relate to a Canadian sample. Few participants were in their 20s. Given that participants from the 1983 study were mostly between the ages of 40 to 60 and had complications that left them seriously debilitated and even house bound, it is not known how these findings would relate to young adults with juvenile diabetes not living with serious complications. More research is needed to examine the specific experience of young adults living with juvenile diabetes, as this condition poses distinct difficulties for the emerging self.

The closest research study to this thesis is an American doctoral dissertation published in 2004 by Bernstein, which examined the impact of early onset juvenile diabetes on the development of self and identity. There were 20 participants ranging in age from 21 to 58. All had been diagnosed at age five or younger. Men and women were equally represented. Bernstein used a qualitative descriptive research approach. Participants were mostly American, distributed relatively evenly across the country. However, one participant was Canadian, and another was an American residing in the UK. All identified as Caucasian, middle or upper class, having some college education, and a high level of diabetes care, reflected in that they tested blood sugars seven to ten times a day and all used insulin pumps.

Bernstein (2004) found that as participants matured and incorporated diabetes into their lives, having diabetes played a major role in shaping their identity, sense of self, and worldview. Almost all of the participants considered their condition to be a significant part of their lives, inseparable from the whole of who they were. Surprisingly, despite the intrusive and relentless nature of treatment, many participants did not experience diabetes as a central aspect of their identity. Some conceptualized diabetes as an internal component of the self, while others also viewed diabetes as external to self, particularly when diabetes was perceived as threatening to one's wellbeing.

A limitation of the study was that participants represented a limited demographic and were therefore more likely to have certain similar experiences and perspectives. For example, having more access to diabetes education and more contact with medical professionals as a result of economic privilege likely would have influenced participants' ideas about diabetes, themselves, and their identities.

These four studies show that living with juvenile diabetes influences aspects of self, personal identity, and self-concept from diagnosis onward. In some ways this is not surprising, because all our life experiences shape who we become and how we see ourselves. However, the specific details of how this condition influences self-concept need to be explored further in order to better work with this client population. In addition, research is needed to see how findings relate to a sample from diverse ethnic and socioeconomic backgrounds, and from varying degrees of diabetes self-management, from those who are coping well to those who are coping poorly.

Intrapsychic Aspects

This first major section touches on some of the relevant internal psychological processes for people living with juvenile diabetes. We begin with developmental and mental health concerns. This is followed by a discussion of illness perceptions and self-care. We then move on to the related topics of body and self-concept, shifting habits and self-concept, and identity questioning.

Developmental concerns. In this section we will discuss diabetes in relation to the normative developmental demands of adolescence and young adulthood. Then we will move on to cover ways that these normal demands interfere with transitioning from pediatric to adult care. We will conclude with ways that diabetes challenges autonomy.

Self-concept and juvenile diabetes need to be understood in the context of the unique developmental challenges of adolescence and young adulthood. Adolescence is a time of rapid physical change. The primary challenges of adolescence are: achieving biological and sexual maturation, developing personal identity, establishing personal values and ethics, striving for social responsibility, adopting appropriate social roles, achieving emotional independence from parents, preparing for occupational roles, developing close peer relationships, preparing for and developing intimate relationships, developing future life goals, and accepting one's own body (Christie & Viner, 2005; Doherty & Dovey-Pearce, 2008; Roisman, Masten, Coatsworth, & Tellegen, 2004). Accepting one's own body is particularly a challenge for people with juvenile diabetes (Bernstein, 2004).

The developmental demands of emerging adulthood are complex and often involve simultaneously managing any number of life-altering decisions and experiences (Harris, Raymond, & Duke, 2012). In older adolescence and young adulthood, the life decisions associated with adulthood, including parenthood and other important long-term issues, such as future health and well-being also come into focus (Arnett, 2000; Roisman, Masten, Coatsworth, & Tellegen, 2004).

It seems that the demands of diabetes create subtle, complex and changing challenges for adolescents and young adults, alongside the "normal" tasks of development. They have to show high levels of self-motivation and self-control in order to minimize the short and long-term health risks. There is a recognition that treatment tasks need to be carried out in the context of their ongoing lives (Doherty & Dovey-Pearce, 2005). Developmental factors such as valuing peer acceptance, risk taking, rebelling against authority, and searching for independence, can lead to compromised diabetes management (National Diabetes Education Program, 2014). Despite findings regarding vulnerabilities, most adolescents with diabetes and their families show a high degree of skill and resilience in managing the challenges they face (Doherty & Dovey-Pearce, 2005).

Another challenge is that normative developmental demands can interfere with transitioning from pediatric to adult care. This transitional time is marked by some of the worst metabolic control a person with diabetes is likely to experience in his or her life. Many emerging adults with juvenile diabetes are lost to follow-up during this transition and others struggle to establish and maintain a connection with their adult diabetes care providers (Harris, Raymond, & Duke, 2012). Clinical evidence suggests that young people may be more likely to disengage from services (Schur, Gamsu, & Barley, 1999). Unfortunately, emerging adults receive less support at a time when they would benefit from more (Harris, Raymond, & Duke, 2012). Disengaging from care is a concern because of the greater risk for complications when blood sugars are not maintained at close to normal limits over the long-term (DCCT Research Group 1993). There is currently a lack of clinical programs and research focused on transitional issues (Harris, Raymond, & Duke, 2012). Research is needed to find ways to help young adults bridge the transition between care providers and prevent or reduce harm. Findings from this thesis could be used to help understand some of the psychological demands of juvenile diabetes in order to better facilitate transitioning to adult care.

Pro-active and preventative work is needed to support young people as they set the foundations for their future health attitudes and behaviours. Health care services need to support young people with self-care, but need also to understand and respond to the personal and social complexities of growing up with a chronic health condition. Psychologists play an important part in supporting and promoting such an approach (Dovey-Pearce, Doherty, & May, 2007).

Establishing autonomy is an important developmental task for adolescents and young adults (Christie & Viner, 2005). Several studies have indicated that the demands of managing juvenile diabetes seem to challenge a young person's ability to become autonomous. In this way, diabetes could disrupt personal development for adolescents and young adults (Dovey-Pearce, Doherty, & May, 2007; Harris, Raymond, & Duke, 2012; Sayer, Hauser, Jacobsen, Willett, & Cole, 1995; Wennick & Hallström, 2007).

Wennick and Hallström (2007) found that children experienced diminished autonomy one-year post diagnosis with juvenile diabetes. Children felt they had gained more independence than at the time of their diagnosis, yet felt supervised because of their diabetes. Parents felt the need to supervise more because of their anxiety about their child's diabetes related symptoms. Separating and individuating was a challenge for adolescents and young adults with juvenile diabetes. Even as they began to rely more on their peers, they still continued to value the safe base of their family, especially at times of challenge and change (Dovey-Pearce, Doherty, & May, 2007). Charmaz (1983) also found that limitations due to chronic illness could become tangible daily reminders of diminished autonomy and, often, diminished self for adults. Having covered some of the developmental context, we now move on to discussing mental health concerns for young adults with diabetes.

Mental health concerns. The 2008 Clinical Practice Guidelines (Canadian Diabetes Association) report that individuals with diabetes are at higher risk for depression, anxiety, and eating disorders, and recommends that individuals with diabetes be regularly screened for sub-clinical psychological distress and psychiatric disorders.

According to the 2013 Clinical Practice Guidelines, the prevalence of clinically relevant depressive symptoms among people with diabetes is in the range of 30%. The prevalence of major depressive disorder is about ten percent, which is double the overall prevalence in people without a chronic medical condition. Studies examining the difference in prevalence rates of depression in juvenile vs. adult onset diabetes have yielded inconsistent results (Canadian Diabetes Association Clinical Practice Guidelines Expert Committee, 2013). While experts are at odds about the relationship between juvenile diabetes and depression, most agree that there is a connection (Juvenile Diabetes Research Foundation International, 2009). One study found that requiring insulin was the factor associated with the highest rate of depression, no matter what of the type of diabetes involved (Canadian Diabetes Association Clinical Practice Guidelines Expert Committee, 2013). A meta-analysis by Barnard, Skinner, and Peveler (2006) estimated that 12% of adults with juvenile diabetes have clinical depression, compared with three percent of control subjects.

Some risk factors for developing depression with diabetes are: female gender, young adults, poverty, few social supports, stressful life events, poor glycemic control, particularly with recurrent hypoglycemia, longer duration of diabetes, and presence of long-term complications (Canadian Diabetes Association Clinical Practice Guidelines Expert Committee, 2013).

Depression can harm diabetes management (Lustman, Anderson, Freedland, Groot, Carney, & Clouse, 2000) and is associated with increased morbidity, mortality, and functional limitations (Peyrot, Rubin, & Siminerio, 2006). When there is depression alongside diabetes, a multidisciplinary approach to treatments is required. Unfortunately, the mental health team and the diabetes care team are often disconnected. In the future, more of an interdisciplinary approach is needed to improve the care and outcome of a significant subpopulation of people with diabetes whether diabetes is a cause or consequence of mental health issues (Pacaud & Conway, 2008).

Evidence suggests that people with juvenile diabetes have a higher prevalence of phobic disorders and generalized anxiety disorders. As many as 40% of patients with diabetes have some symptoms of anxiety, and fear of hypoglycemia is not uncommon in those with diabetes. A 2004 meta-analysis suggested that the presence of clinically significant anxiety disorders among those with juvenile diabetes is associated with poor glycemic control (Canadian Diabetes Association Clinical Practice Guidelines Expert Committee, 2008). Anxiety and depressive symptoms are commonly found together. One study found that an estimated 14% of people with diabetes had generalized anxiety disorder with double this number having a subclinical anxiety disorder and triple this number having at least some anxiety symptoms (Canadian Diabetes Association Clinical Practice Guidelines Expert Committee, 2013).

Eating disorders, such as anorexia nervosa, bulimia nervosa, and binge eating are more common in people with juvenile diabetes than in the general population (Canadian Diabetes Association Clinical Practice Guidelines Expert Committee, 2013). Studies suggest that girls and women with juvenile diabetes have an increased incidence of disturbed eating behaviour, which includes sub-threshold and full-syndrome eating disorders as well as milder eating disturbances, than their non-diabetic peers (Colton, Olmsted, Daneman, Rydall, & Rodin, 2004; Jones, Lawson, Daneman, Rodin, 2000; Nielsen, 2002). Eating disorders are associated with poorer glycemic control and increased risk of long-term complications. Studies have demonstrated prevalence rates of full syndrome and sub-threshold eating disorders that are twice as high as peers without diabetes (Canadian Diabetes Association Clinical Practice Guidelines Expert Committee, 2008). Depressive symptoms affect up to 50% of people with eating disorders. Juvenile diabetes seems to be a risk factor for developing an eating disorder, both in terms of higher prevalence of established eating disorder features as well as through intentional under-dosing or insulin omission. This is known as diabulimia (Canadian Diabetes Association Clinical Practice Guidelines Expert Committee, 2013).

Findings regarding depression, anxiety, and disordered eating show the psychological strain that diabetes places on individuals and the need for people to be referred to mental health professionals if they are diagnosed with mental health issues. Regrettably, mental health comorbidities are often the most overlooked, despite their potential to compromise self-management and increase the risk for serious complications. According to a recent opinion paper, most physicians do not recognize the psychological toll that diabetes places on patients, and for that reason they fail to take action. Mental health comorbidities of diabetes are not well understood by many physicians. Also, physicians often do not know that these mental health comorbidities of diabetes are treatable, if a timely referral is made to a mental health provider for diagnosis and treatment. It is particularly important to be aware of those most at risk including those with limited family and social support, and those with multiple life stressors in addition to diabetes (Ducat, Philipson, & Anderson, 2014).

Charmaz (1991) also noted how poverty could complicate managing chronic illness. She found that struggling to meet basic needs such as food, shelter, and medical care could preclude attending to health. Constant crisis with no viable solutions were overwhelming. When participants were in survival mode, the long-term consequences of their health care practices seemed more distant than they did to other, more fortunate individuals with similar health issues. The more fixed they became on survival in the present, the less they attended to the long-term implications of their choices. These findings show the importance of including young adults from a variety of socioeconomic backgrounds in research. Financial strain can affect ways of living with and experiencing juvenile diabetes, which may influence self-concept as well.

Findings reported in the 2008 Clinical Practice Guidelines (Canadian Diabetes Association Clinical Practice Guidelines Expert Committee) demonstrate the need to further understand the psychological aspects of living with diabetes in order to treat and ease this burden on mental health. Adolescent women with juvenile diabetes seem to be particularly at risk for depression and eating disorders. Findings also seem to indicate that adolescent girls are also more distressed by their diabetes and experience lower self-esteem than adolescent boys (Luyckx & Seiffge-Krenke, 2009). Studies are needed to address the concerns of this at risk group. Further research is required to explore self-concept for individuals with juvenile diabetes in light of these specific psychological challenges. Having examined mental health concerns, we now move on to how illness and identity perceptions affect self-care.

Illness and identity perceptions and self-care. Illness perceptions can influence care seeking. In 2007, Lawson, Lyne, Bundy, and Harvey examined illness perception and care-seeking among people with juvenile diabetes. Their sample was between the ages of 18 and 65. They found that more positive perceptions of diabetes were associated with problem-focused strategies, which were in turn associated with regular care-seeking and improved medical outcomes. Negative views of diabetes were related to coping strategies considered to be less effective in the long run, such as denial and behavioural and mental disengagement. Those who did not attend diabetes care clinics were more likely to use avoidance and emotion-focused strategies such as using humour or resorting to alcohol, or illegal drugs. Humour, although a potential asset, was negatively correlated with active care-seeking. From these findings, it seems that counsellors could help improve diabetes care by helping clients resolve unhelpful illness perceptions.

Identity perceptions in relation to living with juvenile diabetes also influence diabetes self-care. In 2005 Tilden, Charman, Sharples, and Fosbury presented a case study of a 26-year-old woman who developed juvenile diabetes in early adolescence and who attended seven short-term psychotherapy sessions. Phenomenology was used to analyze therapy transcripts, case notes, and a reflexive journal to extract major themes. They found that that the client's identity had been overshadowed by the development of a "diabetic identity" that she had rejected. Her poor adherence to her diabetes regimen was linked to this rejection. Her motivation to manage her diabetes changed during therapy once her identity was confirmed as being separate from her diabetes. She was then able to integrate diabetes into her life. Accepting and integrating diabetes into one's lifestyle, rather than rejecting a "sick" or "diabetic identity," may be part of the process of coming to terms with having juvenile diabetes.

These findings show how identity, and illness perceptions can affect diabetes management. Their findings have implications for people with diabetes who are resistant to taking the necessary steps to manage their diabetes, possibly due to rejecting a "sick" identity. Understanding the impact of diabetes on identity can enhance the effectiveness of therapeutic interventions with clients who would like to improve their diabetes management. Having glanced at how illness and identity perceptions affect diabetes self-care we now consider how changes in bodily functioning affect self-concept.

Body and self-concept. The onset of chronic illness and the change in bodily functioning profoundly affects self-concept. Chronic illness may also change how others perceive and construct the identity of those who are living with the chronic health condition. However, as an individual's body changes and their illness develops there is still a sense that they are the same person before their body began to change, although in a different social situation. They are also known, at least to significant others, as the person they were before they developed a chronic condition. Although some identities may change, other core identities remain unaltered. Yet with changes in the body, pain, discomfort, and restricted activities, comes a change in self-conception (Kelly & Field, 1996).

The body, often taken for granted in many situations, ceases to be taken for granted once it malfunctions and becomes more prominent in the consciousness of self. Especially in the early stages of an illness, the body has to be acknowledged as limiting or interfering with physical and social activities. Self-concept and identity are held in tension between continuity and change (Kelly & Field, 1996).

Alterations to self and identity are more substantial and permanent in chronic illness than in acute illness. However, this may not be recognized or acknowledged at first. Rather than going away, the sick role becomes transformed and periods of being sick and living with the problems of impaired functioning become permanent features of self and publicly defined identity. The nature of the chronic illness and its bodily consequences has to be incorporated permanently into self-concept. The relationship between self and identity in chronic illness alters over time as bodily contingencies change (Kelly & Field, 1996). This thesis further explores how self-concept is affected by this tension between body and self for those living with juvenile diabetes.

Shifting habits and self-concept. Habits are important in the development of self-concept. People develop relatively enduring self-concepts by having habitual modes of responses to and about themselves. Multiple and confirmatory social experiences result in a habitual set of emotional, thought-based and behavioural reactions that hold together and become relatively fixed. People learn who they are and who they are becoming through life experiences; repeated experiences can become powerful lessons. Chronic illness may force small to radical changes in daily habits over time (Charmaz, 2002).

Habits are often taken for granted and not articulated. Changes brought on by illness and treatment of illness shift a person's way of being in the world and therefore can directly affect a person's sense of self. Chronic conditions often disrupt taken-for-granted ideas about self, as well as habits that support this self. People many not be aware of the daily habits that form self-concept until those habits are challenged and no longer function. People with chronic conditions frequently discover that actions and activities that they once took for granted have become problematic. Something that was once second nature may become a hard-won achievement or a permanent loss. Self-concept often remains unchanged in chronic illness until people experienced disruption in their daily habits, thus experiencing themselves and changed (Charmaz, 2002).

Self-concept does not always keep up with changes in life experiences that illness brings. Particularly in the early stages of chronic illness, the meaning of new life experiences for self can be contested. When a new experience associated with illness contradicts a former view of self, people sometimes try to rationalize it away in order to maintain former self-concepts. Not all people with chronic illness define the disruption that they experience as a serious illness with lasting consequences. For some, their habitual ways of defining self prevent them from adapting an altered self-concept, even when an altered self-concept would fit with their current experience. Some resist seeing themselves as chronically ill and avoid altering their sense of self around illness until they have exhausted other plausible explanations and have learned over and over in their daily lives that they have changed. Habitual ways of feeling and thinking about one's body are seldom easily relinquished. When habitual views of self are predicated on invincibility, agelessness, unceasing functioning, and strong personal control, people with illness change their self-concept slowly through many experiences (Charmaz, 2002).

From these findings it would seem that young adults with juvenile diabetes could resist altering their self-concept around illness until multiple experiences have confirmed a changed self. Further research is required to explore how habits set the foundation of self-concept for young adults with juvenile diabetes.

Identity questioning. Charmaz (1991) found that immersion in illness, dependency, and social isolation caused participants to question their identity. Participants wondered where their illness would take them, who they would be, how their illness would affect their future, how they could continue to be themselves while experiencing relentless illness, and what being dependent would do to their self. Behind these reflections on past, present, and future was a concern that their condition could override other sources of identity in their lives. As participants questioned their identity, they also asked themselves what they had learned about themselves through illness and how to use that knowledge should a return to their former lives become possible. Participants immersed in illness became open, and in some ways vulnerable, to the identifications imposed on them by others, such as medical professionals (Charmaz, 1991). These findings suggest the tremendous impact that counsellors can have on people who are questioning their identity.

Identifying moments were telling moments that were filled with new images of self. These moments sparked sudden realizations of self, revealed hidden images of self, or showed what others thought. Identifying moments could be positive by being an inspiration to others, or they could be negative by being demeaning and even shocking. If people had strong positive views of themselves and their conditions, they were more likely to reject negative messages encountered in the identifying moment. However, if the other person was significant or powerful in their lives, negative labels could stick and undermine a person's taken-for-granted assumptions about self. These moments could escalate into crisis and become significant turning points, where assumptions about self were shaken and self-concept was reconstructed (Charmaz, 1991).

Whether validating or disruptive, identifying moments became significant turning points revealing present or possible selves. Emotional reverberations of a single event could echo through the present and future and shape thoughts and feelings about self. Positive events took on significance because they were seen as turning points that mirrored growth and resiliency of self. Past distressing events could later be seen as turning points toward a more aware self (Charmaz, 1991). These findings show the strong social aspect of self-concept and also how pivotal moments can shape self-concept. Identifying moments were noted in the interviews because they often illustrated shifts in participants' self-concept.

Having looked at how various researchers have dealt with intrapsychic aspects of self-concept and chronic illness we will now look at how psychosocial aspects are addressed.

Psychosocial Aspects

This section covers some of the relational and social contexts of life with juvenile diabetes in young adulthood. We will discuss inconsistencies in findings regarding psychosocial delays for young adults with juvenile diabetes. Then we will look at "loss of self" in chronic illness, intimacy and social support, and disclosure and stigma management. A substantial amount of time is spent on disclosure and stigma management given its importance for young adults with diabetes.

Evidence suggests that emerging adulthood is a critical developmental period in the lives of young people with diabetes in terms of their general psychosocial functioning (Harris, Raymond, & Duke, 2012). There are inconsistencies in findings regarding the psychosocial aspects of diabetes. A Canadian study by Paucaud, Crawford, Stephure, Dean, Couch, and Dewey (2007) found that young adults ages 18 to 25 with juvenile diabetes did not show delays in aspects of their psychosocial maturation compared with age matched healthy controls. No group differences were found on the total scores assessing the areas of responsibility and independence, social maturation, internal or external locus of control, or social network. Helgeson, Reynolds, Escobar, Siminerio, and

Becker (2007) found that adolescents with diabetes and healthy adolescents reported similar levels of friend support. However, Harris, Raymond, and Duke (2012) wrote that evidence suggests young adults with chronic illness, such as diabetes, are more likely to be delayed in overall development. This is also contrary to several older studies, which suggest adolescents and young adults with diabetes may have specific vulnerabilities associated with the demands of diabetes, such as social isolation, poor intimate relationships and low perceived control (Kokkonen & Kokkonen, 1995; Lloyd, Robinson, Andrews, Elston, & Fuller, 1993; Wysocki, Hough, Ward, & Green, 1992).

These differences in findings may be the result of improved treatments over the past decade. Most of the literature on psychosocial maturation in adolescents and young adults with diabetes predates the intensification of diabetes management, which provides more flexibility with schedule and meal planning but demands more complex management, including frequent blood glucose monitoring and analysis, carbohydrate counting, and multiple daily injections or continuous insulin infusion (Pacaud, Crawford, Stephure, Dean, Couch, & Dewey, 2007). Today's array of new tools, insulin and strategies has given adolescents and young adults greater flexibility in deciding what to eat and when to eat (Juvenile Diabetes Research Foundation International, 2009) and has made a tighter level of control possible. The discrepancy in findings highlights the need for psychosocial research to keep up with advancements in care.

Loss of self. Having covered some discrepancies in findings regarding psychosocial development, we now explore how chronic illness can lead to a feeling of "loss of self." Charmaz proposed that "loss of self" is a primary form of suffering for those with chronic illness. Loss of self is defined as the loss or diminishment of former self-concepts without the development of new and equally valued ones. A narrow, medicalized view of suffering, solely defined as physical discomfort, ignores or minimizes the broader significance of the suffering of loss of self experienced by those living with serious and debilitating chronic conditions. Physical, mental, social, economic, and psychological losses can result in a loss of self (Charmaz, 1991).

In her study, loss of former self-images was most marked at the onset of a serious, debilitating illness or at points when participants living with illness defined former actions, lives, and selves as now made impossible or overshadowed by illness. As a result of illness, they suffered from the interrelated experiences of leading restricted lives, experiencing social isolation, being discredited, and becoming a burden to others. Together, these sources of suffering led to losses of control and action, which are typically foundational to the sense of self. In a culture that emphasizes the importance of doing rather than being, debilitating chronic illness posed questions about, if not a direct assault upon, the self (Charmaz, 1983).

Having a chronic condition created a restricted life with fewer possibilities for constructing a valued self. Illness structured their lives and shaped their self-concepts. Chronic illnesses became the focus of participants' lives as medical appointments, treatment regimens, periods of discomfort, and difficulties of completing mundane activities structured and filled their days. However, as long as they felt they could exercise choice in valued activities and had some freedom of action to pursue these choices, everyday life did not seem as restrictive, suffering was reduced, and self-image was maintained (Charmaz, 1983).

Loss of control from life restrictions usually resulted in losses of self. Fear and uncertainty surrounding the unpredictable course of many chronic conditions led some to restrict their lives more than necessary. Through such self-limiting, participants intended to protect their lives but did so at great costs to their self-image. The greater amount of potential embarrassment and loss of control from unpredictable illness, the more likely they were to restrict their lives voluntarily and the more likely their self-concept suffered. Some voluntarily restricted their lives, whereas others were forced to do so due to diminished health and related factors such as the financial burden that it placed on them and their families. Living a restricted life fostered a retreat into illness as concerns became increasingly constricted to illness. Friends and family also observed participant's consuming thoughts about self and illness (Charmaz, 1983).

Living with chronic illness was socially isolating due to three main factors: large amounts of time were spent following a medical regimen, treatment often occurred in the privacy of their home, and managing their condition focused attention on self. As a result, participants tended to suffer from loneliness. Living with chronic illness seemed to have fostered a greater dependence on others for self-definition and value while at the same time it placed extra strain on those relationships. While participants looked for and needed more intimate social contact to preserve their former self-image and to monitor their image in the eyes of others, they often became less able to maintain these relationships as they became increasingly wrapped up in their illness. Openly expressing their suffering with emotions such as guilt, anger, and self-pity sometimes resulted in further estranging them from others (Charmaz, 1983).

Immersion in illness forced participants to shrink their social worlds. It meant facing dependency and experiencing bodily vulnerability. As participants pulled into their inner circle and away from their outer circle they were better able to cope. However, this set the stage for future isolation. When their physical condition restricted their social life, there were fewer opportunities for creating self. This constrained social world resulted in a loss of self that was felt acutely and often was fought against. Recurrent or spiraling complications involved some so much that they did not realize how immersed they had become in their illness and how it had caused them to turn inward (Charmaz, 1991).

Loss of self was caused by discrediting definitions of self due to negative interactions with others and unmet expectations of self. Discrediting definitions are those that discount, undermine, and devalue the person with illness. Participants had a heightened self-concern about the person they saw themselves becoming and about losing valued past self-images. Their heightened self-concern raised several dilemmas because they now saw themselves and their lives as fragile. They scrutinized social interactions for hints of discrediting and negative reflections of self, became sensitive to the intentions and meanings of others toward themselves, and even began to read the actions and statements of others in self-discrediting ways, thereby increasing their own suffering (Charmaz, 1983).

The sense of becoming a burden to others was another loss. According to Bury (1982), chronic illness disrupts the normal rules of reciprocity and mutual support of individuals, families, and wider social networks. The dependency that chronic illness places upon the individual is a major issue. Charmaz (1983) found that as participants became more immobilized and dependent, hopes of recapturing a positive self-image of the past were lost. Participants felt concerned about the psychological, economic and physical burdens that their condition caused others. Becoming a burden meant onerous and continuous obligations for family members. It meant that they were no longer able to fulfill obligations implicit in past relationships. This placed strain on relationships, particularly those that were already strained. Becoming a burden stood in contrast to how participants wanted to see themselves. It meant experiencing physical dependency, feeling useless, and facing difficulty in small everyday things. Alternatively, it could also mean developing an appreciation for little things that were previously taken for granted.

Young adults with juvenile diabetes may experience some of these losses, although probably in a lesser form because they have likely not faced debilitating complications that so contribute to loss of self. This thesis further explores the notion of loss of self in chronic illness for young adults.

In this section we have examined some of the negative psychosocial dynamics that can lead to feelings of loss of self. We now review some of the literature that shows the positive influence of social support on self-concept.

Intimacy and social support. A number of studies have shown the importance of social support in developing and maintaining a positive self-concept. Charmaz (1991) found that social support from various relationships, such as intimates, parents, peers, and role models, made it easier to manage chronic conditions.

Charmaz (2002) looked at the importance of intimate relationships for the development of self-concept. She found that intimate relationships could be strained or torn apart by chronic illness. However, those who made it through the difficult times were able to find rewards within their experiences as compassion and understanding spread through relationships and beyond as friends and family became involved.

Images of self reflected by intimates were crucial for either sustaining or discrediting self-concept. Supportive intimates typically strengthened self and created continuity with the past, pre-illness self. They were often in tune with the mood, discomfort, and symptoms of those living with chronic conditions, sometimes more than their loved one was themselves. They were able to see their loved one's behaviour in the light of their illness and regimen maintenance without diminishing her or him. In this way supportive intimates were able to minimize discrediting their partner or disrupting ongoing relationships. They did this by comforting their loved one about attributes, functions, and actions that were lost, and by emphasizing positive aspects of their current existence (Charmaz, 1991). Without these supportive intimates, participants were more vulnerable to discrediting definitions, particularly when they could no longer take for granted some valued attribute or function which they saw as fundamental for their self image (Charmaz, 1983).

Parents were another source of social support that strengthened self-concept. Parents helped support and guide their adolescent or young adult child to accept their diabetes by normalizing and depersonalizing diabetes. Parents' responses to diabetes seemed to be an important influence in learning to live with diabetes (Schur, Gamsu, & Barley, 1999).

The need for social support from intimates and family members was tempered by the desire to maintain autonomy. Charmaz (1991) found that when someone saw themselves as accountable to only a small circle of concern, such as to their spouse or parent, accountability around treatment regimens could cause an adversarial relationship. For instance, taking medications, following diet, eating regularly, and so on could cause people to enter into an unhealthy power dynamic such as treating their partner like a child or their child like a patient. This could develop into a power struggle, while deflecting away from the reason for following the regimen in the first place.

These kinds of unhealthy relationship dynamics are often discussed in diabetes literature. Calmly and openly talking about irritations and misunderstandings regarding being monitored helps avoid friction and misunderstandings (Juvenile Diabetes Research Foundation Canada, 2013). It seems possible that friction in relationships as a result of being supervised could negatively affect self-concept for young adults living with juvenile diabetes.

Peer relationships were also a source of support. For young adults, talking to others with juvenile diabetes was considered an important support mechanism to reduce the anxiety of isolation (Samson, 2006). Peer relationships helped normalize their experience and allowed them to feel a sense of belonging and kinship (Bernstein, 2004; Schur, Gamsu, & Barley, 1999). Sharing with others gave them practical tips and coping strategies for managing their diabetes. Peer support often acted as a buffer against negative psychological effects of stigma and difference, especially if adolescents and young adults controlled the disclosure of their diabetes (Dovey-Pearce, Doherty, & May, 2007).

Role models were another source of social support. Seeing people with juvenile diabetes that survived and took part in all sorts of activities gave people hope (Schur, Gamsu, & Barley, 1999). Leaders in the diabetes community served as an inspiration to many young adults living with juvenile diabetes. One example is Sebastien Sasseville, who at age 28 became the first Canadian with juvenile diabetes to summit Mount Everest, showing that diabetes need not be a barrier to accomplishing one's goals and aspirations (Juvenile Diabetes Research Foundation, 2008). Although each person has her or his range of abilities, Sebastien's accomplishments show that many of the challenges of diabetes can be overcome with perseverance, hard work, and human spirit. The role of social support for young adults with juvenile diabetes needs to be explored further because of its importance in maintaining a positive self-concept and living well with juvenile diabetes.

We have highlighted the importance of social support from partners, parents, peers, and role models for maintaining positive self-concept for those living with chronic conditions. In this next section we will summarize some of the research on disclosure and stigma management.

Disclosure and stigma management. The literature shows that disclosure and stigma management are major issues for young adults living with juvenile diabetes. This section covers feeling "different" on account of having juvenile diabetes, concerns about stigma, reasons to disclose and types of disclosure, strategies for preserving self and minimizing difference, and finally, gender differences.

Feeling different. Adolescents and young adults described feeling "different" as a result of living with juvenile diabetes. They felt different from others on account of their diabetes, both in an ontological sense of *being* different, and because of the self-care behaviours and routines that were necessary. Adolescents and young adults feared being discovered as being different and being judged as less acceptable than the norm, either on account of their diabetes or the associations that others had with diabetes (Dovey-Pearce, Doherty, & May, 2007). Other studies echoed these findings (Schur, Gamsu, & Barley, 1999; Bernstein, 2004). Although, surprisingly, Bernstein (2004) found that some people with juvenile diabetes felt that being different made them special in a good way.

Those not living with juvenile diabetes were generally perceived as having a lack of understanding (Bernstein, 2004). This lack of understanding continued even after disclosures were made. Since diabetes was less visible, friends, family, and co-workers often discounted the person's illness or failed to comprehend how it affected him or her, even when informed (Charmaz, 1991). As a result, some felt angry, frustrated, guilty, or disempowered. However, those with less intrusive symptoms and diabetes regimens were less affected (Bernstein, 2004).

Concerns about stigma. Diabetes could reinforce a sense of stigma, further impacting self-concept (Dovey-Pearce, Doherty, & May, 2007). Adolescents and young adults expressed a fear of stigma despite little or no experience of enacted stigma. Fear of stigma seemed more anxiety provoking than actual situations where their difference had become apparent. Participants tried to manage stigma by hiding the visibility of their diabetes and maintaining their identities as healthy people (Schur, Gamsu, & Barley, 1999). When stigmatized, adults with juvenile diabetes became introverted or shy and felt the need to prove their normalcy and avoid attention (Bernstein, 2004).

Young adults seemed to feel psychologically threatened when experiences of discrimination, stereotyping, and non-acceptance were personally interpreted and felt. Externalizing the problem (seeing the source or experience provoking anxiety not in oneself, but rather in the social world) and rationalizing (focusing on cognitive rather than emotional responses and reasoning about the situation) seemed to function as psychological defenses that helped young adults experience negative social experiences as non-personal, and protected them from uncomfortable or distressing emotions (Schur, Gamsu, & Barley, 1999).

Disclosing involved risk, particularly for young adults. It meant revealing feelings and vulnerabilities and risking stigma, rejection, and alienation. Lovers, spouses, friends, and jobs were put in jeopardy. Disclosing could strain relationships and could also mean risking loss of control and autonomy. In disclosing their illness, facts and feelings about the illness affected their self-esteem and self-concept. Talking about illness could reveal potentially discrediting information about self and also often meant revealing hidden emotions. Young adults had to deal with their own emotions about telling as well as their emotions about the responses of those they told. They often developed a plan for disclosing to help protect self, others, and relationships (Charmaz, 1991).

Reasons to disclose and types of disclosure. How and when to disclose illness repeatedly brought up difficult problems. Illness could take on enormous significance for images and definitions of self. Talking about a shocking diagnosis, or invisible impairment, growing impairment, or a terminal prognosis could be frightening and painful. Problems in telling mirrored the meanings of illness for the emerging self. When the meanings were heavy, people often agonized about telling others about their illness (Charmaz, 1991).

Telling others about diabetes was seen as both self-protective and threatening. There were two main reasons that participants talked about their diabetes. The first primary reason was for purposes of safety. This primary involved informing and educating others, especially those who they spent the most time with, about diabetes so that they could provide appropriate assistance if necessary. The second reason seemed to be mainly for the purpose of disclosure, particularly with people whom participants had, or hoped to have, an intimate relationship. Disclosure brought about fears of rejection. However, disclosure also provided participants a sense of relief. Telling others about their diabetes took away the need for stigma management and seemed to act as evidence that they were not controlled by diabetes (Schur, Gamsu, & Barley, 1999).

Participants' stance on disclosure often shifted over time (Charmaz, 1991). Most chose not to openly disclose their diabetes during childhood, but became more open as they became older and as they experienced personal and social acceptance. Those who felt some level of personal and social acceptance about having diabetes were more likely to disclose. Those who were encouraged to disclose by their parents and felt accepted by their peers at a young age said that they had always been open about disclosing their diabetes with others (Bernstein, 2004).

Two primary ways of disclosing were protective disclosing and spontaneous disclosing. With protective disclosure, participants controlled how, what, when, and who they disclosed to. With spontaneous disclosure, participants openly expressed self and unfiltered emotions with little or no control over how, when, where, and whom they told (Charmaz, 1991).

Kelly and Field (1996) found that people maintain private and public accounts of chronic illness. Public accounts are typically geared towards presenting a social identity that is healthy, comfortable, and socially acceptable to others. Most public accounts are aimed at directing attention away from the potentially stigmatizing nature of illness, repairing or overlooking social faux pas, covering up misunderstandings, and generally making social interactions work. In contrast, private accounts arise out of bodily experiences, including experiences of pain and socially unacceptable aspects of body experience. Public accounts are tested when the body intrudes into interaction in ways that others cannot overlook or ignore. The intent of this thesis was to get a picture of young adult's private and personal accounts of self in illness.

Preserving self and minimizing difference. In order to contain the sense of being different, participants developed a "normal" or valued identity that was relatively independent of diabetes. Participants' self-protective strategies appeared to be oriented towards minimizing the experiences of difference (Schur, Gamsu, & Barley, 1999).

"Packaging" and "passing" were two ways of containing illness, preserving self, and managing concerns about stigma. Packaging means presenting the public, and sometimes the private self, as separate from illness. According to Charmaz (1991), defining one's physical status as a "condition" rather than an "illness" was one way of conceptually packaging. Many participants saw themselves as relatively healthy despite having some ongoing symptoms. For these participants, the term "illness" carried with it the status of being sick, allowing closer surveillance by medical professionals, and sometimes taking on a patient role. "Illness" carried with it connotations of current, serious, and incapacitating symptoms. By not defining it as an illness, participants attempted to separate it from their lives and self-concepts.

"Passing" means functioning without others detecting their illness or its effects. Participants attempted to pass because they believed their illness might have been counted against them or because their illness could bring them special privileges out of pity or concern. Passing depended on concealing symptoms and presenting oneself as if unimpaired. They may have acknowledged their diagnosis but hid its implications in order to avoid exposing infirmity. Passing depended on competent performances at crucial times and places. Passing could be risky, as others could be completely unaware of how and when their assistance was needed in the event of a medical crisis (Charmaz, 1991).

On the topic of passing, Kelly and Field (1996) write that how self-concept is affected by chronic illness varies greatly depending on how visible the illness is. Someone with a less visible disease such as well-managed diabetes can have an easier time passing, with only those closest to him or her being fully aware of the difficulties diabetes creates. In such instances, identity is less altered than for those with more visible illness. However, for someone with well-managed diabetes, their sense of self is still intricately tied into the routines attached to managing their condition (Kelly & Field, 1996).

Charmaz (1991) found that packaging and passing were strategies that helped participants contain illness and preserve self. However, the very reasons for keeping illness contained, such as developing a relationship, pursuing a career, or keeping a job, could create the conditions for illness intrusiveness to escalate. Attempts at containing illness could end up magnifying illness and having illness overtake and overwhelm their preferred, previously established self-concept. As an example, one participant decided not to disclose his diabetes at work because he did not want it to define him. During one incident he risked possible residual brain injury or even death from insulin shock rather than ask for minimal help and thereby disclose his illness.

Concealing illness and avoiding disclosure were ways of distancing illness from self and avoiding stigma. When illness was less visible there was more freedom about when to tell. Avoiding disclosure limited the reality of illness to self and for others and made it easier to claim other identities than illness. To the extent that concealing and avoiding disclosure worked, participants were able to limit stigma and support preferred images of self. Participants often chose not to grant illness the legitimacy to shape their lives and self-concepts, nor did they wish to exploit their illness to their advantage (Charmaz, 1991).

We have looked at ways that those living with chronic conditions have worked to limit the visibility of their condition in order to maintain an identity that is not defined or limited by it. We now briefly look at some gender differences when it comes to incorporating diabetes into identity.

Gender differences. Williams (1999) found that gender has a major impact on how adolescents manage their diabetes. Boys and girls differed as to whether or not they assimilated diabetes into their identities. Adolescent boys in the study often aimed to make their disease publicly invisible and were unlikely to perform injections in public settings, such as at school. All of the girls in the study incorporated diabetes into their identities to a greater or lesser degree. In contrast, nine of the 10 boys interviewed chose to manage diabetes by making it as small a part of their lives as possible, particularly in the "public world."

It appeared that for most of the adolescent boys interviewed, diabetes was seen as something to be hidden because of its potential to threaten their status within masculine hierarchies. Boys in the study tended to keep a strict routine in their diabetes regimens and lives, which helped them "pass" in public. Girls tended to have more flexibility in their daily routine and sometimes took this flexibility further than recommended by health professionals, which resulted in only moderate control of their diabetes (Williams, 1999).

Williams (1999) suggests that, in their ways of managing diabetes, adolescents should be seen as acting rationally within the confines of their gendered identities. These findings suggest that young adult men and women may differ in how they integrate juvenile diabetes into their self-concept.

In this section we have looked at loss of self in chronic illness, intimacy and social support, and disclosure and stigma management. We have highlighted a number of psychosocial demands that can work together to alter self-concept for young adults living with this condition.

Experience and Personal Formation

Now that we have covered some of the psychosocial aspects of life with juvenile diabetes, we move on to discuss ways that young adults experience and are formed by their condition. Information is covered under the following headings: good days and bad days, finding health in illness, adjusting and transcending, and being shaped by juvenile diabetes.

Good and bad days. Charmaz (1991) found that people experienced chronic illness in three primary ways: as an interruption, as intrusive, and as immersion. Each way of defining and experiencing illness had implications for self that were revealed when people were forced to live with their ongoing illness and disclose it to others.

Experiencing illness as an interruption meant seeing it as a temporary disruption on the way to recovery. Illness was experienced as intrusive when it placed ongoing demands that required continued attention, allotted time, forced accommodation, and when symptoms permeated routine activities and interrupted the rhythm of the day. People experienced immersion in illness when illness threatened to take over their lives and consume them.

People experienced "good" days and "bad" days depending on the intrusiveness of their symptoms. A "good" day allowed for a planned schedule, whereas a "bad" day forced attending to immediate needs. On a good day, illness remained in the background and people had a sense of being in character, or being the self that they recognized and acknowledged. They had the opportunity to be the people they wished to be. Earlier questions about present self, doubts, shaken confidence, and fears about the future receded into the background and were often forgotten. On bad days the intrusiveness of illness increased. Bad days elicited anger and frustration, often at self, because they did not allow people to be their preferred selves. In those moments or days, the self that was experienced bore little or no resemblance to the "real" or "ideal" self the person held. Hence the expression: "I'm not myself today" (Charmaz, 1991).

Finding health in illness. People can experience health in chronic illness. The positive potential model of health states that one has the potential to live a healthy lifestyle despite chronic conditions. Health is not the absence of illness, nor is health care merely the treatment of disease. Rather than focusing on trying to attain perfection or control over diabetes, the focus is on engaging one's strengths and resources and rising to the challenges of chronic conditions and one's immediate circumstances (D. Wong, personal communication, June 7, 2008).

Having a chronic condition can lead to making healthier long-term lifestyle choices. Murray, Pullman, and Rodgers (2003) found that middle-aged adults perceived illness as causing destruction and struggle. However, illness could also lead to healthy lifestyle choices and better self-care. Despite physical illness people could still be defined as healthy depending upon their orientation, lifestyle, attitude, and social engagement. Experiencing health in illness seems to be a matter of perspective and choices.

Wennick and Hallström (2007) found that children with juvenile diabetes identified as "being healthy yet invisibly ill." Needing insulin and having insulin reactions made children with diabetes feel as if they had an illness. Paradoxically, children also felt healthy, since diabetes had become a routine part of their lives. They did not consider themselves as diabetics or as ill but as functioning normally, and therefore almost completely healthy. Children with diabetes described how they had become so confident with injections that they sometimes forgot they had diabetes. At the same time they were well aware that they would not survive unless they followed their diabetes management regimen.

These findings suggest that people with juvenile diabetes could experience some flux in their self-concept depending on how intrusive their symptoms were at the time. This thesis takes the existing research a step further to explore how ways of experiencing illness affect self-concept.

Adjusting and transcending. In 1982, Bury proposed that being diagnosed with and living with chronic illness creates a "biographical disruption" for the individual; the ways one see oneself and the ideas that one has about the future are challenged from the moment of diagnosis. Expectations and plans that the individual holds for the future have to be re-examined. The development of chronic illness can lead to a fundamental re-thinking of one's biography and self-concept. The reality of physical symptoms can cause one to re-evaluate the relationship between the now-visible disease and selfhood.

Conceptualizing disease as separate from self relieves some of the burden of responsibility that the illness places on the person. Some use medical knowledge as a way of separating the disease from self. However, strict separation of disease and self, or for that matter disease and social relationships in general, is precarious. There is an uneasy balance that is struck between seeing the condition as an outside force and yet feeling its invasion into all aspects of life. As much as one might try to hold the disease "at a distance," it is still inextricably linked to the person, affecting all areas of life (Bury, 1982).

Charmaz (1995) found that adapting to chronic illness brought to light several tensions in opposition such as: self vs. body, struggle vs. surrender, struggling with vs. struggling against, and bodily control vs. loss of function. These tensions came to light with each disruptive episode or with deteriorating social conditions. The process of adapting and resolving these tensions happened repeatedly as people experienced new losses and the ups and downs of their condition (Charmaz, 1995).

Adapting to serious impairment took people on an odyssey of self. The body with chronic illness became unfamiliar. An altered body posed new constraints that required careful scrutiny and attending to time, space, movement, and other people in new ways. By struggling with illness while constructing their lives, people with chronic illness felt that they could regain the control that was lost over their bodies and their lives. As they adapted to bodily changes and regained control, what was once foreign became familiar (Charmaz, 1995).

Samson (2006) looked at how young adults, ages 18 to 25, adjusted to life with juvenile diabetes. She found that young adults described life with juvenile diabetes as a journey. Some moved quickly to accept and integrate diabetes into their lives, while others moved more slowly, depending on their coping skills, barriers, knowledge, and support. They showed a wide range of abilities to integrate diabetes into their lives and cope with their condition. Some were able to move from shock, biographical disruption and feeling "different" to integration of diabetes into their lives and feeling "normal" (Samson, 2006).

Schur, Gamsu, and Barley (1999) found that, in learning to live with diabetes, adolescents and young adults seemed to reach a place of acceptance in their relationship with diabetes. Diabetes had been depersonalized and was understood as something that just happened, and they had to deal with it. Acceptance was an important part of coming to terms with the challenges of diabetes. From these two studies it seems that a person's relative adjustment to diabetes may influence how it affects her or his self-concept.

Chronic illness had an effect on self-concept that ranged from loss to transcendence, and often somewhere in between. With transcendence, the self was much more than the body or illness. Transcendence implied self-acceptance, reevaluation, and renewal. Transcendence required making choices and taking action. Loss and transcendence were dynamic states of being. An individual could experience both. Both loss and transcendence hinged on autonomy. For those who gained a sense of autonomy, their stories could shift from stories of loss to stories of transcendence. Subsequently, they could look back on the past and reconstruct turning points into stories of a changed, more aware self. Chronic conditions could become an opportunity for an individual to see a new aspect of his or her self. Illness became valued when it was seen as a path to self-knowledge. Some said they would not trade their experience of illness because it made them the person they had become (Charmaz, 1991). However, those who were in the midst of health crises were less positive about their experience and spoke instead about loss and heightened self-concern (Charmaz, 1983).

Transcendence was somewhat of a fragile state partly because it depended on the person both experiencing and affirming it. Participants could feel that they transcended their condition only to plummet into loss at a later time. Nevertheless, transcendence was possible for participants who had time for reflection, found the tools to do so, and defined essential qualities of self as distinct from their bodies (Charmaz, 1991).

From these findings it is clear that chronic conditions can impact self-concept as people experience loss, adjust to new circumstances, and at times, transcend those circumstances. This study aims to take these findings further by exploring how experiences of loss and transcendence influence self-concept.

Being shaped by juvenile diabetes. A number of characteristics were thought to have developed as a response to living with diabetes such as being disciplined, cautious, regimented, or vigilant; skilled in organization and planning; feeling greater appreciation for health and being more health conscious; being proud of surviving so long; developing inner strength; and feeling greater appreciation for life (Bernstein, 2004). Charmaz (2002) found that many of those interviewed said that they learned to become more giving. Women talked about becoming more compassionate (Charmaz, 2002). As participants adjusted, something that was initially devastating could become a path to developing confidence, compassion, and competence (Charmaz, 1991). Ways that self-concept is shaped by living with juvenile diabetes needs to be explored further.

Becoming organized. The problems with which people struggled were often existential, but their solutions were often organizational. Becoming more organized was one way of keeping illness contained and minimizing illness intrusiveness (Charmaz, 1991; Wennick & Hallström, 2007). Planning reduced anxiety and helped with diabetes management (Wennick & Hallström, 2007). Developing a routine often became so commonplace that participants no longer thought of it as structuring their lives around caring for illness. Before becoming ill, many participants had not thought about organizing their day, but, afterwards, managing illness became a consuming part of their day. Managing illness often hampered spontaneity, as travel or any change in routine required more planning (Charmaz, 1991).

Learning to effectively organize required fitting self-care activities within hopes and plans. This often meant scaling down hopes and former expectations of self and planning around personal limitations. The trade off for putting in the effort to maintain a structured routine was gaining a sense of control over illness (Charmaz, 1991). Not surprisingly, many of Charmaz' examples about the importance of keeping routine were people with juvenile diabetes, which requires a structured lifestyle for survival.

Seeking balance. A meta-analysis of qualitative studies conducted by Paterson, Thorne, Crawford, and Tarko (1999) concluded that achieving a balanced life-style was the central construct for people with diabetes. Living with juvenile diabetes was seen as a threat to life's equilibrium and a healthy lifestyle (Kyngas & Barlow, 1995). Adolescents and young adults felt that diabetes had to be in balance with lifestyle in order for diabetes to not take control of their lives (Schur, Gamsu, & Barley, 1999). Successfully adapting meant living with, rather than for illness (Charmaz, 1995). Finding balance required a certain amount of practical attention to self-care tasks. Emotionally it involved the use of psychological defenses. There seemed to be an optimal balance between worrying about diabetes so that it was given sufficient attention and using denial to minimize negative emotional consequences (Schur, Gamsu, & Barley, 1999).

Finding balance was a process of trial and error. They had to learn to juggle needs and responsibilities to keep up with others, such as those in the workplace who did not have the added burdens of illness and regimen. Paradoxically, some discovered that their developed ability to plan, organize, and make trade offs allowed them to outshine their peers. Those who were able to invent ways to handle tasks that posed major barriers and made trade-offs to preserve valued pursuits often gained a sense of pride and accomplishment (Charmaz, 1991).

Seeking control. A core concept that emerged for adolescents living with juvenile diabetes was the issue of control. Adolescents felt that diabetes limited, or controlled, their freedom and independence (Kyngas & Barlow, 1995). Adolescents and young adults feared that diabetes would reduce the control and efficacy that they experienced in their lives, but that instead diabetes would control them (Schur, Gamsu, & Barley, 1999). Chronic conditions threatened control over self and situation and brought about uncertainty. Working at managing their condition was one way of gaining more control over their lives (Charmaz, 1991).

Managing their relationship with diabetes seemed to be at the core of adolecent's and young adult's experience of living with diabetes. Loss of control of diabetes was associated with feelings of vulnerability and worry. Control over diabetes, both practically and psychologically, was seen as an essential in order to protect oneself. Taking control of diabetes involved taking practical steps to manage diabetes and keep it in its place so that they could get on with the rest of their lives (Schur, Gamsu, & Barley, 1999).

Facing risk and gaining maturity. Chronic illness disrupts the structures of every day life and the forms of knowledge that underpin them. It involves a recognition of pain and suffering, and the possibly of death, which are normally only seen as distant possibilities or as the plight of others (Bury, 1982).

A central challenge for young adults with juvenile diabetes appeared to be coming to terms with risk and mortality (Dovey-Pearce, Doherty, & May, 2007). Engaging with the long-term consequences of diabetes and with personal mortality was likely to make normal development all the more complicated, as the awareness of having an imperfect body was not likely to fit in well with adolescent or young adult life (Dovey-Pearce, Doherty, & May, 2007; Sayer, Hauser, Jacobsen, Willett, & Cole, 1995).

For many, the growing awareness of the potential for long-term complications was experienced as a constant threat (Sayer, Hauser, Jacobsen, Willett, & Cole, 1995). Diabetes was threatening practically with respect to the time and hassle of self-care tasks, and emotionally with respect to a fear of being overwhelmed by the vulnerability and distressing emotions associated with having a life threatening condition. Adolescents' and young adults' experiences seemed partially organized around efforts to manage emotional and practical threats from diabetes (Schur, Gamsu, & Barley, 1999).

Diabetes seemed to vary in its salience as a threat. At diagnosis and/or other times when the affects of diabetes were particularly adverse, adolescents and young adults described a realization or increased awareness that diabetes was serious and permanent. They seemed to feel powerless to change the situation. The desire to know why they had developed diabetes seemed particularly threatening to self when participants asked themselves what they had done to deserve diabetes (Schur, Gamsu, & Barley, 1999).

Adolescents and young adults developed interrelated self-protective strategies to manage diabetes related threats. They identified an inherent vulnerability associated with having juvenile diabetes and felt that diabetes had to be coped with in order to avoid distressing emotions (Schur, Gamsu, & Barley, 1999).

The responsibilities of managing diabetes caused young people to mature. Siblings of children with juvenile diabetes perceived their brother or sister to be more mature than their friends of the same age but, at the same time, felt they had to show consideration and sympathy for them due to their illness (Wennick & Hallström, 2007). Adolescents and young adults expressed that they had become more mature and responsible as a result of living with juvenile diabetes (Schur, Gamsu, & Barley, 1999).

Further research is needed to address how dealing with ongoing threats and risks related to diabetes influences self-concept and personal formation for young adults.

Summary

In this review of the literature, we have looked at the unique aspects of life with diabetes in childhood, adolescence, and young adulthood. This review began with core studies about self-concept and life with juvenile diabetes, setting the stage for the research question. Then we reviewed the intrapsychic and psychosocial aspects of life with juvenile diabetes. Finally, we concluded with ways of experiencing and being personally formed by having juvenile diabetes.

There are several commonalities across these studies. Young adults living with diabetes have the same developmental demands as other young adults, but they also face the additional challenge of learning to manage and live with their condition. The transition from child to adult care poses specific difficulties. Some disengage from diabetes care in young adulthood and their diabetes management suffers, affecting other areas of their lives as well. A number of studies have explored psychological vulnerabilities that are common for those managing life with diabetes, including increased incidences of depression, anxiety, and disordered eating. Several studies have explored self-concept and identity in chronic illness. There are similarities between how various chronic conditions such as multiple sclerosis, cardiovascular disease, cancer, lupus erythematosus, arthritis, and juvenile diabetes can influence self-concept. Juvenile diabetes is one in a myriad of health conditions that can cause a shift in how one understands self.

Across these studies, one sees that chronic health conditions and particularly juvenile diabetes bring specific hardships and difficulties that shape and influence aspects of self. However, people chose not to let their diabetes define them. It seems that people of all ages respond to the pressure that diabetes places on their self and interpersonal relationships by striving to keep diabetes at the periphery of their self-concepts.

Depending on the intrusiveness of their symptoms, this is more or less possible on any given day.

There are several limitations across these studies as well as areas that require further research. Very few studies related to the lived experience of young adults with juvenile diabetes have included emerging and young adults in their sample. Of the studies that are available, the focus has been predominantly on children and adolescents. The young adult period falls outside the primary focus of both pediatric and adult medicine, and, as a result, the specific needs of people with diabetes going through this transitional phase have received less attention (Anderson & Wolpert, 2004).

Findings so far are limited to studies that examine self-concept and identity as one aspect of the larger experience of living with diabetes. Key studies are predominantly from the United Kingdom and the United States. A Canadian perspective on self-concept and life with juvenile diabetes is needed because of the differences between Canadian and American health care systems. This study provides a more detailed look at young adults' experiences of self-concept and juvenile diabetes from a Canadian perspective.

Many of the previous studies came from a medical perspective and were written by medical professionals interested in diabetes management. This study is unique in that it explores how participants create and share meaning in their experience of living with juvenile diabetes from a counselling psychology perspective. It helps address a gap in the literature by focusing on self-concept and diabetes, rather than looking at the experience of living with juvenile diabetes as a whole.

Chapter 3: Methods

Design of the Study

Qualitative semi-structured interviews were used to explore young adult's self-concept in relation to living with juvenile diabetes. Descriptive phenomenology is personal, interactive, open, and flexible. It is ideal for gaining an understanding of the lived experience of sense of self and juvenile diabetes in young adulthood.

In descriptive phenomenology, the focus is on how reality is understood and constructed by participants (Streubert & Carpenter, 1995). Post-positivists recognize that the theories, hypotheses, and background knowledge held by the investigator can strongly influence what is observed. Therefore, it is important for the researcher to remain as objective as possible by observing in a dispassionate and impartial manner and by following prescribed procedures rigorously. Alternatively, constructivist researchers acknowledge that values are never fully independent from the research. The researcher and the participants are interlocked in an interactive process, each influencing the other. Constructivists therefore opt for more personal, interactive modes of data collection (Mertens, 2005). Descriptive phenomenology strives for objectivity by using methods such as phenomenological reduction, suspending beliefs, assumptions, and biases as much as possible about the phenomenon under investigation in order to maintain rich, thick descriptions of the phenomenon under investigation (Streubert & Carpenter, 1995).

Qualitative research is essentially a way of describing and analyzing the behaviour and culture of people from the point of view of those being studied (Bryman, 1988). Qualitative research applies to a broad range of types of interviews, varying in flexibility, that are used to uncover the aspects of "what," "why" and "how" from the perspective of the participant (Samson, 2006). It allows the wholeness and complexity of the phenomenon to be studied and represented, rather than trying to delimit people's experience into predetermined categories derived from existing theory (Orford, 1995).

Due to the limited prior research and existing theory in the area, the heterogeneity of findings, and lack of conceptual clarity in the literature, a qualitative method is the most appropriate approach in the current study. Qualitative approaches can make a useful contribution to the evidence base, especially when existing research findings are heterogeneous (Dovey-Pearce, Doherty, & May, 2007).

Descriptive phenomenology as a research method is a rigorous, critical, systematic investigation of phenomena that is qualitative, contextualized and interactive (Streubert & Carpenter, 1995). It seeks to explore and describe phenomena as they present themselves in the lived world in order to find the meaning of the phenomena. Descriptive phenomenology is particularly concerned with the details that make up commonplace, or everyday experiences (van Manen, 1997). It is a discovery-oriented method that requires an attitude of openness to let the unexpected meanings emerge (Giorgi, 1997). This method allows for the research questions to develop and change as the study progresses (Mertens, 2005). Descriptive phenomenology proposes that individuals interpret their own world to make it meaningful and that these interpretations are the participant's social reality. The goal is to understand participant's interpretative processes in order to understand their experiences. Phenomenological research emphasizes and attempts to understand and describe the individual's subjective experience. The focus is on understanding how participants create and understand their own experiences (Mertens, 2005). Attention is paid to silences in the interview, for instance, because silences can point to what participants usually take for granted as self-evident (van Manen, 1997).

Descriptive phenomenology is a strong research method because it allows for vivid and rich clarifications of the meaning and significance of the journeys of young adults with juvenile diabetes. The deep process of immersion allows the researcher to minimize the distractions that can emerge from theory, and thus to clarify what theory, research, and clinical perspectives are teaching us.

Participants

The inclusion criteria was as follows: between the ages of 19-29, self identified as having juvenile diabetes, diagnosed between childhood and adulthood, living in Canada, and English speaking. An attempt was made to strengthen diabetes research by including young adults from diverse ethnic and social backgrounds. Purposeful sampling was used to recruit an equal number of male and female participants to reflect the experiences of both genders. An effort was made to recruit both participants who were managing well and those who were struggling with their diabetes.

Demographic information was collected, including sex, age, marital status, number and ages of children, ethnic background, age when diagnosed, method of treatment (insulin pump, insulin injection, or other), additional serious medical, physical, or psychological conditions, parents, siblings or family members with juvenile diabetes, level of education completed, occupation, and place of residence. These demographics provided a context for participants' stories. See below for summaries of the background of research participants.

Recruitment

Participants that had direct experience related to the focus of the study were recruited purposefully using snowball sampling. With this form of recruitment, the researcher starts with key informants that are viewed as knowledgeable about the phenomenon being studied. These key informants are then asked to recommend others that have first hand experience with the phenomenon. In this way, a relatively small list builds into a larger list of potential participants (Mertens, 2005).

Key informants were gathered from personal contacts and from participants at support groups and conferences such as the Canadian Diabetes Association's Diabetes Expo and World Diabetes Day Celebration, the Canadian Diabetes Association "Branching Out" event for young adults with juvenile diabetes, and the Abbotsford Children with Diabetes Family Support Network, an informal support group for children and families. See Appendix A for the recruitment script.

Contacts were asked if they knew young adults with juvenile diabetes that might want to participate. They were given a recruitment flyer outlining the study and an extra one if there was anyone they knew that they thought might want to participate. Contacts were emailed a description of the study, asked to participate, and encouraged to forward the invitation to others that might want to get involved (Appendix B).

Researcher's Self-Description

I was diagnosed with juvenile diabetes at 18. As a young adult with juvenile diabetes I am close to the research topic. Being diagnosed and learning to live with the challenges of juvenile diabetes reshaped how I saw myself. The characteristics, attributes, attitudes, and sentiments that I had about myself were called into question as I attempted to integrate diabetes into my life. It changed my lifestyle, outlook, self-perceptions, relationships, and ideas of what I thought was possible for me. Learning how to manage my condition forced me to become more mature, responsible, structured, aware of my own health, and sensitive about the health concerns of others. At times, not being able to master diabetes made me feel vulnerable. After diagnosis it took some time to regain my balance as I adjusted to a new way of living life.

I wanted to explore how other young adults adjusted to life with diabetes and how it shaped their outlook and self-concept. I was sensitive to the negative aspects of life with diabetes: self-esteem and identity concerns, not wanting to accept a sick role, difficulty accepting the intrusiveness of diabetes in my life, and feeling frustrated when I was not able to manage my diabetes. I wanted to explore how other young adults adjusted, coped, and even thrived in their circumstances. I wondered if adjusting to life with juvenile diabetes altered their self-concept. I wanted to explore how living with juvenile diabetes shaped their sense of self in positive, negative, or neutral ways.

Having an insider's perspective had several advantages. I was able to ask questions that helped participants talk about the psychological aspects of diabetes, whereas someone less intimately familiar with the condition might focus on trying to understand the definition and treatment of juvenile diabetes. Being able to understand related medical terminology minimized confusion and helped keep the interviews focused on the research question. Being personally familiar with juvenile diabetes helped me to establish rapport with participants early on.

I took a reflective stance throughout the research process; I constantly took a step back to reflect on the meanings participants gave to their thoughts, words, or actions in order to avoid misinterpretations. As the researcher, I took into account that each person's story was unique and that each individual brought his or her own strengths and weaknesses, copings skills, and personal characteristics to the task of dealing with a chronic condition. I was looking for common threads of experience that tied this diverse group of young adults together.

Sources of Data Collection

Data was collected from participants' oral descriptions, personal reflections, and relevant accounts from the literature and previous research regarding self-concept and juvenile diabetes. Semi-structured interviews allowed participants to define and explore issues that were important to them in their own words. Questions were based a review of the literature and on personal reflections regarding life with diabetes. Interview questions were developed as a guide in order to become more sensitive to aspects of the phenomena that were important for participants.

Interviews were audio recorded, with consent, and transcribed to form the data for analysis. On completion of the study, each participant was offered a summary of the study. Background and screening information was gathered prior to the interview through the Background Questionnaire found in Appendix C. Interview questions are found in Appendix D.

Analysis

Descriptive phenomenological analysis cannot be formalized into a series of technical procedures. However, van Manen (1997) did attempt to clarify the process as an interplay between six research activities: turning with commitment to an "abiding concern" or phenomenon of interest; investigating the experience as it is lived; reflecting on essential themes; describing the phenomenon through writing and rewriting; maintaining a strong, oriented stance toward the question; and balancing the research context by considering parts and the whole.

In descriptive phenomenological research, the process begins with a description of the phenomenon, often through an interview. The purpose of the interview is to have the participant describe in as faithful and detailed a manner as possible, an experience of a situation that the researcher is investigating. The participant's role is to share his or her lived experience of the phenomenon. The transcript of the interview becomes the text or raw data of the research. Once the researcher has the transcription there are four main steps that are used in analysis (Giorgi & Giorgi, 2003a).

The first step of analysis is reading for a sense of the whole. Once the researcher has transcribed the interviews, the description is read in its entirety in order to gain an overall sense of the description before moving on to the next step of the analysis. An attitude of scientific phenomenological reduction is taken (Giorgi & Giorgi, 2003a). This means taking an attitude that focuses on experience rather than being concerned with the existence of what is experienced. It is a reduction because the investigative field is reduced to the psychological. This focus on the psychological aspects allows the researcher to reflectively describe the meanings and psychological performances of lived experiences (Wertz, 2005).

The second step involves rereading the entire description and demarcating spontaneous shifts in meaning, or "meaning units," in the text, while keeping a psychologically sensitive interest in the phenomenon under investigation. The text is broken down into these smaller meaning units in order to facilitate a more thorough analysis. It is important to note that there are no "objective" meaning units, as these meanings are tied to the perspectives of the researcher. They are used as practical outcomes to aid in the analysis and do not need to be consistent between researchers in order to be valid (Giorgi & Giorgi, 2003a).

The third step involves transforming meaning units into psychologically sensitive expressions. The goal at this step is to produce meaning discriminations that are psychologically relevant with respect to the phenomenon being researched. The researcher, still within the scientific phenomenological reduction, transforms the participant's everyday expressions into expressions that highlight the psychological meanings lived by the participant. This step requires the researcher to use free imaginative variation and involves making factors that are implicit in the text more explicit (Giorgi & Giorgi, 2003a).

In this stage the researcher needs to avoid two potential errors. Firstly, the researcher needs to pursue the meanings with respect to the participant's personal lives only to the extent that they clarify the context in which the psychological phenomena manifest themselves. Secondly, the researcher needs to avoid using familiar psychological terms from the literature in order to avoid making interpretations based on associations with pre-existing concepts (Giorgi & Giorgi, 2003a).

The last step is the determination of the structure. Based on the transformed units of meaning, and while still using scientific psychological reduction, the researcher uses the transformed meaning unit expressions as the basis for expressing the lived experiences of participants (Giorgi & Giorgi, 2003a). In other words, the researcher synthesizes the reflections and insights into a consistent statement that expresses the psychological structure of the experience (Wertz, 2005). The structures obtained are not universal, but only general because of the role of context. Ideally, the research organizes the data under one coherent structure. However, it is important not to force the data into one structure if it does not fit. Several structures may be necessary to account for the lived experiences of participants (Giorgi & Giorgi, 2003a).

The purpose of the preceding stages is to establish a structure of the lived experience. Once this structure is established, the researcher conducts poststructural analysis. In poststructural analysis, a myriad of details are reduced into their essential components, thereby deepening the essential understanding of the phenomenon. In this way, the researcher can get to the essence of the experience as lived by those most familiar with the phenomenon. The structure is used to help understand the empirical data in a more systematic and methodical way. Key components of the structure are used to clarify variations found in the data. In order to move beyond the rich descriptions of participants, psychological dimensions within the participants' descriptions are highlighted, thematized, and made explicit. Both implicit and explicit factors are thematized, as the lived experience of the phenomenon may differ from the psychological everyday understanding of it. Predominant psychological terms are avoided because they may or may not accurately reflect participants' lived experience of the phenomenon. New psychological phrasing is used to describe the essences of experiences in order to refine, clarify, and further understand the phenomenon in a fresh way. Respect for the complexity of experience and refinement of psychological understanding are two consequences of phenomenological analysis (Giorgi & Giorgi, 2003a).

Rigour / Validation

In phenomenology, there are two procedures called epochés, which are ways of protecting against short-circuiting or biasing the description. Bracketing, the first epoché, involves setting aside prior scientific assumptions in order to gain access to the things themselves (Wertz, 2005). It is used to avoid the common error of subsuming later experiences under the rubrics of earlier ones. In order to help the researcher to be fresh and open to the concrete experiences being researched, knowledge about the phenomenon that comes from other instances or indirect sources is bracketed off. The researcher may be aware of these other sources but chooses not to engage them so that there can be no influence from them on the phenomenon being studied. Bracketing other instances of the same phenomenon may help the researcher to notice different nuances or new dimensions of the phenomenon (Giorgi & Giorgi, 2003b).

The second epoché is what Husserl referred to as the "the epoché of the natural attitude" (Wertz, 2005). The existence and validity of human situations are bracketed off in order to allow the shift from naive, straightforward encounters to a reflection on how the life-world presents itself, that is, to its subjective performances and constitutive meanings. This allows the researcher to recollect his or her own experiences and to empathically reflect on and enter into the lived experience of other persons in order to understand the meanings of the world from their first-person point of view. Rather than focusing on issues concerning the existence of what is experienced, the researcher focuses on the experience itself. This is referred to as "the phenomenological psychological reduction" because the investigative field is reduced to the psychological. This allows the researcher to reflectively describe the meanings and psychological performances of lived-through situations (Wertz, 2005).

Ethics

Participants may have found aspects of the interviews distressing if they had not previously reflected on how diabetes affected their self-concept. They were given a list of local counselling resources if needed and were given the opportunity to take breaks in the interview as needed. Participants may have gained self-awareness and insights from sharing their stories and reflecting on their experiences. Findings may have helped them realize their strengths and resources so that they could better face the challenges of chronic illness. Reading about others' experiences could have also enhanced social support.

The Trinity Western University Research Ethics Board approved this study (REB file number 09G11). See Appendix E. Responses were confidential. Participant's names did not appear on the transcriptions and answers were coded in such a way that no single individual could be identified in the results of the study. All the information provided by participants through the interviews was only used for the purposes of this study. Interview recordings were kept for analysis and destroyed at completion of the study. Anonymous transcripts of interviews were kept for future research purposes. Transcribed data was stored in a locked file cabinet. Specific references that could be used to identify individual participants were left out when reporting findings.

Participant Descriptions

Participants were Caucasian between the ages of 19 and 29. Some were diagnosed in childhood (ages 12 and under), some in adolescence (ages 13 to 19), and others were diagnosed as adults (over 19 years old). All had completed some higher education.

Tiffany. Tiffany was 23 years old at the time of the interview, single, attending university, and had no children. She struggled with diabulima, an eating disorder in which one manipulates insulin to lose weight. She had no other major health issues and no family history of juvenile diabetes. Tiffany was diagnosed in adolescence and took insulin injections. She was a motivated, positive, and inspirational activist who had a lot of compassion for people in poverty who could not afford adequate diabetes care. Her family was very supportive of her activist role. She had gone on two major athletic expeditions to raise funds for juvenile diabetes education, support, and research to find a cure.

Josh. Josh was 19 years old at the time of the interview. He was in first year of university, working, single, and had no children. He had no health issues besides juvenile diabetes and no family history of his condition. He was diagnosed in childhood. His best friend, who happened to have juvenile diabetes, was the first to recognize the symptoms and told him to get it looked at. Josh used an insulin pump. He was an energetic, outgoing, healthy looking young person with dreams of traveling around the world. He consciously chose to focus on the positive rather than dwelling on the negative aspects of life with juvenile diabetes.

Ashlyn. Ashlyn was 25 years old at the time of the interview. She had a positive outlook on life and was outdoorsy, athletic, motivated, and driven. She was diagnosed when she was 12 years old. She was in a long-term relationship and had no children. She had no family history of juvenile diabetes and no other major health conditions. Ashlyn had completed a degree and worked in childcare. She used an insulin pump. As an athlete she participated in long distance running, half marathons, and a triathlon. She also participated in two major mountain climbing expeditions to raise awareness and funds for research to find a cure. She found meaning in inspiring others to overcome the challenges of juvenile diabetes. Her experiences helped her develop confidence to meet and educate others about her condition.

Tim. Tim was 19 years old at the time of the interview. He attended university, was single, and had no children. He had no major health concerns besides juvenile diabetes. He used an insulin pump to manage his diabetes. Tim was diagnosed when he was 11 years old. He had an uncle with juvenile diabetes. Going to diabetes camp as a child was meaningful to him because he had people around him that knew what it was like. Being able to joke around with other guys who understood his experience was therapeutic. Tim's easygoing temperament was evident in how he did not focus on his condition or let it define him.

Andrew. Andrew was 23 years old at the time of the interview. He was single, had no children, and no other major health concerns. He had no family history of juvenile diabetes. He managed his diabetes with insulin injections. Andrew was diagnosed at the age of 12. He was a student and had completed a Bachelor of Arts degree. He described himself as a competitive person. He pushed himself academically and did not want to slow down. He was social, outgoing, enjoyed travel, and had been on several mission trips. His Christian faith was very important to him. Three years prior to the interview he experienced what he described as partial healing from his juvenile diabetes. Since that day his insulin requirements had been gradually dropping. He looked forward to the day he would either be completely healed of diabetes, either in this life or one day in heaven. He said things as he saw them and did not try to make things sound easier than they were. His friends and family were a big support for him. Joking about his diabetes, especially with his guy friends, kept him smiling.

Steve. Steve was 27 years old at the time of the interview. He was a professional driver and had completed a Bachelor of Art Degree. He was in a long-term relationship, had no children, and was looking forward to marrying and starting a family. Steve self identified as having juvenile diabetes. However, he later shared that he was diagnosed with adult onset diabetes when he was 21 years old. His interview was kept in the study because he self-identified as being part of the juvenile diabetes group. Steve was similar to other participants in that he was diagnosed as a young person and took insulin for an extended period of time. For the first three years Steve managed with insulin injections and for the past three years he managed with diet and pills. He did not consistently take his medication and as a result was sick for extended periods of time. Some days he did not take his insulin or pills and tried to manage with diet alone, only taking medication when he felt very foggy and disoriented. He did not have adequate medical coverage in Alberta and sometimes chose to pay tuition over buying medicine. He had no family history of juvenile diabetes. He was seeing a counselor for addiction issues. Steve did not talk about his diabetes much with others or let it bother him. His girlfriend was a major support for him.

Roberta. Roberta was 24 years old at the time of the interview. She was a married homemaker and had two children. She had completed a Bachelor of Arts degree and was working on further education. Roberta was diagnosed in childhood and used an insulin pump to manage her diabetes. In addition to juvenile diabetes she had celiac disease. She had no other family members with juvenile diabetes.

Olivia. Olivia was 29 years old at the time of the interview. She was a health care professional and outdoor enthusiast. She was single, had no children, and no other serious medical conditions. She had no family history of juvenile diabetes. Olivia was diagnosed as an adult and managed with insulin injections. She did not go through the typical process of being diagnosed, namely entering the hospital with diabetic ketoacidosis, and going through the process of figuring out an insulin regime. The onset of her condition was much slower. For a time her body was still producing some insulin but she was still dealing with serious symptoms. She started on oral hypoglycemics and tried to manage with diet and exercise. She tried various types of oral medications until she got to the point where they were not working and had to go on insulin. Her type of diabetes is referred to as type 1.5 diabetes because it has characteristics of both juvenile and adult onset diabetes. Although she did not have juvenile diabetes, she identified as being part of this group. Olivia was very active in her free time and required less insulin than typically taken by others. She was an inspirational person, participating in many events to educate others and raise funds for a cure.

Chapter 4: Results

The following themes emerged from interviews with participants. Diabetes was part of self and part of life experiences that shaped self-concept but diabetes was not a central, defining aspect of self. Diabetes was part of life experiences that helped participants become more mature, compassionate, proactive about health, in tune with physical status, involved in advocacy, and balanced in their approach to managing diabetes so that they could live life fully and have a good quality of life. The chronic nature of diabetes, the threat of complications, lack of understanding from others and daily hassles of managing the condition were ongoing concerns. Diabetes was a burden that involved constant planning, critical thinking and discipline. Participants chose to have a positive outlook. For many participants, connecting with peers living with juvenile diabetes was meaningful, influential, inspiring, and normalizing. Quotes from the interviews are used to illustrate themes. A diagram outlining findings can be found at the end of this chapter.

Being Shaped by Juvenile Diabetes

Juvenile diabetes was not a central, defining aspect of self. Despite, in some ways, affecting most experiences and activities, juvenile diabetes did not change the participants' core sense of personal identity as students, employees, travelers, friends, family members, or partners. Nor did it affect core self-concept in other aspects of life and relationships. However, having juvenile diabetes indirectly influenced self-concept because it was woven into life experiences and affected people they had met, friends they had made, values, and direction in life, all of which helped form who they had become.

> Through all these secondary channels all these things have come together . . . from being diabetic . . . [you make certain] friends [as a result of having juvenile diabetes] and then [those] friends influence you and influence your values and morals. That's one way that it has affected my life . . . not directly but indirectly. (Josh)

> It's part of who I am because I think it's shaped my personality somewhat . . . with . . . critically thinking, problem solving, communication, being outgoing . . . understanding, being more self-aware. I think that being affected personally by [juvenile diabetes] . . . has shaped who I am. (Olivia)

> On so many levels it's changed my life . . . It's shaped me . . . in every aspect . . . with what I want to do with my life now as far as career, as far as what kind of person I want to be . . . It's shaped my life hugely . . . I don't want to say it's who I am, but it has shaped a lot of who I am (Tiffany)

Not Being Defined by Juvenile Diabetes

Having juvenile diabetes was a biological reality but it did not define who they were just as someone is not defined by her or his eye colour. It was something about which friends, family, coworkers and others were often aware, but it was not how participants primarily described, defined, or identified themselves.

> I never felt a need to, just out of the blue, go and say [I was diabetic] just to explain myself or define myself . . . but, if it came up through conversation, sure . . . Not that I feel that I have to hide it. It's just not necessary to flag it off. It doesn't define me. It's just part of my life. (Olivia)

> It's not really part of who I am. It is who I am . . . I am diabetic . . . I wouldn't say it defines me. (Ashlyn)

> It's a part of me as much as my blue eyes are part of me. It's just the way I am. (Tim)

Juvenile Diabetes Permeated Participants' Lives

Juvenile diabetes was part of everyday life. It permeated the participants' lives and even their thoughts about what could be. They had to bring their diabetes supplies with them everywhere to manage their diabetes, which sometimes meant they connected themselves with those things. For example, Josh joked about being known as "Pump Boy."

> Having just that extra thing to think about that applies to almost every area of my life . . . every activity I'm involved in or thing I want to pursue . . . you can't not deal with it . . . It's just there and must be dealt with . . . or you will be ill, and if you are ill it's even worse than having to think about [it] . . . [It's better to] just put in that little bit of effort. (Roberta)

> I don't bother hiding it . . . It's a part of who I am now . . . There isn't any separating me from it. It's not like I can one day pretend to not be a diabetic and [laugh] not think about it . . . It's with me everywhere I go . . . There isn't something I do where it's not an issue (Andrew)

> I'm always conscious of it as I always have it in the back of my mind. (Olivia)

> I can't really see myself without my pump . . . I don't know if other people would be able to see me without it either. It's always with me . . . more than my cell phone or my wallet or anything. It's never not on me so . . . maybe . . . in that way . . . people would be like, "Oh the kid with the pump" or something like that (Josh)

Separating Symptoms from Self

Symptoms of low and high blood sugar were seen as reflective of the condition and not of participants themselves. When they had low blood sugar they had symptoms such as feeling confused, irritable, inarticulate, and distracted. When they had high blood sugar they had symptoms such as feeling discouraged, weak, and fatigued. Alterations in mood and energy due to blood sugars and body chemistry affected relationships, productivity, and many other aspects of their lives, but these transient altered states due to blood sugars did not change participant's core notions of self. Some aspects of managing diabetes felt unnatural and not like themselves, such as eating because of hypoglycemia instead of hunger and having to eat quickly to recover from a low.

> I know if I'll go through a lot of highs and lows in a couple days I'll feel drained and that will affect my mood . . . That affects our body chemistry . . . We have no control over that, whether you're having a couple of crappy days, you're just going to feel down and that's going to affect everything . . . your relationship with others . . . and everything that you do . . . With myself, if I don't feel as energetic, it just brings me down (Olivia)

> The other day I was driving home from work and . . . I had low blood sugar . . . and I almost started to swerve into the other lane . . . I walked into a Seven Eleven . . . I don't do drugs but I felt like I was like a stoner and I was like, "I need candy" . . . I grabbed an M&M's and I ripped it open and I was downing them and I'm like, "that's not me" . . . A lot of times I don't let myself go low because . . . you are a different person . . . even when I'm getting a little bit low . . . I can usually feel it when I'm around 4. I'll quickly pop something in my mouth [laughs] because I don't want to become that person that, you know, you just need to eat whatever (Ashlyn)

> When I'm snappy at my mom she knows that I've got low blood sugar . . . [because] that's not me. I'm not an angry person. I get frustrated and I get

> flustered when I've got low blood sugar and I can’t speak, and I can’t focus on things, and I just start snapping at people and I’m really not myself (Ashlyn)

Becoming Responsible, Mature and Resilient

Most participants said that adjusting to life with juvenile diabetes had helped them become stronger and more resilient. With added challenges they were able to recognize their ability to cope and rise above hardships. Some described how being diagnosed with diabetes forced them to grow up at a younger age. Being responsible for something that was potentially quite serious forced them to mature. In the process they gained wisdom and insight beyond their years.

> I would figure that . . . it would make me more responsible, because I am responsible for something that is potentially quite serious . . . The only way it could possibly define you is it would make you maybe slightly more responsible or mature, because it's something you have to deal with . . . With responsibility comes maturity. (Tim)

> I always say that I feel ten years older than I actually am. I think people agree with me . . . Not only feeling . . . but . . . maturity-wise . . . when do you grow up? I grew up when I was diagnosed. I was no longer a twelve-year old, maybe in age but not in mind. (Ashlyn)

> If anything happens that's a negative thing in my life, I just put it in perspective . . . Diabetes has made me stronger that way . . . I've become a lot more resilient than I would be without having this condition . . . Being able to control diabetes and work that into your daily life . . . gives you more confidence if you are able to overcome those challenges. It definitely makes you step forward and say, "If I can manage this . . . what else can't I do?" (Olivia)

Planning Ahead and Thinking Critically

Participants learned to plan ahead, be prepared and think critically to solve diabetes related problems. They managed their diabetes by being organized, structured, and creative. Participants were able to do activities such as hiking, snowboarding, and even compete in triathlons without diabetes interfering greatly if they planned, developed a routine, and worked out problems by trial and error. Participants had to be more conscious of things and had to take extra precautions such as bringing along extra food in case of hypoglycemia. Andrew and Roberta normalized the extra planning they had to do for things like travel and outdoor recreation by saying that it was not much more preparing than what any responsible person would do.

> It teaches you structure with things, I guess, organization (Tim)

> It's always in the back of my mind. There's nothing I do - I don't go anywhere without an insulin pen. I don't go anywhere without preplanning how or where I'm going to get food . . . I can't just up and leave and be like, "Whatever. I'm not

> concerned about it." There's always some form of planning. My life is revolved around planning for it somehow. (Andrew)

> I've had to problem solve and do things differently, I think, compared to if I wasn't diagnosed with diabetes . . . It's . . . improved critical thinking skills . . . I would . . . phrase it as . . . being more conscious of things . . . If you're going for a walk down ten blocks, you'd back track and think of what you'd done in the past hour or so. Did you take insulin recently? Did you have something to eat? Should you take a monitor along? All of these questions come up and, if you didn't have that, you would never be conscious of those things that you may or may not need . . . It just takes a lot more thinking and a lot more planning. (Olivia)

> It's not really a big deal, the planning that you need to do, because that's what a responsible person in . . . an active activity should do . . . You plan to bring food because you're expending energy. So I would plan to bring food because I'll be hungry, but also because I might go low. (Roberta)

Developing Empathy

Having juvenile diabetes helped participants become more empathetic, compassionate, and understanding towards others with medical concerns or issues beyond their control. They were more aware that others could be dealing with issues that were not readily apparent. Olivia said her empathy helped others open up to her.

> I've become more compassionate and sensitive towards people that are not only dealing with diabetes but other diseases and challenges. (Tiffany)

> It's shown me there are people that have things that they have to deal with that you may not know about and them dealing with that would reflect who they were . . . I know what it means to have to deal with something that you have to deal with . . . like a situation where you can't just say no . . . where there's no real choice. (Tim)

> It's helped me gain a lot of compassion for others with chronic conditions . . . I can kind of feel what they're going through as well because I've gone through the whole diagnosis stage and everything as well . . . My clients can see [my empathy] . . . and not only do they open up with health issues but they open up with other issues as well . . . They definitely will come to see me and talk to me more so than if I didn't have the diabetes – if I didn't have that compassion and understanding (Olivia)

> My ability to be compassionate with other people who are sick has also changed me a lot because before I didn't really give a rip . . . Mind you I was twelve when I got it, so I didn't even think of sickness or disease before . . . I just have a different . . . empathy for people who are . . . sick. (Andrew)

Increased Bodily Awareness

Participants learned to be more aware of their physical status. Some participants described feeling vulnerable and fragile when they were first diagnosed. It took time to learn the symptoms of high and low blood sugar and to know how to keep their sugars in balance. They had to learn to take care of things that their body would normally do for them. Participants gained a greater appreciation for the complex physical processes that were going on in their bodies. They had to develop an ongoing sensitivity to how they were feeling emotionally and physically.

> It makes you have to take care of yourself for things that you wouldn't have to even think about . . . like, I don't know, your brain just does it for you. (Josh)

> You're definitely more aware of how you're feeling. You can really sense more things and you're aware of how your body is acting and reacting to things, whereas, I think without diabetes - well I did live 21 years without it - you're not so sensitive to the way that you think that you're feeling. So, if you're having a low, you have all those feelings that are coming along with that and you sense that that's happening, whereas, if you don't have diabetes . . . you would never even be aware of that happening. (Olivia)

> I pay more attention to [my body] and I can appreciate how when it does badly I also do badly mentally or emotionally . . . [In] parenting or in relationships it affects those things and I need to learn how to listen to it. (Roberta)

> I have definitely gained more appreciation for my body . . . Having something go wrong makes me realize how much the body can do and just how much is going on. I think we take a lot for granted but having diabetes makes you more aware of how complex it all is. (Tiffany)

Selective Disclosure

Disclosure was a salient issue for participants. The ways that they chose to disclose protected their sense of self so that their diabetes was not at the forefront of how they presented themselves. Participants were open about having juvenile diabetes when it was appropriate or relevant but did not go out of their way to bring it up. They were more likely to talk about it if others were interested and not judgmental. Some situations where they might disclose were when they were going through airport security with medical supplies, when they had low blood sugar and needed sugar quickly, or when their diabetes could have affected the safety of others. Some participants had been judged or treated rudely because of their diabetes and became more intentional about how and when they disclosed as a result. Despite some having bad experiences, participants became more comfortable talking about their diabetes over time. Being open helped others understand their situation.

> I generally don't tell anybody that I'm diabetic unless they ask me (Josh)

> I'm not going to brag about it, but if I'm in a situation where I need to move and act to get something then I'll bring it up (Andrew)

> I'm not going to go out there and be like "I have diabetes" [laughs] . . . but it's not something that I hide . . . The first two years I . . . was not wearing it on my sleeve . . . [but now] I think it's really important to tell people and talk about it. It might be embarrassing sometimes, but if it helps someone understand someone else then I think it's worth it. (Tiffany)

> There's really no reason to be private about it because the more you tell people about it the more they'll understand. I think it's great if everybody knows what's going on . . . but sometimes, I'm [concerned about being judged] . . . I'm not going to get into it with [someone who is] being rude to me. I will tell [them] the bare minimum. But then there are people [who are sincerely interested] and you really go more into detail about it (Ashlyn)

Dealing with Lack of Public Awareness

Participants had to deal with lack of public awareness about juvenile diabetes ranging from getting in trouble during an exam for a beeping cell phone, which was actually their insulin pump, to being apprehended by security for supposedly taking illegal drugs. A common misconception was that people thought the contributing factors to adult onset diabetes such as obesity, inactivity, and an unhealthy diet, were also the causes of juvenile diabetes. This led to confusion and judgmental remarks, which at times were hurtful. Participants tried to brush hurtful remarks off as shallow or misinformed. Participants maintained privacy and managed other's reactions by being discreet about things like taking insulin. It was easy for others to minimize their condition because many of the aspects of managing their diabetes were hidden.

> I don’t feel that I have been misunderstood. I feel that the disease has been misunderstood. (Ashlyn)

> The most awareness they have is that they know what The Walk for Diabetes is on the news or something. That's basically all people will hear (Josh)

> It's almost viewed as . . . not as bad as a common cold . . . unless you're going low and collapsing on the ground. It's a disease that you can easily hide and so I think often times people approach it as nothing more than a common cold out of ignorance not realizing . . . the huge repercussions of having it . . . long term and short term. (Andrew)

Educating Others and Becoming an Advocate

Participants dealt with lack of awareness about juvenile diabetes by sharing about it, educating others, inspiring others by being a role model, and by sending out a positive message about what people with juvenile diabetes could accomplish. Several participants were connected with the Juvenile Diabetes Research Foundation and were involved with raising awareness and financial support for research to find a cure. Some said having juvenile diabetes helped them connect with people they would have never otherwise met. Those who became involved in advocacy developed their communication skills and became more open about their experiences.

> I think it's really important to tell people and talk about it. How else are people going to learn about it . . . and get awareness out there? Part of having it is being able to step up . . . confront people . . . and educate them. (Tiffany)

> Talking to younger people about it, you're seen as a role model too. Just being out there and being open and honest helps with communication skills and being more open . . . There are so many more people that I've met that I would have probably never met if I didn't have diabetes. There is a huge network of people that I know because of that . . . I find myself completely willing and open to connect with others. (Olivia)

> I really was really in the closet and I didn’t bother to deal with it or anything but when I started reading more . . . [and after joining a mountaineering expedition to promote awareness and raise funds for a cure] it made me really confident in a lot of the things like talking to people and being able to go to functions and conferences and standing up in front of everyone and talking and stuff like that. I really feel it’s given me the confidence I’ve needed . . . because with being so quiet and keeping it under wraps and [then] all of a sudden being like, "oh, there are people out there" . . . I really do feel it has given me confidence . . . especially

> with learning the pump now. I call it my conversation starter . . . I never really like talking about myself . . . but when it's diabetes . . . I'll talk about it . . . because I do live a positive life style and I want to spread that to other diabetics. (Ashlyn)

Valuing Understanding, Support and Encouragement

Participants valued support and understanding from significant others, family, friends, employers, coworkers, teachers, and others. They wanted positive support rather than pity. Participants appreciated having others they could count on, especially if they had low blood sugar and needed help.

Valuing support from family. Families were supportive, open, and involved. They were a huge support to many of the participants, especially when they were first diagnosed and learning to live with juvenile diabetes. Some talked about how family relationships deepened as family were there to help with the day-to-day struggle of managing diabetes.

> My family is always watching out for me . . . Their level of attention to everything I do has heightened a little. They don't treat me any differently but they'll pay more attention . . . looking for symptoms of if I'm high or low, and I can't take a nap . . . on the couch because one of the symptoms I get for going low is I get tired . . . so I'll just want to sleep . . . I'll go to take a nap and the same

> question out of anyone's mouth who is in the family is "Do you need juice? Are you low?" (Andrew)

> My brother probably knows the most . . . It's given us a connection with our training for the triathlons and all that . . . He knows . . . he's like, "You’re really pale. You should go test your blood sugar," and stuff like that. I think it’s just an understanding that they have that, I mean, they’re not going to judge me if I don’t want to come out [training] or . . . when I snap at [my family] . . . my mom’s like, "Okay you have low blood sugar. Let's talk about this later." (Ashlyn)

> I think when I was first diagnosed, going through that whole brittle stage, I think that's when my family saw my struggles of trying to keep things relatively normal . . . They were a lot more supportive and a lot more understanding . . . They can sympathize more too because they saw what I went through when it was really difficult . . . With family you're already super close so I'm not sure you could say that brought us closer together [laughs] but maybe just a different level of understanding between each other. (Olivia)

Valuing positive connections with others and joking around. Friends that cared and understood were a great support. Andrew and Ashlyn said that some of their friends knew them well enough to tell if they had a low blood sugar before they even knew. Three of the four male participants (Tim, Josh and Andrew) said that joking around with friends eased the burden of juvenile diabetes. Participants shared that it was important to surround themselves with positive, supportive people.

> Asking [for help] never really is the case because [my friends] can tell now. They're at a point of being comfortable with it where they can see the symptoms. I get a glassed over look or I'll start shaking, or I'll talk really differently and they'll say "Andrew's low" and then someone will get a coke and candy and whatever food is around will be brought. (Andrew)

> . . . because I'm pretty positive and understanding of other people's situations, I seem to surround myself with friends who are like that too . . . A lot of the time that I spend with friends is in physical activity type things . . . They understand and they're quite patient if I have to stop for a break to check my sugars or have something to eat . . . It's just become part of the whole routine . . . just as though I stop for them when they need a snack or they need a water break . . . They would stop for me the same way (Olivia)

> You stick around those friends that you know are going to take care of you . . . You've got to surround yourself with people that you trust, that understand you . . . that will leave you alone when you need to be left alone. (Ashlyn)

> [Friends], in treating it as a joke, ease the weight of that burden in a big way . . . We'll all laugh at the fact that I have diabetes, and it's really sadistic in a way but at the same time . . . it's good. (Andrew)

Valuing support from employers, coworkers, and others. Participants valued practical support at work, school, and in other settings. Practical support included such things as work and safety practices that helped manage health, being able to get diabetes supplies if they forgot something at home, and being able to go get food and take a moment to recover from low blood sugar or take insulin to recover from high blood sugar if necessary. Unsupportive employers or coworkers made life with diabetes more difficult. Andrew shared a difficult experience working under a manager that did not understand when he often needed to stop to treat his plummeting blood sugar during rush time at a café.

> My boss is pretty good . . . Sometimes I’ve gone to work and I’ve run out of insulin in my pump or I forgot something and I’ll say to her, "I have to go home and grab it" and she’ll let me go . . . Everybody I work with knows about my situation and I’ve got a fridge there that’s always got juice boxes in it . . . My boss is pretty easygoing when it comes to stuff like that and she’s very considerate. If she goes and gets drinks for everyone she makes sure there’s diet coke for me (Ashlyn)

> Health and safety [in Alberta] are kind of side-by-side . . . In my company, before I got hired, I had a drug test and I had a physical to do . . . A week later they hired another guy and they caught him with diabetes before he even started work. He had no idea . . . When you say that other people have support networks . . . from a BC perspective, that look a lot more like almost sympathy networks . . . Where I come from it's a lot more proactive. (Steve)

> Most of my employers have been pretty good . . . The last one actually asked me if I needed a break because they knew that I was diabetic . . . but then again that job wasn't a physical job. Maybe people that need a more physical job would be more upset, but for me personally I haven't really had any kind of problem with that. (Josh)

> It's difficult when you have to slow down to eat and you're always trying to explain it . . . That one supervisor was on my back continually and didn't clue in that it was not a one time deal. (Andrew)

Valuing positive connections with others that had juvenile diabetes. Most participants said connecting with other young adults with diabetes was helpful, influential, inspiring, and normalizing. Knowing others who could give personal advice and understood first hand was helpful. Those who had friends with the condition before they were diagnosed said it was easier adjusting because they knew what to expect. Some participants valued having friends with the same condition from the start. Others discovered the value of these friendships over time. Andrew and Steve did not find the need to go out of their way to make these connections but they found support in other ways. Participants that were involved in groups to raise awareness and funds for research found rich and meaningful friendships that provided practical help for managing their diabetes.

> You can make stronger relationships with people who live with it as well. You can connect on a pretty high level. (Tim)

> I never really got that connection until just recently and I didn't realize how . . . much it helps and how impact-full it is . . . To be with other people who are going through the same things as you . . . It's nice knowing you're not alone . . . because it gets lonely. (Tiffany).

> Those support groups and stuff I think are a colossal waste of time . . . I went to one meeting . . . and everybody there . . . looked miserable . . . [I don't need] a shoulder to cry on . . . I don't really let it bug me enough to sit down with someone and have a heart to heart about it. (Steve)

> Health professionals can go through the standard solution but you never really get a personal opinion on it. With a peer you can problem solve a little bit better and I think you can bounce things off of another person a lot easier and you can really

> gain a lot of value from those ideas being bounced back and forth. They can speak from experience. (Olivia)

Being encouraged by role models. Many participants felt inspired by athletes with juvenile diabetes who managed their condition well and were accomplishing astounding things. Their example challenged many participants to live without limits and not let their diabetes stop them from reaching for their dreams.

> I think it also helps that there are lots of . . . people who do really amazing physical feats, climb mountains and do things . . . go to the Olympics or something . . . It seems doable . . . Lots of people . . . get involved in professional or semi-professional sports and they just deal with it and it doesn't seem like it's too difficult for them. They just need to be really diligent and have lots of sugar on hand . . . Their existence makes it seem easier and more possible . . . It's encouraging. (Roberta)

> I did a triathlon last year in March . . . [My friend with juvenile diabetes] did the Ironman and then he texted me and said, "Hey I want to do the Ironman with you in 2011," and I was like, "It’s a lot of work and it’s a lot of psychological work too" . . . having a low blood sugar takes a lot out of you . . . He did it in 10 hours and 50 minutes or something like that. That’s almost pro time. That’s amazing . . . He's an inspiration that makes me want to do more and more. (Ashlyn)

Looking for understanding in romantic relationships. Participants did not want their condition to be a burden or stressful in romantic relationships. They wanted to bring up that they had diabetes at some point early on, unless the other person already knew about it, because there was the possibility that the other person might not be able to deal with it. Most of the time the other person already knew and was understanding about their diabetes. Tiffany was conscious about her appearance and chose to take injections because it was less conspicuous. She was hurt when one date called her gross after she took her insulin injection. Their relationship ended after that. However, she said that most people she dated were inquisitive and supportive. In mature and committed relationships participants grew together and experienced support, connection, closeness, trust, affirmation, help, and encouragement.

> I feel a little bit more obligated . . . to bring it up as a topic . . . There may be guys out there . . . that would be something that would close the deal possibly. I've never met anyone like that but that's why I'd like to bring it up, because I wouldn't want to lead someone on and say that this isn't part of my life . . . I would discuss it. (Olivia)

> I think for a girl it's kind of hard [using an insulin pump] because you don't want to . . . gross someone out. The last thing you want to be is gross . . . Anyone I've ever dated or seen has been very . . . inquisitive and supportive, and I like being asked questions . . . I have had one person . . . I don't know if it was a joke and if it was meant to be a joke it wasn't funny . . . but they told me after I'd injected that

> I was disgusting . . . I like to think of it as . . . a great sieve to weed out all the shit heads, you know? There are some awesome people but . . . there are some terrible ones too. (Tiffany)

> [My girlfriend is] really supportive . . . She knows what to watch for if I do go into diabetic shock. She's a smart girl. She knows me better than I know myself . . . Her alone is a better support network than the entire family on my side. It's ridiculous. She's a rock. You couldn't ask for a better girlfriend than her. (Steve)

> I question my boyfriend quite a bit, "Does it bug you that I'm diabetic?" I get frustrated sometimes when I have to go fill my pump and it's been beeping all night [because it's low on insulin] . . . He finds it so annoying but then he just laughs it off . . . Or he'll roll over and lie on [my pump] and I'll push him and say, "Get off my pump" . . . [Thoughts about being judged] never phased me . . . because if [he judges] me then he shouldn't be with me. (Ashlyn)

> With my mom . . . the whole purpose was always to move away from her care, whereas with [my husband] it's to . . . move into it . . . It's special that he cares and wants to know and makes suggestions and things like that. (Roberta)

Wanting to be Cared About but Not Worried Over

Participants wanted to be cared about but not worried over or policed. They had to deal with parent's anxiety. Some said it was difficult to see their parent's vulnerability, especially when they were first diagnosed and trying to learn to manage their diabetes. Participants did not want to be treated condescendingly. They were not looking for sympathy, pity, or special treatment. However, at times they enjoyed privileges like being able to bring food into the movie theatre. Some participants talked about not wanting to cause others hardship or distress. This theme was closely tied with the theme of looking for understanding in romantic relationships. Some participants talked about the intimacy of having their partner help manage their diabetes and the tension of not wanting to be a cause of worry, burden, or concern for their partner.

> My biggest concern would be that I wouldn't want somebody [that I'm in a relationship with] worrying about me like my parents would have worried about me when I was first diagnosed. I just totally would not want that . . . I wouldn't want to be a burden . . . I don't want somebody to constantly worry about me . . . (Josh)

> It feels special that [my husband] says he can tell the difference between my breathing in my sleep if I'm low or fine . . . [It] makes me feel special that [family and friends] know you that much and they want to know you that much [to recognize lows and highs and help out] . . . but then on the negative side you can feel like a burden to those people. There's sort of worrying and concern that you don't feel inferior and then there's a kind that makes you feel not equal or inferior to someone. It's the way it's done . . . Maybe it's the tone of your voice . . . all

> those unspoken things that either say "I care" or they say, "I care and I don't think you can take care of yourself and I'm worried." (Roberta)

> It was scary for me to see [my parents] vulnerability. Especially when I was diagnosed, I think one of the hardest parts was seeing my mom and dad struggling to cope with it (Tiffany)

Juvenile Diabetes Added Challenges to Everyday Aspects of Life

Juvenile diabetes added challenges to everyday aspects of life that others took for granted. Participants dealt with many difficulties by planning ahead and thinking critically and by trying to keep things in perspective. They had to plan to take care of themselves because they could not expect others to understand or be prepared to help them in times of emergency.

Facing obstacles and sometimes feeling burdened. Juvenile diabetes was sometimes felt as a burden participants had to shoulder. At times, juvenile diabetes was demanding, frustrating, isolating and intrusive. Obstacles in daily living were things like having to slow down to balance blood sugars at work and in other situations, not being able to be the best possible parent at times because of blood sugar difficulties, not being able to purse a chosen career because of health requirements, and cost of caring for the condition. Managing diabetes was an extra burden in their daily routine. Sometimes diabetes was more burdensome than at other times.

> It costs money . . . to be a diabetic because you have to buy the supplies for it and then you're limited in what you can and can't eat. You can't go out and party. You can't do all this stuff. There's a lot of "you can't do this,'" not a whole lot of "you can do this" just because you're diabetic. (Josh)

> When I was in high school I wanted to apply to the military and be a medic and I was really jilted that they wouldn't let diabetics in . . . [My boyfriend] was still in the military at that time and he said, not very tactfully, that I would be a liability . . . It just sounded like a burden. That's what I heard. It was purely pragmatic but I was still irritated . . . I want all things to be possible and they're not. (Roberta)

> As an employee . . . the difficulties are trying to balance work and being a hard worker while maintaining diabetes healthfully. Doing construction, which I used to do pouring concrete, I'd want to work just as hard as the other guys and not take as many breaks but I'd still have to because I'd either need food or insulin or whatever . . . For whatever reason it would intrude and I hate that . . . That gets frustrating . . . because I know I could do just as well as they could but in a sense it almost acts like a hindrance, not just a burden but like an actual hindrance (Andrew)

> In the jobs I have had it's really unhelpful to be low . . . You sort of can't take care of yourself . . . and there's more pressure on you because . . . I felt like it's not acceptable . . . to do a bad job [laugh]. (Roberta)

> As a mom, I do notice a big difference . . . I think my parenting really suffers if my glucose is bad. If it's high or low I have probably less than half of the amount of patience. I react with more stress or anger than I would like to. I don't like that very much but that's true of many things, like lack of sleep or being hungry . . . but it's one extra thing that can prevent me from doing as good a job as I want to on any given day. I have to look for those signs . . . If I'm low and getting angrier than I think the situation really warrants, I have to go deal with being high or low, come back, and then start again. (Roberta)

Concerns when traveling. Participants had some extra concerns when traveling. Spontaneity was somewhat limited. They had to prepare to bring enough diabetes supplies and had to plan how to keep insulin the right temperature and to protect their blood glucose meter from extreme temperatures so that it would function accurately. Josh and Olivia said they brought along a physician's note explaining that they had diabetes and needed to bring diabetes supplies in case there was an issue with airport security. Tiffany and Roberta thought about proximity to a pharmacy so that they could get supplies if something ran out or was lost, damaged, or stolen. Participants walked through the metal detector or had a hand search rather than putting their insulin pump through the x-ray machine because it could alter settings. Language barriers sometimes made communicating with border authorities difficult. Participants had to be creative to work around issues. For example, Roberta wrapped her non-water proof insulin pump in a few plastic bags sealed with duct tape so she could go snorkeling. Knowing how much insulin to give for unfamiliar foods could also be challenging. Participants' comments about travel concerns highlighted one more way that having to plan ahead and think critically played out.

> I'm the guy who gets searched at airports a lot. Generally airport security doesn't like it when you carry boxes of needles through the security or vials of whatever. That's led to different searches and . . . great times at the airport (Andrew)

> Sometimes it is annoying because you have to bring so many supplies with you. I wouldn't just be able to be swept off my feet and go on a vacation. I need to prepare. (Ashlyn)

> You have to ensure that you have enough supplies because if you're traveling in a different country you're not always sure that they have the same supplies and insulin in the other country if something goes wrong and you lose some of your packages. It just takes a lot more planning. So breaking it down and having a list, knowing what you need, knowing what you need for back up . . . and just ensuring that I had a letter too from my physician to explain what are some of the equipment and devices and everything that I need. There are challenges in traveling when you're going to countries that are super hot or super cold. You have to really plan. That seems to be a big challenge too, in super hot climates to try to keep insulin cool and you're not always in contact with a fridge . . . You just

> have to deal with it in other ways with cool water and things . . . There are just more technical issues. (Olivia)

> Sometimes I wondered how possible that would be if I had an opportunity to go . . . do something really crazy for a long time, live in some kind of a tent in a desert and do some kind of cool archeological thing . . . It's not as easy to be in difficult climates or . . . situations where . . . unpredictability is more dangerous than it would be for someone who could do perfectly fine being away from a pharmacy for months, or being away from food for a day or more . . . or things like that . . . I have been to quite a few countries, some of them developing countries, and it hasn't been that difficult. It just requires planning. I've been to a few Latin American countries. I went to Greece but . . . it wouldn't have been hard to find a pharmacy if I'd needed one in Greece . . . Snorkeling I just stuck my pump in a bunch of plastic bags, so many things can be accommodated. (Roberta)

Managing blood sugar in different situations. Participants had to be proactive to manage their blood sugars to prevent high and low blood sugars, especially when they were active. They had to monitor more frequently when they were doing active things like construction work, snowboarding, running, or kayaking, and had to correct accordingly with insulin or food when needed. With time and training, Olivia, Ashlyn and others learned how their body reacted to different types of physical activity so that they could adjust their food and insulin accordingly. Roberta and others said that low blood sugar was unhelpful, inconvenient and sometimes embarrassing. There was not always time at work to take care of their diabetes. Participants wished they did not have to worry about managing blood sugars. Despite the added issues of having to manage their blood sugars in different situations, juvenile diabetes did not change their perception of their ability to do any sort of physical activity.

> If I was going to go . . . skiing or snowboarding I'd have to check every once and a while because . . . with goggles on and just the movement and stuff like that you can't really tell if you're going low . . . It doesn't really prohibit anything that I do . . . It doesn't really change any of my physical abilities to do stuff . . . I just wish that I'd be able to be active . . . and not have to be concerned about . . . going low . . . I guess in that way it's kind of disappointing. (Josh)

> The way that I've managed to deal with that is testing lots, being super aware of how I'm feeling, if I'm questioning at all in any way just test and not be shocked with any of the numbers that come up . . . It's really about knowing your own body, how you're going to react to these things [like cycling, kayaking, and hiking] and trying to prevent any serious lows, because that's definitely what you don't want to deal with. (Olivia)

> Doing a presentation or with people I don't know, or someone I want to impress I don't want to be low and fall all over my words . . . Intelligence is really important to me. I want people to think I'm smart. I feel more embarrassed than I think I

> need to if I say silly things or express myself kind of silly, either because I can't think of the right words or because I'm low. (Roberta)

For some, difficulty losing weight. For Josh and Ashlyn, the biggest frustration that they had with diabetes was the difficulty that they had losing weight. They would often have to eat to correct a low, especially after being active, and that seemed to defeat the purpose of exercising in the first place. But even in this area, participants kept a positive mindset. If this was the worst thing, then maybe they did not have it so bad.

> For other people losing weight can be a lot easier because they can work out and then not eat anything, where as with me, if I go low then I have to eat something sugary. It's a pain. The whole point of exercising sometimes gets defeated. That's the biggest thing that makes me angry. Considering that's the worst thing for me, I guess it's kind of a good thing. (Josh)

> With having diabetes . . . I find it hard to lose weight . . . They tell you to cut back on the food that you're eating but all of a sudden you have a low blood sugar and you have to have that extra piece of bread that you're not suppose to be eating for the day . . . I find it hard having diabetes. I kept doing . . . really well and then all a sudden I'd go through really bad lows a couple days in a row and your eating crap and you know you have to have the coke or . . . whatever . . . I find that's really the only really hard part. (Ashlyn)

Managing diabetic emergencies. Participants had to be aware of the potential of serious, life threatening incidences if they had very high or very low blood sugar. Accidentally taking too much or not enough insulin had serious consequences including seizure, coma, and even death. Emergencies sometimes required hospitalization. In times of diabetic emergency, there was no denying that they had a serious illness. In those moments, they could not avoid identifying with a sick and vulnerable self.

> It was quite a few years ago I was on NPH and Regular and I switched the dose. I usually did 18 units of NPH and 8 of Regular and I switched them by accident and so I gave myself way to much fast acting and I was at my mom’s house and I just dropped to the floor. I said, "Get the glucagon," and I’m drinking juice and nothing was happening and I started having a seizure and I was like, "I messed up." I remember coming in and out of them and she was trying to [inject the glucagon] and she kept bending needles and she had to call the - the neighbour who’s a nurse and she came running in and stabbed it in my butt . . . I still had to go to the hospital because they tell you once you’ve used it you have to go. I got to the hospital and the reading on their machine read "low." It was almost like the glucagon didn't do anything. Even though I was aware of everything that was going on it just said "low." I felt like I had been hit by a bus after that. (Ashlyn)

> When you come down from a high blood sugar and you get that goopy feeling in your eyes or the fruity taste in your mouth or . . . whatever other symptom there may be from having a high blood sugar and you come back down to normal . . .

> there isn't really . . . a . . . oh that's just a normal thing . . . I wouldn't know any other word to describe that [other than being sick]. Or when you go low and . . . you do have a seizure . . . I wouldn't see how you couldn't say that is sickness . . . I remember waking up from one seizure and there was blood all over my wall because my head had slammed up against the wall so many times that it had literally worn a hole through my scalp. I was bleeding all over the wall and my head killed after that. I didn't clue in right away. I came out of the seizure. I woke up. I ate. I was just like, "man my head hurts so bad," and then I touched my head and there was blood on my fingers. I'm like what the . . . and then went downstairs and there was blood on my wall . . . I wouldn't see how you couldn't call that sickness. (Andrew)

Dealing with the Threat of Complications and Living Life to the Full

Participants were motivated to do their best to manage their diabetes so that they could minimize the risk of complications. They focused on doing what they could to manage their diabetes rather than fearing worst-case scenarios. Participants took comfort knowing that they could minimize their chances of problems in the future by caring for their condition. Some had begun to develop complications. Uncertainty about the future motivated them to seize opportunities that they may have otherwise passed up. Paradoxically, going through suffering caused some to appreciate life more.

> I know there are a lot of serious consequences to having diabetes. You can lose your eyesight, limbs, fingers, toes - you name it. You can die from it. If not

> properly managed. There's always that little tag on there, if it's not properly managed and I think I'm doing a really good job of properly managing it and that helps. (Steve)

> My eyesight has gotten worse in the last couple years . . . It just seems really early [to get complications] . . . In that kind of way you start to see things that would happen when you're older, younger . . . The uncertainty of what's going to happen when I get older would be a major negative (Josh)

> I think I'm more open to everything. I don't want to miss out on opportunities. I'm more open to living. If I didn't have it I would probably back out of things like crazy trips and taking off school, or going traveling. With diabetes I just have to do it because you never really know what's going to happen and I think you really get that sense when you're diagnosed with a disease or chronic illness. (Tiffany)

> God has used it in a way to shape and form me to be thankful for the days that I do live. So you wake up like from a really bad low blood sugar . . . You were in a coma . . . or whatever . . . You seizure . . . and . . . you wake up and you can either curse the day or you can be thankful for it. That has definitely changed a lot. How I can be thankful for a day has changed. I have a different appreciation for life (Andrew)

Becoming Proactive About Health But Facing Obstacles

Managing diabetes became part of participants' lives. They had to look after their body because it was unable to look after itself. Surprisingly, some participants described managing their diabetes as similar to caring for a child or pet that could not care for itself. Having juvenile diabetes helped participants become more proactive about eating healthy, staying active, and living a healthy, balanced lifestyle. Prioritizing health was no longer an option. Participants strived to manage diabetes so that they could feel well and have a good quality of life. For Roberta, pregnancy became the imputus for her to take her diabetes management seriously. When she felt better as a result, she decided to continue those behaviours beyond pregancy.

> It became part of my life . . . It's just something you have to be aware of . . . If you have a dog you're responsible for that dog. If you have a child you're responsible for that child and if you have, you know, a disease that affects your way of life you're responsible to maintain that. (Tim)

> I appreciate that it's forced me to take better care of myself than I might have . . . Being pregnant and a diabetic, that forced me to take better care of myself . . . I'm proud of how diligent I've been since then and I hope to continue doing that . . . I didn't care that much until there was another person involved. But now I care, not just for a baby but for myself . . . It probably took me being forced to do that to be like, wow, this is actually pretty nice to feel good and put some effort in.
> (Roberta)

> Now after I've been diagnosed . . . I'm quite a bit more proactive about my health . . . A lot of the areas in my life [have] changed for the better . . . I still smoke but I'm working on it. I've cut back quite a bit, so in many ways it's been a positive thing because the consequences or the reactions of getting diagnosed were nothing but good. (Steve)

> It comes down to . . . being more aware and understanding your body, being on top of it with health, prioritizing that maybe more so than I did before . . . You want to keep yourself healthy so that you live a long healthy life . . . It's not a maybe or an option. It's something that you've got to do if that's what you value and believe in. So just, you know, taking care of yourself I think more and making sure that you go in for your regular checkups and your routines. I would have never thought of that before, to be so on top of checkups and routines and all of that. That's what old people do, right? [Laugh] . . . But that's something that I do now without even thinking about [it] (Olivia)

Obstacles and conflicting priorities sometimes hindered participants' desire to proactively manage diabetes. Steve could not afford insulin on a regular basis, as health care in Alberta did not cover it. Tiffany struggled with diabulimia. Body image issues conflicted with her motivation to manage diabetes. She hoped the times she managed well would make up for the times she had not. Participants still wanted to live their lives; diabetes management took time, energy, and effort away from other things they enjoyed.

When they did not manage well, some participants felt hypocritical, sad, ashamed, or guilty. They did not want to let parents, loved ones, or others down. The effort that participants put into managing their diabetes fluctuated. Due to the chronic nature of diabetes, participants sometimes experienced fatigue or diabetes burnout.

> I'm probably going to regret it later in life. I realize that already, but I don't really take as best care of myself as I probably could and I don't test myself as often as I should . . . and I know that I'm not doing all these things as often as I should . . . I'm just living in the moment I guess, which is kind of foolish I guess when I look at it but [laughs] . . . Oh, that's depressing . . . I just try to get by I guess . . . I'm not really doing everything that I could (Josh)

> I kind of always struggled with self image and eating disorders and I realized after two years of having it that you could really lose weight if you just stop taking your insulin . . . I've been really struggling with that the last while and that's what's put me in the hospital . . . It feels like an addiction . . . You do good. You do good, and then you relapse and it's super hard to get back on track . . . As a person who was always dealing with that issue, it just rocketed after diabetes, because you are so obsessed with food, counting things, and writing things down (Tiffany)

> I know it's hypocritical of me, but I just paid my tuition bill and I think I've got five bucks, so I'm not going to get that prescription filled for two weeks, but . . . with diet and everything I will - I manage it fairly well. (Steve)

Staying Positive and Maintaining Hope

Participants' positive perspective resonated through each interview. Participants chose to focus on the positive and were hopeful for but not counting on a cure. They were living with juvenile diabetes, not dying from it. Having juvenile diabetes helped them become more aware of their own strength and ability to overcome. They were able to transcend their condition without denying the difficulties of it. Participants had good days when they felt well, and bad days when they felt ill from blood sugars being out of control. They tried to keep crises and difficult situations in perspective. For some, there was a sense of pride about having overcome problems. Many participants used what they had accomplished to send a message of hope and inspiration to others, especially children with juvenile diabetes.

> Life is way too short to be worrying about all the little stuff like that [diabetes]. I mean you could turn around and get hit by a bus tomorrow morning . . . Worrying about oh, "I'm going to die from this" doesn't do anybody any good. I focus on the positive stuff. (Steve)

> I'm not feeling as happy . . . when I've just been up and down on roller coasters of blood sugars [but I know] I'm going to get it back on track and get off the roller

> coaster . . . You [need to] put it into perspective and see that, okay, you did have control over this before . . . You might have to attack it differently . . . go at it a different angle and try new things, but if you could manage it before . . . there are ways of [getting it under control again]. (Olivia)

> I'm more positive. I've realized all the things that I'm capable of and can overcome. I think I've become aware of that [strength] within myself. I've taken a lot from it (Tiffany)

> When you go to conferences they do the whole "in memory of" and they put up all the people who have died in the last year of diabetes . . . My philosophy is living with diabetes and not dying from it . . . A lot of the people get up and talk about how it kills, but I am living proof of living with diabetes (Ashlyn)

> I wouldn't necessarily look at the negative side of [having diabetes]. I try and stay away from that . . . It's given me the confidence to do a lot of things . . . to meet people . . . I know what it's really like to help the kids . . . I hate being in the spot light, but if it has anything to do with a diabetes function I'll be there. I love it . . . There's no negative side to it besides the bad days . . . I'm here today and I'm healthy and I think I've helped a lot of people too. (Ashlyn)

> There are a lot of crazy cures that are coming out . . . There's a lot of controversy around stem cell research and all that kind of stuff but now that the States have it .

> . . you never know what's going to happen in the next ten years . . . You've got to stay hopeful. (Josh)

Adjusting to Life with Juvenile Diabetes

Getting a diagnosis of juvenile diabetes was a relief but at the same time it meant that things were never going to be the same. Those who had peer support had an easier time adjusting than those who did not. Olivia, who did not have peer support early on, described diagnosis as traumatic, depressing, confusing, and "a huge emotional blow at that time." She went through the stages of grief. Josh, Tiffany, and Ashlyn said that they wanted to get out of the sick role and back to regular life. Josh said at first being hospitalized and diagnosed was a novelty but soon the novelty wore off and reality set in. Tiffany, who was seventeen when she was diagnosed, had to struggle to regain her independence. Many participants talked about striving to independently manage their diabetes. They valued their autonomy, especially after having to fight to regain it.

Diagnosis was traumatic and transformative. Eventually participants were able to adapt and make caring for diabetes part of their daily routine. It took time for them to figure out how they were going to relate to their diabetes. Participants felt different ways at different times about their diabetes. For example, some days Tiffany felt sad about having diabetes and other days she felt okay and accepted it. Over time, living with juvenile diabetes became so common place that past experiences without it seemed blurry.

> It cleared up a lot of confusion . . . I knew there was something wrong but I didn't really know what it was . . . It was a lot more of a relief . . . Not knowing was terrible. (Steve)

> When I first was diagnosed . . . I thought it was going to be cool . . . It's going to make me different than other people . . . and that was kind of like a good thing, but that was short lived . . . like a month maybe (Josh)

> Being diagnosed with . . . any type of chronic condition is a huge amount of stress and it can be somewhat depressing too . . . It goes in waves. At times you could feel really isolated and that you've got this whole burden on your shoulders . . . I didn't have anybody that had diabetes around me, so I pretty much dealt with it on my own . . . I guess I say it was traumatic because it still sticks in my mind that that was a huge emotional blow at that time . . . You know that your life is going to be significantly different . . . You go through all the stages too . . . the initial shock . . . the denial, the anger, the acceptance and then the managing it afterwards. (Olivia)

> I think the hardest part was losing so much independence . . . You were about to graduate and then you're . . . stuck at home, stuck in the hospital. Your mom's nagging you to eat peanut butter sandwiches . . . It's terrible. It's like going backwards . . . That was the worst part . . . You really feel like why should I have to earn [my independence] . . . back . . . It doesn't feel fair. (Tiffany)

> I think it takes a lot of time to kind of get to know . . . the relationship you're going to have with diabetes . . . what kind of role you're going to let it take in your life . . . That took a while for me. (Tiffany)

> I'm constantly going through "phases," maybe not "phases" just feelings. I think every day I'm feeling something totally different towards it . . . Some days . . . I will be so sad . . . and there are some days when I . . . totally embrace it . . . I don't think I could commit to . . . one feeling about it . . . Right now I guess . . . I've just accepted it. (Tiffany)

Drawing from Philosophy of Life

Participant's philosophy of life shaped how they understood their condition and living with it also shaped their philosophy of life. Some participants talked about their spirituality in relation to their diabetes. Responses were personal and varied. Participants searched for and found meaning in their experiences and sought to make sense of disease and hardship.

> I’m a very material person, not really very spiritual, so I would say . . . it has taught me that our bodies are very sensitive to what they’re composed of . . . It has to be a very, very tight balance of things, the way we’re suppose to work . . . [It's] sort of a biology lesson I guess. (Tim)

> I guess I'm kind of Greek about it . . . Your body's just housing . . . who you are . . . If your body is having a problem that's hindering who you are to be communicated effectively, but it doesn't take away from who you are . . . I don't feel like you are your body . . . but your body can affect who you are or it can make who you are harder to come out . . . Even people who are disabled. I feel like they have a truer self that is not hindered by a body or a mind that's having trouble . . . The real person is not broken spiritually or mentally or emotionally or physically. They're whole the way they were supposed to be, whether they experience it in this life or not. That's the real them. They may never experience that person until heaven. (Roberta)

> There's no such thing as disease. It's just a human life and everyone's getting these things and they're just living a mortal life. What really gives us the right to not get sick and to have hardships? You have to just accept it and move on. I'm not diseased. It's just my body. We think that we all have the right to live the most perfect, healthy, beautiful life and it's kind of bizarre and weird because we're all mortal. (Tiffany)

> I got it. I'll deal with it by the grace of God. I know one day I won't have it, either in this life from some supernatural thing or if I die - if I'm in heaven . . . It's just something that I have and . . . for now . . . I struggle with it and I accept it but at the same time I'm not going to give up on hoping for something that God alone could do right now . . . It's not part of me in the sense that I do realize this isn't . . .

> the intended design of humanity, right? Disease and death and all of that is a result of the fall of man and so I take great comfort in knowing that one day if I die or when Jesus comes back there will be a day where I don't have to have it anymore and that's sweet (Andrew)

> I am one with it. I probably never really felt like that till I went to Nepal . . . Nepal was a very spiritual place and it's all about the inner being . . . You really start to embrace it. You really start to become it . . . Seeing all these other diabetics feel the same thing, you're like okay, maybe this is where I am suppose to be. What I'm suppose to do . . . What I am suppose to be (Ashlyn)

Striving for Balance

Participants strived to be balanced in their diabetes management. They managed their blood sugars but also lived life and did not obsess about attaining perfect control. Some wished they could master their diabetes but knew at best it could only be managed. Even the best tools fell short of the complex natural processes of the pancreas. Olivia and others did not let striving for perfect blood sugars get in the way of pursing dreams and living life. Finding balance was about not letting diabetes management control their lives.

> It's that balance again . . . I think being obsessed with it, writing every single thing down, which I've done before is probably more depressing than feeling crappy all the time and not taking [insulin] . . . I've been totally opposite where I've wanted no sort of connection to [diabetes] . . . and then basically lived a life where that's

> all I was, so I think it's about finding balance and not letting it run your life . . . I think in those times when you're so obsessed, counting everything, keeping track of everything . . . you kind of have this feeling that . . . you can master it . . . It's impossible [laugh]. (Tiffany)

> You can't be a perfectionist if you want to do these kind of extreme activities and sports . . . You can't have perfect numbers . . . There are so many things that could affect your blood sugars . . . You can only do as much as you can . . . If you're going to beat yourself up over trying to have perfect numbers when you are doing these certain types of activities it would limit you and you would never go out and do them . . . If your perfectionism of your blood glucose is affecting [living your life] . . . then that's when it's a problem. (Olivia)

As Much As Possible Not Letting Diabetes Become a Limitation

As much as possible, participants did not want to let juvenile diabetes limit, direct, or dictate their lives. They faced real obstacles, which they tried to overcome. Some things like extreme activities and sports took more effort but, if it was something that they really wanted to do, it was worth it. It was empowering to accomplish things that would have been very difficult for someone without health issues. Participants gained confidence by testing their limits and by not letting diabetes get in the way of pursing their dreams. Having juvenile diabetes challenged participant's autonomy. In response, it seemed that many participants attempted feats that would be difficult for peers without chronic illness. This may have been an attempt to prove to themselves and others that diabetes was not a limitation.

> One of the things I want to do is to travel around the world for a really long time, like a year or more . . . I wouldn't let diabetes hold me back. I'm not going to let it affect me . . . That's one of the very few things I feel strongly about. I'm still going to do what I want to do. (Josh)

> I think my limitations wouldn't be my diabetes . . . if I think about athletics and outdoor [pursuits], my limitations on certain things is my technical expertise . . . I can't see [diabetes] stopping me. I can see it making the activity harder and me putting more work into it, but if it's something that I really want to do then I will put that extra work into it. I don't really see diabetes as limiting me doing anything. (Olivia)

> I'm not controlled by it . . . I'm not going to let diabetes choose my path . . . It's part of me now . . . It's something that I live with and I work with. I don't work against it. It doesn't conquer me. It doesn't direct me. It's just something that you've got to be strategic with and understand that it's there . . . You can't ignore it (Olivia)

> That [mountaineering] trip was huge for me . . . It was really empowering to be able to accomplish something . . . that's difficult for the average person. (Tiffany)

Answering the Research Question

Together the findings paint a picture of young adults' experience of self-concept and juvenile diabetes. Results are summarized in Figure 1 at the conclusion of this chapter. Numbers in this section refer to items from this diagram.

The main finding was that juvenile diabetes shaped but did not define self (1). Self-concept was shaped in several ways. Living with it caused participants to become more responsible and mature (2). This was in part because they had to become more responsible in order to manage their diabetes. Dealing with their mortality at an early age deepened their maturity. As they dealt with problems that arose, participants became more aware of their inner strength and resilience (2). Participants became more adept at planning ahead and thinking critically in order to minimize illness intrusiveness and improve their quality of life (3). Facing a significant health challenge caused participants to develop more empathy for others (4).

Having diabetes led them to become more proactive about their health (13). At times however, personal or practical barriers made it more difficult for participants to manage their diabetes (13). In learning to manage diabetes, participants developed heightened body awareness; they became more attuned to the sensations associated with changes in blood glucose (5).

Diagnosis was a major adjustment that changed participants' perspective on life. As they tried to make sense of their experiences, their philosophy of life both formed and was informed by their experience (16). Participants tried to find balance by doing what they could to manage diabetes while still living their lives (17).

There was complexity and richness to the participants' responses. A total of eighteen themes emerged. Underlying seven of these themes was the choice that participants made to maintain hope and a positive attitude (14). See Figure 1 for details. This may be a unique aspect of how young adults managed chronic illness. Rather than dwelling on public misconceptions (7), many participants became educators and advocates to increase awareness and help raise funds for research to find a cure (8). They were hopeful for a cure and at the same time they moved forward with their lives. They chose to have a positive outlook (14) despite difficulties, burdens, and emergencies (11). They made every effort not to not let diabetes stop them from pursing dreams or living life to the full (18). Participants expressed their agency. They could not change their diagnosis but they could choose their attitude and in that way experience less illness intrusiveness. Another way that they chose to be positive was making efforts to manage their diabetes well rather than focusing on possible complications (12 & 13).

Participants kept diabetes at the periphery of their self-concepts (1) by, as much as possible, separating symptoms from self (1d.) and not letting diabetes limit (18) or define them (1). Paradoxically, limitations forced them to gain skills that put them ahead in other areas of life.

Social support went a long way to ease the burden of diabetes (9). Participants appreciated being cared about but not worried over or managed (10). Positive connections provided support, understanding, encouragement, and inspiration. These relationships helped normalize experiences (9).

Participants shared positive and negative aspects of their journey with diabetes. In many cases their struggles were unseen (11). To varying degrees, participants made a choice to be open about their diabetes (6). They were intentional about disclosure in order to preserve their identity as a well person and to avoid being judged (6). They disclosed their diabetes when it was appropriate or relevant (6) but did not go out of their way to talk about their diabetes, because it did not define them (1).

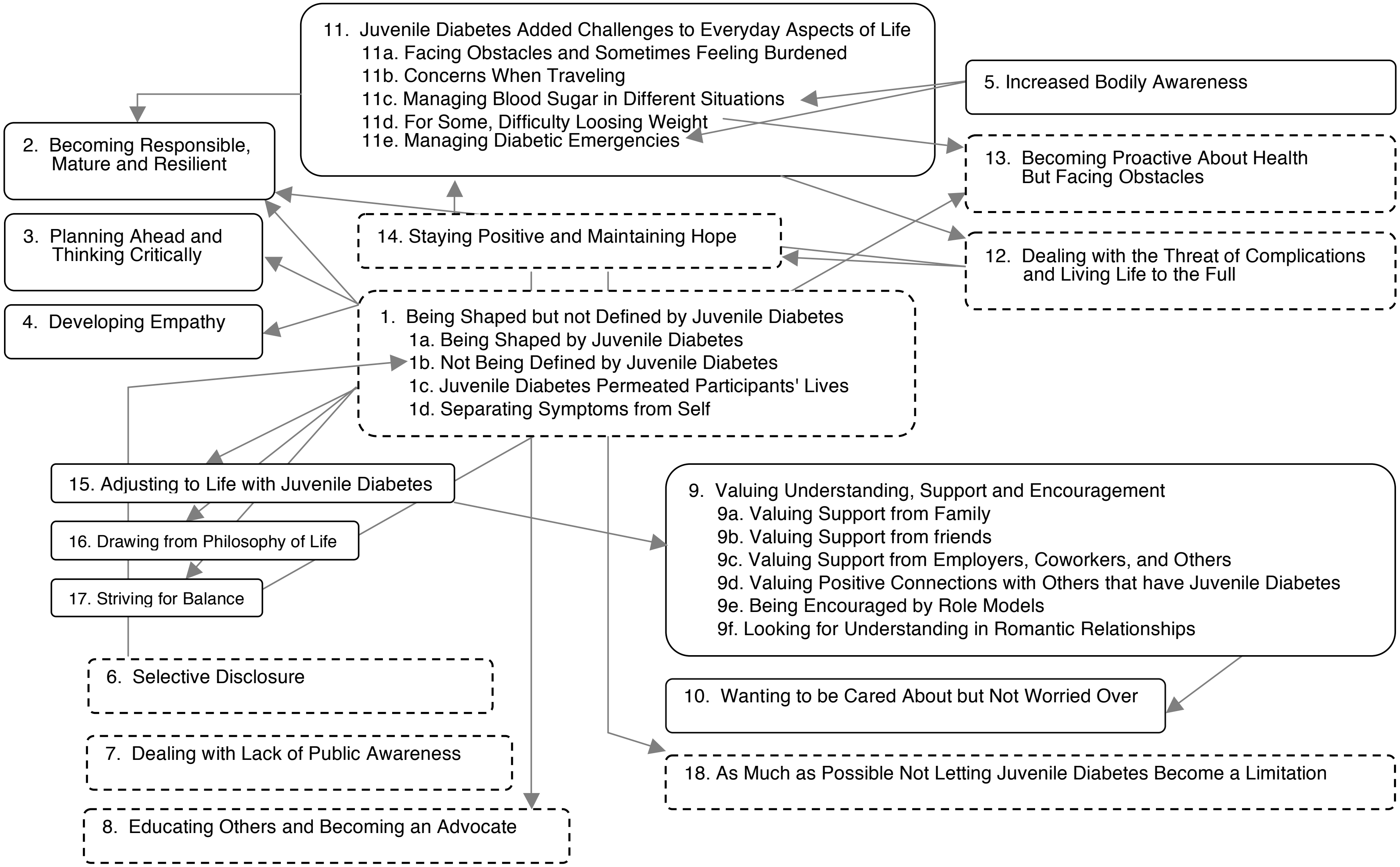

Figure 1. Self-concept and juvenile diabetes in young adulthood. Items one through four were central to the research question. Those with a dashed outline indicate where participants chose to take a positive mindset.

Chapter 5: Discussion

The intent of this project was to explore how sense of self was influenced by the ongoing challenges of having juvenile diabetes in young adulthood. I succeeded in finding some very interesting people from diverse backgrounds to share their lives with us. A number of activists were represented. This phenomenological study has allowed us to dig into the depths of the lived experience often neglected in previous research. This study has contributed a richer, more nuanced understanding of how having juvenile diabetes can influence the kind of person one becomes without it defining who one is.

Charmaz (2002b) and others point out that people do not always talk about some of the important aspects of life with chronic illness. There can be disparities between lived experience and accounts of it. An over reliance on stories without considering silences can be problematic. The ways that people share their stories and leave out certain things can of course affect results. In this analysis, consideration was given to things such as silences, pauses, false starts, and fumbling over words. One of the things I noted was that participants' often moved from personal to more general statements when talking about complications and chose not to dwell on the topic. From a counselling perspective, it is important to keep in mind that clients may not share important aspects of their experience that are none-the-less relevant to their lives and the issues that they face. This is where becoming more informed about juvenile diabetes, from studies such as this one, can help.

Connections with Existing Research

Many of Charmaz' (1983, 1991, 1995, 2002a) previous research findings on chronic illness and self-concept were consistent with research findings. However, the degree to which self-concept was affected was comparably less, likely due to differences in age and severity of symptoms. After diagnosis, thesis participants were able to maintain former actions and selves to a large degree.

Thesis participants did not seem to be as immersed in illness as Charmaz' (1991) participants were. However, the focus and enthusiasm on diabetes advocacy may have indicated some degree of being absorbed in diabetes management. Because the diabetes regimen had become routine, thesis participants may not have been fully aware of how much time they put towards planning and restructuring their lives to manage their diabetes. Charmaz (1991) alludes to this possible lack of awareness of illness immersion.

Findings may have differed slightly due to changes in perspective over time. Charmaz was able to follow participants over decades, whereas this thesis provided a snap shot of participants' young adult lives. It would be interesting to follow participants to see how diabetes and self-concept developed over a longer period of time.

In keeping with Charmaz' (1983) findings, thesis participants experienced loss in the form of facing restrictions, feeling discredited, and being concerned about burdening others. However, thesis participants would likely not have identified these difficulties as a "loss of self." They did not seem to have suffered from a lost or diminished self-concept. Rather, thesis participants seemed to develop their existing self-concepts and integrate diabetes into their selves in ways that seemed meaningful to them.

The issue of being discounted or misunderstood because of misconceptions about juvenile diabetes was an ongoing problem that was mirrored in Charmaz' (1991) and Bernstein's (2004) research. These misunderstandings continued even after disclosures were made. Thesis participants felt some degree of difference from those not living with juvenile diabetes. They perceived that people without this condition generally had a lack of understanding. This was frustrating at times. There was a sense that only those living with the condition could fully understand what it was like. Support from people close to them in their lives seemed to buffer negative effects. Thesis participants identified ways that diabetes made them different because of self-care behaviours and routines. Some mentioned being uncomfortable when noticed as different. Thesis participants strived to develop a normal and valued identity that was relatively independent of diabetes. They developed self-protective strategies that seemed oriented towards minimizing difference. This was congruent with what several researchers wrote about this topic (Bernstein, 2004; Dovey-Pearce, Doherty, & May, 2007; Schur, Gamsu, & Barley, 1990).

Some talked about not wanting their diabetes to cause others distress or hardship and not wanting their diabetes to be a cause of worry, burden, or concern for their partner. Wanting to be cared about, but not worried over, was a subtle way that participants expressed not wanting to burden others. This desire not to burden others was consistent with Charmaz' (1983) findings.

Thesis participants seemed to have healthy levels of friend support. They did not express being inwardly focused or socially isolated. This finding was supported by research on psychosocial development by Helgeson, Reynolds, Escobar, Siminerio, and Becker (2007) and Paucaud, Crawford, Stephure, Dean, Couch, and Dewey (2007). This was opposite to Charmaz' (1983, 1991) findings, likely due to differences in severity of symptoms.

The importance of caring and compassion in committed relationships, family, and friendships came through in this thesis. A prime example of this was Roberta who expressed how much her husband had supported her with her diabetes and rescued her at times when her blood sugar had dropped dangerously low. Many participants shared how much they valued support they received from parents, partners, and close friends. This was consistent with Charmaz' (2002a) findings on how vital supportive intimates were for maintaining positive self-concept.

Charmaz (1991) found that chronic illness could cause difficulties in relationship dynamics. This was consistent with what thesis participants said about not wanting to be monitored by others, nor treated in a condescending way. Difficulties in relationship dynamics were rooted in thesis participants' desire to maintain autonomy and control in their lives. Tiffany's frustration about having to "go backwards," "losing so much independence," and feeling indignant about having to fight to "earn" her independence back in her mother/daughter relationship captured this tension well. The importance of preserving control over diabetes and the challenges to autonomy that juvenile diabetes brought were supported by several studies (Dovey-Pearce, Doherty, & May, 2007; Harris, Raymond, & Duke, 2012; Sayer, Hauser, Jacobsen, Willett, & Cole, 1995; Schur, Gamsu, & Barley, 1999; Wennick & Hallström, 2007).

Parents and others with diabetes helped support and guide participants to accept their diabetes by normalizing and depersonalizing it. Sharing with others with diabetes gave them practical strategies for managing diabetes and helped them feel less alone and different. Those who knew others with diabetes during childhood said that it normalized their experience and allowed them to feel a sense of kinship and belonging. This was consistent with Schur, Gamsu, and Barley's (1999) and Bernstein's (2004) findings on peer support. In some instances the diabetes connection helped forged valued friendships for thesis participants, although, just as Bernstein (2004) found, that alone was not enough to establish a connection. Most of the thesis participants found that seeing others living well with their condition gave them inspiration and hope. However, a couple of the male participants found support from other non-diabetics in their lives and did not feel the need to establish connections with peers living with juvenile diabetes.

Many participants demonstrated empathy and compassion in the diabetes advocacy work in which they became involved. A number of thesis participants talked about gaining empathy for others dealing with issues that may or may not have been obvious to others. This was consistent with Charmaz' (2002a) and Bernstein's (2004) findings. However, Charmaz (2002a) found that women gained compassion for others and in this study and Bernstein's it emerged in both sexes.

Some thesis participants described feeling vulnerable and fragile when they were first diagnosed. They did not want diabetes to take control of their lives. It was threatening to know that they could face complications in the future. Many thesis participants talked about striving to independently manage their diabetes and valuing autonomy, especially after having to regain it. These findings complimented Charmaz' (1991) and Schur, Gamsu, and Barley's (1999) research about experiencing and resisting feelings of dependency and vulnerability and fearing that diabetes would take control of their lives.

Similar to Dovey-Pearce, Doherty, and May's (2007) and Bernstein's (2004) findings, one of the primary challenges appeared to be coming to terms with risk and mortality. This came through in participants' comments about being aware that they had to be more proactive about their health, and their concerns about the threat of complications. They were more aware of their mortality than before their diagnosis. Thesis participants expressed the threat that diabetes posed in their lives regarding the risk of complications and diabetic emergencies that could result in hospitalization or even death. Consistent with Schur, Gamsu, and Barley's (1999) study, they managed this threat with various strategies such as using downward comparisons, not dwelling on the risk of complications, trying to manage their condition so they could live life well, and rationalizing and externalizing problems. Thesis participants managed the threat of complications by not thinking too much about the future and by living life to the full so that they could make the most of what they had. This fit with Charmaz' (1991) finding about gaining a sense of control over illness by not dwelling on it and by living in the present.

Disclosure emerged as a salient issue for thesis participants. Despite some having negative experiences, thesis participants became more comfortable talking about their diabetes over time. They were more likely to disclose if others seemed interested and nonjudgmental. These findings were consistent with Bernstein's (2004) findings on disclosure. When disclosing, thesis participants seemed to have a brief public narrative that reduced their experience down to its essentials and minimized differences, as well as a personal narrative that included more sensitive and socially unacceptable aspects of life with diabetes. This was what Schur, Gamsu, and Barley (1999) found as well.

Thesis participants identified the risks and rewards of disclosure. They disclosed in dating situations because it was an important aspect of their lives and there was a possibility that the other person might not be able to deal with it. However, in their defense, a couple participants said that they would not want to be with someone who was shallow enough to reject them on the basis of their diabetes anyhow. Participants expressed concerns about disclosure and stigma similar to findings from several studies (Bernstein, 2004; Charmaz, 1991; Dovey-Pearce, Doherty, & May, 2007; Schur, Gamsu, & Barley, 1999). Concerns about stigma were rooted in widespread misunderstandings about juvenile diabetes that led to being judged. Because of this, thesis participants seemed to have a need to prove themselves. This fit with Schur, Gamsu, and Barley's (1999) results.

Thesis participants often had unique disclosure scripts that helped protect self, others, and relationships. These were aimed at keeping illness understated, not letting it define self, and protecting preferred images of self. They did not want to let their condition take over their lives or define them. This was consistent with Charmaz' (1991) findings on disclosure.

Thesis participants shared that living with juvenile diabetes had helped them become more organized. Learning to live with juvenile diabetes meant learning to plan and think critically in order to manage diabetes. Before diabetes they did not think much about planning, but after diagnosis, planning ahead and developing a routine became an essential strategy for managing diabetes. This fit with Schur, Gamsu, and Barley's (1999) and Bernstein's (2004) findings about planning to reduce the burden of diabetes and

Charmaz' (1991) findings about becoming organized out of necessity and solving existential dilemmas in this way.

Thesis participants expressed their frustration at times when diabetes held them back, exemplified by Andrew's comment that having a low blood sugar forced him to stop at times so that he could pick up before returning to a strenuous, physical job. However, consistent with Charmaz' (1991) findings, some discovered that their developed ability to plan, organize, and make trade-offs allowed them to outshine their peers in the workplace and elsewhere. For example, Olivia had incredible self-discipline and drive that allowed her to accomplish long-distance cycling adventures and other demanding physical activities.

Thesis participants strove for balance so that diabetes would not overrun their lives. Over time they learned to place themselves and learned to balance their activities and priorities. They had to work to manage their diabetes so that it would not get out of hand. They had to balance caring for their diabetes and living life. This confirmed what several studies found about the importance of achieving a balanced life-style for people with diabetes (Charmaz, 1991; Paterson, Thorne, Crawford, & Tarko, 1999; Schur, Gamsu, & Barley, 1999).

Thesis participants gained awareness of their own resiliency and inner strength. They felt a sense of pride and accomplishment when they were able to invent ways to handle tasks that posed major barriers and when they made trade-offs to preserve valued pursuits. This fit with Bernstein's (2004) and Charmaz' (1991, 1995, 2002a) findings about taking pride in resiliency and gaining awareness of inner strength.

In this thesis, Eddie had to make health trade-offs due to financial strain. In the desperation of the moment, at times he seemed to lose sight of the long-term implications of his decisions. This was in keeping with Charmaz' (1991) finding that crisis often precluded attending to health and caused participants to lose perspective on the long-range implications of their choices.

Thesis participants expressed both feelings of loss, in the form of sickness and setbacks, as well as transcendence of illness, feeling that they were a whole person and much more than a body with a disease. To varying degrees, they took time to reflect on their experiences and defined core attributes as distinct from their diabetes. Several thesis participants expressed feelings of transcendence in the context of physical and personal accomplishments that celebrated their personal freedom. Whereas, they expressed feelings of loss when their autonomy was challenged or diminished. Transcending allowed them to see themselves and their lives with juvenile diabetes in a new light. Moments of transcendence led to feelings of growth and increased self-awareness. These findings were consistent with Charmaz' (1991) research on body and self-concept and loss as well as transcendence in illness.

Contrary to Schur, Gamsu, and Barley's (1999) findings, thesis participants' search for meaning after diagnosis did not seem particularly threatening to self. Several participants talked about embracing their whole self rather than separating body, self, and chronic illness. A number of participants shared that they had been influenced by Buddhist philosophy that caused them to think of their selves more holistically. Philosophical differences may have accounted for this discrepancy in findings.

Adapting to life with juvenile diabetes caused thesis participants to become more attuned to their physical status. They developed more body awareness and a deeper awareness of self, situation, and of their place with others. They gained a new appreciation for the complex processes in their bodies and learned, over time, to be more attuned to changes in physical and emotional status in order to manage their diabetes. This supported Charmaz' (1995) and Bernstein's (2004) findings about gaining deeper self and body awareness.

Juvenile diabetes seemed to bring about gradual changes in self-concept. This was consistent with Charmaz' (1995) findings. Changes in self-concept generally occurred in ways that helped manage the life stressors of juvenile diabetes. According to Showers, Abramson, and Hogan (1998), there is some evidence that the structural features of self-concept may change over time in ways that help counteract negative mood and stress.

Diabetes was a significant part of participants' day-to-day lives. It was inseparable from the whole of who they were and yet it did not define who they were. Despite how juvenile diabetes permeated their lives and added challenges to everyday aspects of life, participants did not let it become a central, defining aspect of their self-concept. Participants saw diabetes as indivisible from self and yet separated symptoms from self. They made every effort to not let juvenile diabetes limit or define them. Although it did not define them, the kind of person they had become showed the influence juvenile diabetes on their lives. Self-concept was influenced in ways that appeared positive and socially acceptable. Paradoxically, having diabetes motivated participants to pursue a healthier lifestyle and to work towards becoming more balanced. These findings were consistent with several studies (Bernstein, 2004; Charmaz, 1995; Dovey-Pearce, Doherty, & May, 2007; Schur, Gamsu, & Barley, 1999).

Participants' character seemed to have been shaped in several ways such as: becoming more responsible, mature, and aware of their mortality and resilience; becoming skilled at planning and thinking critically; gaining empathy; becoming more bodily aware and proactive about health; and striving to live a balanced lifestyle. Some of these points have already been addressed in more detail. It was surprising how closely these findings supported and complimented Bernstein's (2004) work.

Contributions of the Present Study

This study gives insight into how participants' lives and self-concepts were shaped by juvenile diabetes from diagnosis onward. It supports existing research by providing a more nuanced, practical understanding of previous findings from a Canadian perspective. Findings support the notion that people are much more than their diagnosis or medical condition. Results highlight the importance of person-centered language, as phrases such as "the diabetic" or "being diabetic" can be misleading and depersonalizing.

This study gets to the heart of what it means from a personal perspective to live with and be shaped by this condition. The entrenched medical model often stresses tight control and patient compliance with diabetes regimen. This study provides a much-needed patient perspective on the importance of striving for balance, managing diabetes but not being so obsessed with attaining tight control that it gets in the way of living life and pursuing dreams.

There were so many unexpected positives in the research findings. The numerous ways that character seemed to have been shaped by living with juvenile diabetes provides a positive reframe about strengths that can emerge through this experience. Despite the ongoing burden of managing diabetes, participants' positive mindset resonated throughout the interviews. This may have been a unique aspect of how young adults faced chronic illness. Their positive perspective was truly inspiring. This study furthers existing research by providing insight into the minds of some exceptional young adults who have overcome huge odds. It seems that the practice of cultivating discipline, combined with a more acute awareness of mortality than normally experienced at this phase of life, brought a deepening of maturity, empathy, and awareness of one's own resiliency. At some distance from these interviews, I still feel inspired by the maturity, insights, and personal developments of participants. This study highlights the possibility of moments of transcendence and a changed, more aware self in the midst of chronic illness.

Limitations and Future Research

Ease of coping with juvenile diabetes is dependent on being able to meet the basic standards of care, such as being able to afford insulin, syringes, and food. Many young people in Canada are not able to afford the medical treatment prescribed by their doctor, in part due to regional disparities in medical coverage (Canadian Diabetes Association, 2005). Only one participant in this study was not able to afford medications all the time. Findings regarding self-concept and living with juvenile diabetes may not necessarily reflect the experiences of those whose circumstances do not permit them to manage their diabetes in the way they would chose to if they were financially able. Future research could explore self-concept and juvenile diabetes for those who are economically disadvantaged.

One limitation was that closeness to the research topic could have hindered my objectivity and may have caused methodological and ethical difficulties. These difficulties were outweighed by the benefits that came from taking a creative, naturalistic approach. Starting where one is provides the necessary meaningful links between scholarly research and personal and emotional experiences. Without a foundation in personal sentiment there is a potential for the research to become ritualistic and hollow. Research that is not personally meaningful alienates the researcher. Being personally invested protects against the inevitable boredom, confusion, and frustration with rigorous scholarship that could endanger the quality of the project (Lofland & Lofland, 1995).

Assumptions were outlined before conducting the study in order to prevent personal bias and assumptions from dominating the analysis. I wrote out my core assumptions ahead of time so that I could challenge and explore these notions in the interviews and analysis. Open-ended questions helped me remain open to other's perspectives and helped take the study in directions that I had not personally experienced.

Another limitation was that the sample population was small and may have been unique. The majority of participants seemed to be coping well and a number of the participants seemed to have excellent diabetes care reflected in their motivation, advocacy work, and athletic accomplishments. Participants that were contacted through a conference held for World Diabetes Day may have represented a more motivated population. This bias was offset to some degree by a few of the participants who were having more difficulty with their diabetes. Participants all identified as Caucasian and had completed some higher education, perpetuating a problem in diabetes research (Cox & Gonder-Frederick, 1992, as cited in Schur, Gamsu, & Barley, 1999). Future research could include a larger and more diverse sample with people from varying socioeconomic and ethnic backgrounds. Participants could be recruited through endocrinology offices to reduce sample bias.

Longitudinal studies that define and measure self-concept and bring together clinical psychology, developmental psychology, and health psychology are required. Future research could expand on findings about characteristics that seemed to have developed as a result of living with juvenile diabetes.

In this study, females tended to take their diabetes into their personal lives, allowing it to shape their goals, interests, and pursuits in ways such as raising support for research to find a cure. Males in the study tended to be more private about their condition and seemed to place less importance on diabetes and the meaning of diabetes in their lives. Some seemed confused even by the questions of how having diabetes related to self and identity. Findings seem to echo that of Williams (1999) and Charmaz (1995) in this area. More research could be done to explore gendered meanings for self-concept and diabetes in young adulthood.

Published research on the impact of diabetes upon young adult's development of self-concept is limited, possibly due to the fact that it lies between disciplines such as developmental psychology, medicine, nursing, medical sociology, clinical psychology, and health psychology. This suggests that researchers from diverse disciplines could come together to further the work in this field. As of yet, adequate definitions of constructs in relation to growing up with chronic conditions need to be developed, along with appropriate measures. Further qualitative research is necessary in order to better understanding the unique challenges that young adults with juvenile diabetes face.

Implications for Counsellors

First, it may be helpful to consider how counsellors are involved in diabetes care. Counsellors can be a vital part of an integrative health care approach, helping young adults overcome challenges that stand in the way of attaining holistic health. Counsellors provide emotional support at diagnosis as people deal with a range of emotions such as shock, denial, anger, and depression (Jacobson, 1996). They can help begin the process of accepting diabetes, often the first step towards improving self-care and management of diabetes. Counselors are able to treat associated anxiety and depression and help develop supports for self-care. They can help clients redefine priorities so that they can participate in more things that they enjoy. They can also reduce illness intrusiveness by helping clients restructure irrational expectations about their condition. Counsellors can provide social support, improve personal coping skills, and help clients connect with additional resources and support groups (Straub, 2002).

Substantial evidence supports that health, behaviour, and mental processes are intimately connected (Straub, 2002). Helping clients come to terms with and accept diabetes can have a powerful impact on wellbeing, both mentally and physically. As Tilden, Charman, Sharples, and Fosbury's (2005) research shows, rejecting a "sick" or "diabetic identity" can lead to poor health outcomes. Helping the clients accept themselves and their condition can have a profound impact on how they care for their physical health and manage their diabetes.

Relaxation training and other stress management techniques have also been found to be beneficial for many people with diabetes, especially those who are under considerable stress (Straub, 2002). Anxiety and stress can negatively affect blood sugar levels so learning to reduce and/or manage stress can be beneficial (Farrell, Hains, Davies, Smith, & Parton, 2004; Hanson, Henggeler, & Burghen, 1987; Juvenile Diabetes Research Foundation International, 2009). These are a few of the ways that counsellors can be involved in supporting young adults with juvenile diabetes.

It is hoped that the findings of this thesis will be used to help counsellors understand, support, and care for young adults with juvenile diabetes so that they can better care for themselves. Findings show how living with juvenile diabetes affects every area of life. Research findings could be used to help counsellors understand how having a chronic condition like diabetes interacts with the client's presenting issue. Thesis results show some of the challenges that young adults with juvenile diabetes face and also show ways that they have overcome limitations. Results bring to light the participants' hopefulness and their desire to normalize their experience and not be limited or defined by their diabetes.

Findings could be used to improve therapeutic goals. It could be uplifting for clients to understand how character can be shaped in positive ways by their condition. Findings could be used to help clients build self-awareness. Reading these findings could help normalize their experience and reduce their feelings of isolation. Findings show the importance of staying positive and maintaining hope. These are things that the counsellor can help foster. Results from this study could be used to encourage and uplift clients suffering from depression who find themselves disappearing under the weight of diabetes. Given the value of close relationships to strengthen the client and relieve the burden of diabetes, counselors can support and bring healing to these relationships. Counsellors can help clients with their desire to achieve balance in their lives. They can help clients build on positive coping strategies and deal with issues that stand in the way of self-care such as poor body image and anxiety. Findings show what adjustment can look like. Reading about how others have adjusted may be helpful for those who are newly diagnosed.

Findings in the present study highlight some of the essential issues related to self-concept and living with juvenile diabetes. Some of these findings may be of significance in living with other chronic diseases. Findings may help counsellors understand how clients with other chronic illnesses might experience this life stage. Findings could be inspirational to others in this age group who are dealing with adversity.

Life with juvenile diabetes can be somewhat of an enigma. From an outsider's perspective it is virtually an invisible illness. It can be hard for others to understand the constant demands of diabetes. Participants were used to being misunderstood. Participants were surprised by and seemed to appreciate the deeper questions that got to the heart of what life was like for them. They were used to being asked more surface questions. About the interview Tim said, "It was cool. Don’t usually talk to people about that." Tiffany said, "When they're asking someone about diabetes it's usually about how many needles you take in a day [laugh] you know, but I think your sensitivity towards - well you have it, so you understand, right? That's what I liked, personal questions."

Although Olivia had done a number of public speaking engagements, she said she had never had an interview like that before. She thought the questions were well rounded and helped get at the real answers. Josh said, "It wasn't too bad [laughs] . . . you already knew what a pump was and you knew, kind of knew, I mean you know what diabetes is and stuff so it was good. It's not like having to explain it to a kid, which happens sometimes, you know where you're like 'Oh, I'm sick because of this or something' . . . It was nice in that way [laugh]." Having an insider's perspective helped to know the kinds of questions to ask to get at the more nuanced psychological aspects of having diabetes. As a researcher it was great hearing people's experiences. It was exciting knowing that I was not alone and that others could relate to my experience. I hope that this excitement and awareness spreads to others who read this thesis.

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Appendix A: Recruitment Script

My name is Lisa, and I am a student at Trinity Western University. As part of the Masters in Counselling Psychology program I am doing a study entitled " Self-Concept and Juvenile Diabetes in Young Adulthood." I am looking for young adults between the ages of 19-29 who have juvenile diabetes to participate in a half-hour to an hour one-on-one confidential interview and brief follow-up call. Depending on the length of the interview the total time commitment would be about 1-2 hours.

In the interview, you would be asked to refelct on you experiences of self-concept and having diabetes by sharing stories about experiences such as going to university (such as eating cafeteria food) work experiences (like first jobs), travel (abroad or otherwise), athletics, and relationships. You would be invited to share stories about how living with diabetes has or has not shaped your sense of personal identity and the defining characteristics or personal attributes that distinguish you from other people in the context of your life as a young adult. You would be asked to reflect on wether diabetes is part of yourself or something separate or external to how you see yourself.

By participating you may also improve your own self-awareness and gain insight into your experiences as well as gain a sense of support as you read about others who share similar experiences. You may also help researchers and counsellors better understand the experiences of young adults living with diabetes so they can provide optimum care and support.

Are you interested in participating or do you know any one else might be? When are you available to meet up for the interview? The interview can be done at a location where you feel comfortable such as a community centre, library, or office. Where would you like to meet? You can reach me at diabetes.study@hotmail.com. Thanks for your willingness to get involved!

Appendix B: Online Recruitment Message

Are you a young adult with juvenile diabetes between the ages of 19-29? Are you interested in gaining insight into your experiences? Would you like to help a master's student finish her degree? Would you like to help researchers and counsellors better understand the experiences of living with juvenile diabetes so they can provide improved care?

If any of this interests you and you would be willing to participate in an interview typically lasting about an hour and a brief follow-up phone call to share your stories of how living with diabetes has shaped your self-concept then check out the attached flyer and contact Lisa at: diabetes.study@hotmail.com for more information or to get involved.

If you don't meet the above requirement but know someone who does, please forward this link to him or her. If you forward the link to more than one person, please respect confidentiality by using the Bcc function.

Your help is greatly appreciated!

Sincerely,

Lisa Nalos

M. A. Counselling Psychology Student

Trinity Western University

Appendix C: Background Questionnaire

A Little background information . . .

Your current age: ___________ years

Marital status (*check all that apply*): Single _________ Engaged _________

Divorced _________ Currently married or cohabiting _________

Do you have children? Yes _________ No _________

If yes, what are their ages? ____________________________________

Ethnic background: ___________________________

Age when diagnosed with diabetes: _________ years old

Do you use an insulin pump ___ take insulin injections ___ or other ___

____ (please specify)

In addition to diabetes, do you have any serious medical, physical or psychological conditions? Yes ______No ______

If yes, please specify: ____

Do you have parents, siblings and/or other family members with juvenile diabetes?

Yes ______No ______

If yes, please explain: ____

Level of education completed? _____________________________

Occupation (if relevant): ___________________________________

Appendix D: Interview Questions

Orientation:

In this interview you will be asked to explore what it is like for you to live with diabetes as a young adult. Diabetes may have brought some unique challenges that have shaped how you see yourself today. The interview questions explore self-concept and living with juvenile diabetes. Self-concept in this study refers to your sense of personal identity and the defining characteristics or personal attributes that make you unique. It also refers to how you see yourself in your reationships with others. You are invited to share stories from different parts of your life such as life at university, work experiences, travel, athletics, and relationships to explain what you mean. The interview should take about an hour. Do you have any questions before we begin?

Self-Concept and Diabetes:

"Do you think diabetes has shaped who you are as a person? If so, in what ways?"

"How might it have helped shape your unique characteristics or personal attributes?"

"In what ways has diabetes shaped how you see yourself as a student, employee, traveler, athlete, friend, family member, in dating relationships, or in marriage?"

Understood/Misunderstood:

"Have you ever felt connected with others who have diabetes?"

"Do you feel like you share a common ground with other people who have juvenile diabetes? Is that meaningful for you?"

"Have you ever felt different or misunderstood as a result of having diabetes?"

"Are there times when others have difficulty understanding what it means to have juvenile diabetes, such as other unintentionally minimizing what you're going through?"

Disclosure:

"What are some times when you would want to disclose or not disclose that you have diabetes?"

"What is it like for you to tell others that you have diabetes?"

"Have you ever felt like others treated you differently when they found out?"

"Is it a big deal or not a big deal to tell others you have diabetes?"

Diagnosis and Personal Change:

"Can you share your memory of first being diagnosed?"

"Did receiving that diagnosis have an impact on how you saw yourself at that time? Can you explain?"

"Have you changed at all since you began living with diabetes?"

"How has your life changed since having diabetes? How would you describe yourself then? How would you describe yourself now?"

"What might have brought about this change?"

"Can you share some stories that illustrate these personal changes?"

"What are some situations where these changes are evident?"

"Can you share some stories to illustrate what you mean?"

Internalizing and Externalizing:

"In what ways is diabetes part of who you are or separate from who you are?"

"What is the relationship between your body and your self-concept?"

"Is there a distinction to you between saying, 'I am a diabetic' versus 'I have diabetes?' Please explain."

"Do you ever feel that your body has betrayed you or that it is somehow not the body that you knew before? Please explain."

"Does your body at times seem separate from who you are as a person?"

"Have you ever felt that your body is something that needs to be controlled, mastered, or repaired? Please explain."

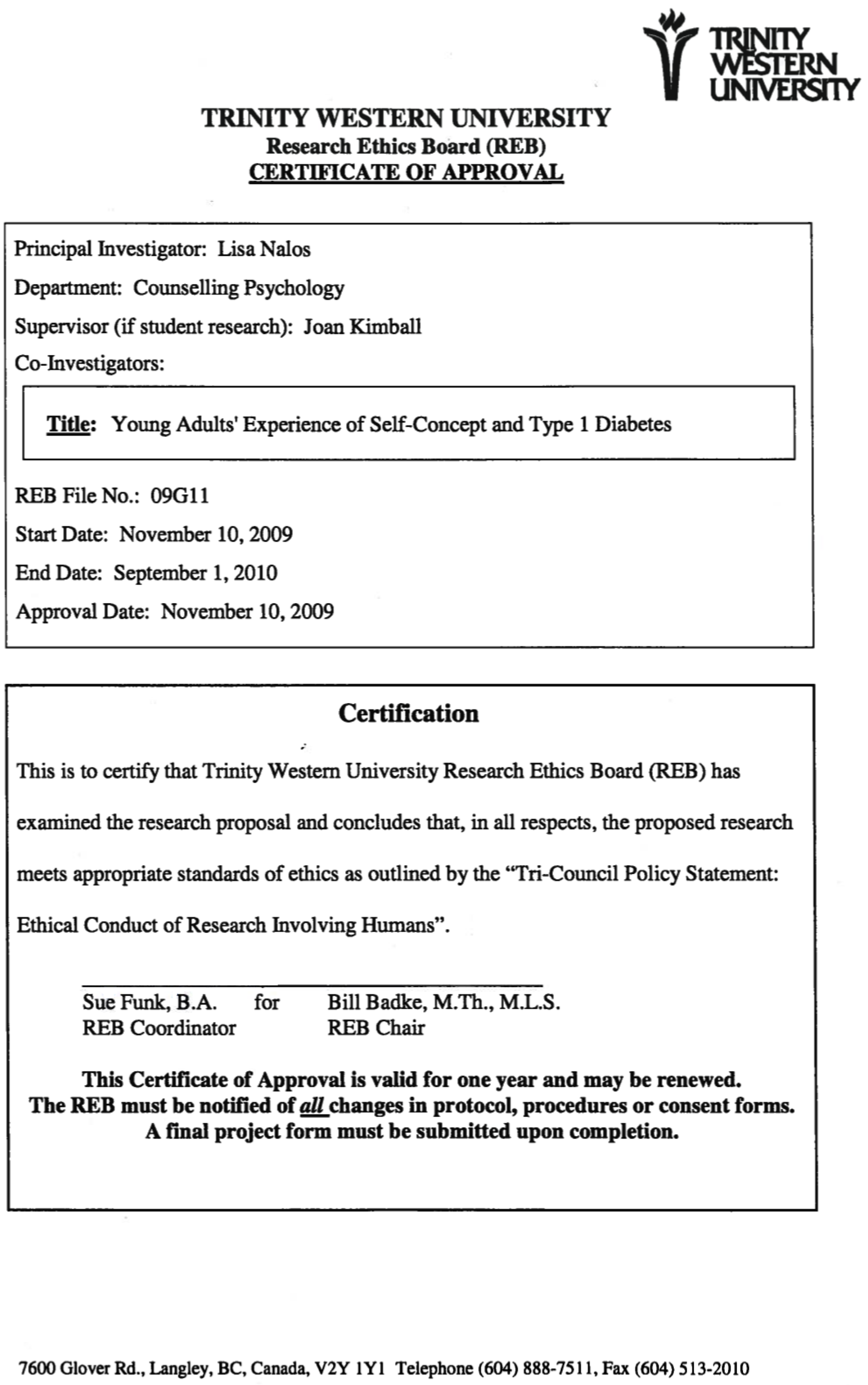
"How would you describe having diabetes? Is it something you try to ignore, minimize, struggle against or struggle with, tolerate, reconcile yourself to, or embrace? Please explain."

Positives and Negatives:

"In what ways has having diabetes helped you gain a new appreciation for your body? What are some of the positive impacts of having diabetes?"

"How has the experience of living with diabetes shaped how you see yourself in negative, neutral, or positive ways?"

Appendix E: Research Ethics Board (REB) Certificate of Approval



TRINITY WESTERN UNIVERSITY

TRINITY WESTERN UNIVERSITY
Research Ethics Board (REB)
CERTIFICATE OF APPROVAL

Principal Investigator: Lisa Nalos
Department: Counselling Psychology
Supervisor (if student research): Joan Kimball
Co-Investigators:

Title: Young Adults' Experience of Self-Concept and Type 1 Diabetes

REB File No.: 09G11
Start Date: November 10, 2009
End Date: September 1, 2010
Approval Date: November 10, 2009

Certification

This is to certify that Trinity Western University Research Ethics Board (REB) has examined the research proposal and concludes that, in all respects, the proposed research meets appropriate standards of ethics as outlined by the "Tri-Council Policy Statement: Ethical Conduct of Research Involving Humans".

Sue Funk, B.A. REB Coordinator	for	Bill Badke, M.Th., M.L.S. REB Chair

This Certificate of Approval is valid for one year and may be renewed.
The REB must be notified of *all* changes in protocol, procedures or consent forms.
A final project form must be submitted upon completion.

7600 Glover Rd., Langley, BC, Canada, V2Y 1Y1 Telephone (604) 888-7511, Fax (604) 513-2010

Appendix F: Consent Form

INVITATION TO PARTICIPATE IN RESEARCH

Study: Self-Concept and Juvenile Diabetes in Young Adulthood

Principal Investigator:

Lisa Nalos, M. A. Counselling Psychology Student, Trinity Western University

The purpose of this study is to gain a deeper understanding of self-concept in relation to living with juvenile diabetes for young adults aged 19-29. An interview time will be set up ahead of time by phone or email. You will be asked to fill out a background questionaire which will take about 10 minutes, followed by an informal interview, typcially lasting an hour, and a brief follow-up telephone interview.

In the interview you will be asked to explore your relationship between your self-concept and your diabetes. You will be asked how you see yourself in relation to having diabetes and whether or not you experience diabetes as something that is a part of yourself or separate and external to who you are. You will be asked how it feels and what it means to say, "I am diabetic" versus "I have diabetes." The way that diabetes intersects with your sense of personal identity as formed and maintained through your social interactions may be complex. You will be invited to share stories about topics such as life at university, work experiences, travel, athletics, and relationships. You will be asked to reflect on how living with diabetes has or has not shaped your sense of personal identity and the defining characteristics or personal attributes that distinguish you from other people.

All of your responses are completely confidential and will be kept in a locked cabinet, and all identifying information will be destroyed when the project is completed. A pseudonym will be used when reporting findings and specific information that identifies you will be removed in order to protect your confidentiality.

Some people may find aspects of the interview mildly uncomfortable or unsettling as sensitive issues may be brough to mind. A list of counselling resources will be provided so that, if needed, you can access counselling in order to process any difficult thoughts or emotions that might arise. If it is helpful, feel free to discuss any issues with the principle investigator once you have finished the interview. You may take breaks at any time during the interview. Participation is voluntary and you may withdraw your participation in this research at any time without consequence.

Keep in mind that your valued partipication will help researchers and counsellors to better understand the experiences of young adults living with diabetes so they can provide optimum care and support. Reflecting on your personal journey may help you to become more aware of your strengths and resources so that you can better face the challenges of managing diabetes. When the results are written up, you may gain insight and a sense of support from others who share similar experiences.

If you have any questions or desire further information with respect to this study, you can contact me, or the Thesis Supervisor Dr. Joan Kimball at joan.kimball@twu.ca, or the project Co-Supervisor, Dr. Marvin McDonald in the Counselling Psychology Program at 604-513-2034 ext. 3223 or e-mail mcdonald@twu.ca. If you have any concerns about your treatment or rights as a research subject, you may contact Sue Funk in the Office of Research at 604-513-2142 or e-mail sue.funk@twu.ca.

Thank you for your participation!

Please keep this top portion of this form

Your signature below indicates that you have received a copy of this consent form for your own records. Your signature indicates that you consent to participate in this study and that your responses may be put in anonymous form and kept for further use after the completion of this study.

Name: _________________________

Phone: __________________________ E-mail: _________________________

Signature: _______________________________ Date: ________________

___ Yes, I would like to receive a copy of the study summary.

Appendix G: Debriefing Script

After the Interview:

"What was it like sharing your story?"

"Did anything during our conversation stick out in your mind?"

"Was there anything about the experience of being interviewed that you would like to talk about?"

"Once a summary of the interview is written up I will give you a call to get your feedback on the interview process and interview themes. If anything comes up in the mean time that you would like to talk about please contact me."

<u>Follow-up Member Checking Phone Call:</u> The purpose of this ten minute call was to see if interview results resonated with participants and to give them an opportunity to comment on what they wanted to add, take away, or clarify from the findings.

"What are your thoughts on the themes drawn from your interview?"

"Is there anything you want to comment on or clarify?"

"Does this accurately reflect your experience?"

"Is there anything you want to add, take away, or change?"

"I hope that participating in this study helped you gain insight and perspective into your experiences. I hope it was helpful finding that there are others that can relate. Your valuable contribution will be used to help counsellors better understand and support young adults with juvenile diabetes. Thank you!"