LIVING WELL WITH LONG TERM TYPE 1 DIABETES

By

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Abstract

Although many studies have explored the experience of the person with type 1 diabetes, most examine the experience of the child, adolescent, or the person in transition to adulthood. Few studies focus on the person living *long term* with type 1 diabetes. This study explored the facilitators and barriers to living well with type 1 diabetes for the long term. Four themes were identified: accommodating and battling the disease, the convenience and constraint of technology and treatment, self-reliance and reliance on others, and external and personal knowledge. Implications for the health care team include: recognize the person is the expert on their diabetes and develop a relationship of collegiality and problem solving; as the context of a person's life affects their diabetes management, have conversations about life, beyond just diabetes control; and screen for, learn about, and be aware of ways to address diabetes distress.

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CHAPTER ONE: INTRODUCTION AND BACKGROUND

Pancreatic beta cell destruction results in type 1 diabetes. This destruction can be due to an autoimmune process or from an unknown etiology (Goldenberg & Punthakee, 2013). To live, the person with type 1 diabetes has to take exogenous insulin. Since the discovery of insulin, and with the many advances in diabetes management, people with type 1 diabetes have been living longer. Although many studies have explored the experience of the person with type 1 diabetes, most examine the experience of the child, adolescent, or the person in transition to adulthood. In contrast there are few studies that focus on the person living *long term* with type 1 diabetes. The purpose of this study was to explore the facilitators and barriers to living well with diabetes over the lifespan for those people who have lived long term with type 1 diabetes.

Background

Although there is evidence that diabetes has been part of the human experience since earliest recorded history, it was not until the discovery of insulin in 1921/22 by Banting, Best, McLeod, Collip, and others (Bliss & Purkis, 1982, p. 6) that the history of type 1diabetes dramatically changed. Prior to 1922, a diabetes diagnosis was considered a death sentence. As Ateteus of Cappadocia wrote in the 2nd century, diabetes was:

> an affliction that is not very frequent. . .being a melting down of the flesh and limbs into the urine. . .life is short, disgusting and painful. . .thirst unquenchable. . .the kidneys and bladder never stop making water. . .(as cited in Eknoyan & Nagy, 2005, p. 224)

Thus, the discovery of insulin was a breakthrough, allowing for type 1 diabetes to be transformed from a terminal illness to a chronic disease.

As remarkable as the discovery of insulin was, however, it was not a cure for type 1 diabetes. To manage the disease, persons with type 1 diabetes continued to require exogenous

insulin to survive. In addition, as people began to live longer with the use of insulin, a whole new set of complications arose. Within the first fifteen to twenty years of insulin therapy, people with type 1 diabetes began to experience microvascular complications affecting the eyes, kidneys and nerves, and macrovascular complications resulting in cardiovascular disease (Nathan & DCCT/EDIC Research Group, 2014). The Diabetes Control and Complications Trial (DCCT), which began in 1982 and was completed in 1993, studied the prevention of the complications of type 1 diabetes (Nathan & DCCT/EDIC Research Group, 2014). The DCCT "demonstrated the effectiveness of INT [intensive insulin therapy] in reducing the long-term complications of T1DM [type 1 diabetes mellitus] and improving the prospects for a healthy life span" (Nathan & DCCT/EDIC Research Group, 2014, p. 9).

Many advances in diabetes management have been made since the discovery of insulin and since the DCCT. These include: the development of biosynthetic insulin; new ways of delivering insulin such as disposable insulin syringes and needles that are less painful and convenient to use, insulin pens, and insulin pumps; self blood glucose monitoring, which promotes the self management of the disease rather than medical management; measurements of glycated hemoglobin, which provides a basis for health care professionals to determine and alter management; and pancreas or islet cell transplants (Bruni, Gala-Lopez, Pepper, Abualhassan, & Shapiro, 2014; Polonsky, 2012). The innovations continue today as new hormones are being identified that may be useful for diabetes management (Ahrén, 2015) and non-invasive glucose monitors become available (Distiller, Cranston & Mazze, 2016).

Since the discovery of insulin, the number of people being diagnosed with type 1 diabetes has grown exponentially. As noted by Rosenfeld (2002), "there was an unexpected by-product to the discovery of insulin. Diabetic individuals lived longer and passed the hereditary

component of this disease to their children" (p. 2286). A steady increase in the genetic component of the disease being passed to following generations was the result. As noted in the Public Health Agency of Canada document *Diabetes in Canada: Facts and Figures from a Public Health Perspective*:

> Canada was found to have one of the highest incidence rates of type 1 diabetes for children under 14 years of age. In Canada, the average relative increase in incidence rates has been estimated at 5.1% per year between 1990 and 1999. Children under the age of five were the fastest growing segment of the population with type 1 diabetes. (Pelletier, Dai, Roberts, & Bienek, 2012, para 6)

Along with increasing numbers of people with type 1 diabetes, the person with type 1 diabetes is also experiencing an increasingly longer lifespan. A study in 1975 by Goodkin (as cited in Miller, Secrest, Sharma, Songer, & Orchard, 2012) suggested that the life expectancy of those with type 1 diabetes in the United States with a diagnosis age of less than 15 years was reduced 27 years compared with individuals without diabetes. In Canada, almost 40 years later, the Public Health Agency of Canada reported that females with diabetes will lose an estimated 11.1 years in health adjusted life expectancy, while males will lose 10.8 years (Pelletier et al., 2012). Miller, Secrest, Sharma, Songer, and Orchard (2012) completed a study in Pittsburgh which further identified a trend towards the closing gap of lifespan for the person with type 1 diabetes and those without. This study delineated between those people with type 1 diabetes born in the 1950-60s and those born in the 1960s and 70s. Those born in the earlier decade have a 17-year loss of life expectancy, whereas those born in the later decade have only a four to six year loss of life expectancy.

Essentially, improvements in diabetes management and an increase in the number of people being diagnosed with type 1 diabetes have resulted in a greater number of people living longer with the disease. As a part of life, they must adhere to administering insulin, match insulin to their food intake, check blood glucose regularly, monitor their diet, be active and maintain medical appointments. As a result, the person with type 1 diabetes is constantly balancing "regimens with physical and psychosocial well-being" (Scholes et al., 2013, p. 1236). More and more people are living more than 40 years with type 1 diabetes. This study will provide the opportunity to learn from people who have lived with the chronic disease of type 1 diabetes for forty years or more.

The Importance of this Research to Nursing

People with type 1 diabetes have provided a rich cache of information for research on living chronically with a complex disease. The main participants, though, have been children, adolescents, or young adults. In contrast there are few studies that focus on the person living *long term* with type 1diabetes. And of those that *do* examine the experience of the adult with diabetes, most focus on a specific type of experience – such as stigma or compliance with treatment. Little attention has been paid to what it means to live well with diabetes over many years.

Purpose of Research

The purpose of this study is to explore the facilitators and barriers to living well with diabetes over the lifespan for those people who have lived long term with type 1 diabetes. Forty years of diabetes or more allows for discussion with participants aged 40 and up. Thus, participants who are still in their working years and participants who are in the retirement years will be included. Better understanding the experience of type 1 diabetes directly from those who

have lived with it long term will assist health care providers to shape care to meet the needs of this population.

Research Question

The overarching research question guiding this study was: What do persons living with type 1 diabetes for 40 years or more perceive as facilitators and barriers to living well with diabetes? The main questions guiding this study were:

1. How do persons living with long term type 1 diabetes define "living well" with diabetes?
2. What do persons with long term type 1 diabetes perceive as facilitators to living well with diabetes across their lifespan?
3. What do persons with long term type 1 diabetes perceive as barriers to living well with diabetes across their lifespan?
4. How might health care providers support "living well" with long term type 1 diabetes?

Method

A qualitative research method was chosen using interpretive description. Data was collected from eight participants with type 1 diabetes through semi-structured interviews. The interviews were transcribed and the data was coded. Then thematic analysis was employed to find meaning in the data.

Outline of Thesis

This thesis is comprised of six chapters. In this first chapter, the background, the significance of this research to nursing, the purpose of the research, the research questions, and a brief description of the method are outlined. Chapter Two focuses on the literature review, including the search and retrieval strategies. Chapter Three describes the methodology, as

guided by interpretive description, including data collection, analysis, scientific quality, limitations, and ethical considerations. Chapter Four outlines the findings and Chapter Five, the discussion chapter, discusses the findings within the context of what is already known in the literature. Finally, Chapter Six provides the implications that the study has for health professionals working with people with long term type 1 diabetes.

CHAPTER TWO: LITERATURE REVIEW

A literature review was conducted to provide the "scaffolding for the study" (Thorne, 2016, p. 60), by determining the current state of knowledge on the chosen topic. The literature search provided information on gaps in knowledge and substantiated the need for this research.

Search and Retrieval Strategies for Literature

A literature search using the terms "type 1 diabetes" OR "diabetes mellitus, type 1" AND "life experience" OR "living with" was completed using CINAHL, MEDLINE, Google Scholar, and the Canadian Journal of Diabetes. A decision tree was created that outlines the number of research articles found and how decisions were made to choose the articles to include in the review (See Appendix A). A total of 23 articles were reviewed prior to the study. A further literature review closer to the end of the study netted four further articles for a total of 27. Since the focus of this study was to explore the experience across the lifespan of the person with long term type 1 diabetes, the articles were categorized into the following: children and adolescent experience; transition to adulthood; and adult experience.

Children and Adolescents with Diabetes

Numerous studies have explored the experience of children and adolescents with diabetes (Babler & Strickland, 2015b; Burke & Dowling, 2007; Freeborn, Dyches, Roper & Mandleco, 2013; Gannoni & Shute, 2010; Gomes & do Espírito Santo, 2015; Huus & Enskär, 2007; Marshall, Carter, Rose, & Brotherton, 2009; Scholes et al., 2013; Spencer, Cooper, & Milton, 2013). The concept of ‘normal’ is highlighted by a number of studies for both children and adolescents (Babler & Strickland, 2015b; Freeborn et al., 2013; Huus & Enskär, 2007; Marshall et al., 2009; Spencer et al., 2013). Marshall et al. (2009) suggested that normal is dominant in the lives of the children and adolescents they interviewed because “diabetes not only makes these

families different, but also makes their pursuit of ‘normal’ more visible” (p. 1703). Babler and Strickland (2015b) developed the theory of normalizing through their interviews with adolescents, describing challenges that hindered the “pursuit of normalcy” (Freeborn et al., 2013, p. 1891). In the Huus and Enskär (2007) study of adolescents with type 1 diabetes, the participants compared themselves to their friends to describe what they felt was normal. These authors suggest that the life experience of the participants is a “pendulum swinging between being normal and being different” (Huus & Enskär, 2007, p. 29). Identified hindrances to being normal included: the difficulty of preventing hypoglycemia, especially when activity is irregular as play and sports often are; having to choose to not eat the treats that others are having; daily hassles of insulin injections and blood testing; telling others about diabetes; the need for support from friends, parents, and school personnel; and the feeling of being different or isolated (Burke & Dowling, 2007; Freeborn et al., 2013; Huus & Enskär, 2007).

In concert with the concept of normalization, several researchers have explored barriers to normal including diabetes distress and stress specifically in the adolescent population. A systematic review of diabetes distress (DD) among adolescents (Hagger, Hendrieckx, Sturt, Skinner, & Speight, 2016) indicated that around one third of adolescents experience diabetes distress, described as "the negative emotions arising from living with diabetes and the burden of self management" (p. 1). DD has been affiliated with deteriorating blood glucose control, lower self efficacy, reduced self-management, poor quality of life, and depressive symptoms (Hagger et al., 2016; Jaser, Patel, Xu, Tamborlane, & Grey, 2016). Coping is challenged by "the adolescent's quest for independence, balancing blood sugars, and integrating diabetes" which often leads to increased conflict with parents (Babler & Strickland, 2016, p. 123). As well

adolescents report stress related to feeling different from peers, guilt related to imperfect blood sugars, and feelings of burnout from the daily grind of diabetes care (Jaser et al., 2016).

Although stress and diabetes distress are noted in adolescents with type 1 diabetes, Gannoni and Shute (2010) found that children and adolescents with chronic illnesses identified positive adaptive processes as well, such as learning about their disease and learning self-control strategies related to diet. Huus and Enskär (2007) found similar results in their study, with the adolescents indicating they had more knowledge of healthy lifestyles than their friends.

Transition to Adulthood

Several researchers have explored the next step in diabetes management - the transition to adulthood (Babler & Strickland, 2015a; Balfe et al., 2013; Karlsson, Arman, & Wikblad, 2008; Kay, Davies, Gamsu, & Jarman, 2009; Samson, 2006; Sparud-Lundin, Öhrn, & Danielson, 2010). Diabetes management is complex and requires self efficacy, good problem solving skills, the knowledge and the ability to manage the many physical tasks related to diabetes, and the constant emotional adjustment of living with a chronic illness (Babler & Strickland, 2015a). The transition to adulthood for the person with diabetes can be fraught with poor glycemic control and increasingly risky behaviour, with low motivation to manage diabetes (Sparud-Lundin et al., 2010). For example, the young person with diabetes has been known to omit or reduce insulin as a way to lose weight (Peveler, Fairburn, Boller, & Dunger, as cited in Kay et al., 2009). This abdication of responsibility/risky behaviour can impact the person's future health negatively.

The time of transition for the person with type 1 diabetes from adolescence to adult independence is similar in some ways to those without diabetes – a striving for autonomy with some support from others (e.g. parents) (Karlsson et al., 2008; Samson, 2006). However, for the

young person with diabetes the transition may have an exaggerated “hovering between parental dependency and a willingness to make one’s own decisions” (Karlsson et al., 2008, p. 562). Sparud-Lundin (2010) noted the increased potential for conflict that diabetes can precipitate, as young adults and parents try to determine their roles; conflict that can have the outcome of substandard control of diabetes. Kay et al. (2013) suggested that support from health care providers could include teaching conflict resolution skills "within families or working with partners or family members to aid their understanding of diabetes and its impact on the individual" (p. 249). This could result in the person with diabetes feeling more understood and supported. Young adults also expressed the desire for support from health providers rather than authoritarian lectures. They suggested that health providers do not comprehend the daily grind of diabetes (Sparud-Lundin et al., 2010).

Young adults in their third (20s) and fourth (30s) decade of life are often experiencing career development, changes in occupation, the development of significant relationships, transitioning to general adult health services, and considering parenthood, all while trying to manage their diabetes (Balfe et al., 2013). This is the time that the person with diabetes is becoming more future conscious and is beginning to lose that sense of adolescent invulnerability (Balfe et al., 2013). Several emotions were described during this time period including frustration and distress with diabetes management, guilt about not being able to manage perfectly, and fear of future complications (Balfe et al., 2013; Kay et al., 2009). Frustration was expressed about: not wanting to be mistaken for having type 2 diabetes and resenting the inordinate amount of attention type 2 gets in terms of prevention, health care, and research funding; the difficulty in getting access to new technology; and the lack of emotional support provided by health professionals (Balfe et al., 2013). Guilt occurred when the person felt they

did not have optimal control. Fear of the future revolved around complications, early death, and, for women, the fear of being unable to conceive along with the fear of passing on diabetes (Kay et al., 2009; Samson, 2006). The young adults in the Balfe et al. (2013) study

> considered diabetes to be a limiting influence on their lives, either preventing them from engaging fully in day-to-day activities such as work or forcing them to spend an excessive amount of time on diabetes management. Interviewees said that they often struggled to find an acceptable balance between their diabetes and their daily activities of their 'normal' lives. (p. 6)

However, the young adults in the Balfe et al. (2013) study and the young women in the Kay et al. (2013) study suggested that this time of life is characterized by a growing confidence in their ability to manage the disease. Strategies to cope were described as: seeking knowledge; denial, which could be adaptive or have negative consequences depending on the circumstances; positive reframing such as focusing on the positives of having diabetes (e.g. increased empathy for others); focusing on the tasks associated with managing diabetes; and downward comparisons with those 'worse off' than them (Kay et al., 2009; Samson, 2006). Participants also indicated the benefit of being able to discuss diabetes with another person with type 1 (Balfe et al., 2013; Kay et al., 2009; Samson, 2006).

Adults with Type 1 Diabetes

Fewer life experience studies have been done with adults beyond the age of 30. Those studies that could be found focused on specific components of diabetes such as: exploring the lived experience of those who were considered expert diabetes managers (Paterson & Thorne, 2000); the concept of compliance or adherence (Ingadottir & Halldorsdottir, 2008); stigma (Browne, Ventura, Mosely, & Speight, 2014); the psychological aspects of diabetes (Jones,

Olsen, Perrild, & Willaing, 2016; Stuckey et al., 2014); the experience of the person with type 1 diabetes and health care (Richards, Morris, Booker, & Johnson, 2006); the experience of family life in concert with type 1 diabetes or relationships when one of the couple has type 1 diabetes (Rintala, Paavilainen, & Åstedt-Kurki, 2013; Trief, Sandberg, Dimmock, Forken, & Weinstock, 2013); and the relationship between the person and their disease (Watts, O'Hara, & Trigg, 2010).

In the Paterson and Thorne (2000) longitudinal descriptive study, 22 people with type 1 diabetes who were experts in diabetes management were interviewed. All 22 had diabetes for more than 15 years (15-41 years) and were between the ages of 24 to 81 years. They theorized from this study that expert status in diabetes management is a trajectory and can include the stages of passive compliance, naive experimentation, rebellion, and active control. The stages are not linear - they may occur in a different order or they may skip a stage altogether. However, the participants indicated they may fluctuate in the amount of control they want, but once they assume active control "you never go back to where you were before" (Paterson & Thorne, 2000, p. 409).

Ingadottir and Haldorsdottir (2008) examined type 1 diabetes from the terms of compliance, questioning whether the difference between evidence-based practice and the "lived best" as chosen by the person should be labeled non-adherence or non-compliance (p. 606). Eleven persons participated in the study; all but one had type 1 diabetes, and had a duration of diabetes from 5 to 60 years. A key learning from the participants was that the person needs to know oneself, respect the disease, and not let the disease dominate in order to successfully manage. Ingadottir and Halldorsdottir (2008) indicated that mastering diabetes has four main themes: knowledge, understanding, and experience (e.g. learning about diabetes and listening to the body); fighting fear in the search for safety (e.g. fear of hypoglycemia, complications);

dealing with conflicting desires (e.g. the desire to be normal); and autonomy (p. 610). The complexity of diabetes management within a full life, of which diabetes is just a part, is acknowledged in this study; it is not a simple manner of adherence or non-adherence. Ingadottir and Halldorsdottir (2008) recognized that a 'one size fits all' management scheme may not be the best for the patient. Richards, Morris, Booker, and Johnson (2006) using focus groups with participants with type 1 diabetes found similar results - the participants wanted to be viewed as individuals, seen as an expert in diabetes management, and treated non-judgmentally by health professionals (Richards et al., 2006).

Browne, Ventura, Mosely, and Speight (2014) explored the specific issue of stigma with a group of 27 adults, age 18 years and older, in Australia. The participants had a duration of type 1 diabetes of 5 to 43 years. These participants felt stigma from friends, media, family, and healthcare providers. This stigma was described as being "characterized by blame, negative social judgment, stereotyping, exclusion, rejection and discrimination" (Browne et al., 2014, p. 1). Interestingly, these participants also reflected the frustration about being confused with type 2 diabetes, similar to the Balfe et al. (2013) study with young adults. They felt that people mistakenly believed that only children have type 1 diabetes, and adults have type 2 diabetes. Type 1 diabetes was often characterized by others as the 'bad diabetes'. Again, they suggested that the media and funding focused on type 2 (Browne et al., 2014). Participants also expressed feelings of stigma on the job; the fear that to even disclose they have diabetes would affect their job advancement. Others perceived stigma in trying to get a license or trying to get life insurance. This stigma caused the participants to have feelings of "dejection, frustration, anger and grief" (Browne et al., 2014, p. 6).

The Diabetes, Attitudes, Wishes, and Needs (DAWN) study was a cross sectional survey administered throughout numerous countries. The purpose was to determine attitudes, wishes, and needs among people with diabetes and their health care providers. Diabetes related distress, lack of self management behaviours, poor collaboration amongst health provider teams, and barriers to the effective use of medication, especially insulin, were identified (Funnell, 2006). Canada did not participate in the initial DAWN study but did participate in DAWN2. The DAWN2 study was established as a large scale multi-national study to examine the psychological aspects of diabetes (Stuckey et al., 2014). The participants were a combination of adults with both type 1 (1368 or 16%) and type 2 (7228 or 84%). Two themes on the negative aspect of diabetes and two themes on the positive were identified. The negative themes identified have also been highlighted in other studies, such as the fear and worry about hypoglycemia and complications (Balfe et al., 2013; Ingadottir & Halldorsdottir, 2008; Kay et al., 2009; Stuckey et al., 2014). Discrimination at work was also identified as a negative consequence of diabetes in the DAWN2 study, similar to the findings in the stigma study by Browne et al. (2014). Two themes on adapting with diabetes were identified: "1) having a positive outlook and sense of resilience in the midst of having diabetes and; 2) receiving psychosocial support through caring and compassionate family, friends, health care professionals, and other people with diabetes" (Stuckey et al., 2014, p. 2466).

In the Danish component of the DAWN2 study, over half of the adult participants had type 1 diabetes with the duration of diabetes having a mean of 14.3 (S.D. 13.1) years (Jones et al., 2016). Questionnaires were completed by participants and family members. From the questionnaires the authors determined that:

> The burden of living with diabetes, whilst challenging for people with type 2 Diabetes, seems to have a greater psychological impact on people with type 1 diabetes, who reported higher levels of diabetes-related emotional distress, lower levels of emotional well-being, lower quality of life, and higher negative impact of living with diabetes compared to people with type 2. (p. 85)

In the Canadian cohort of persons with diabetes in the DAWN2 study, a startling 1 in 2 persons (approximately) reported significant diabetes distress (Vallis, Burns, Hollahan, Ross, & Hahn, 2016). It was also noted that emotional burdens were higher for those with type 1 diabetes. However, those with type 1 diabetes scored higher in empowerment. The conclusion of this paper suggested that the psychological challenges of diabetes "should be addressed within diabetes management services" (Vallis et al., 2016, p. 234)

Rintala, Paavilainen, and Åstedt-Kurki (2013) interviewed 19 people with type 1 diabetes for the purpose of exploring family life from the point of view of living with type 1 diabetes. The study participants ranged in age from 28 to 65 years and had a duration of diabetes of 2 to 58 years. These participants indicated that "the balance between self management and the daily routines of family was challenging" (Rintala et al., 2013, p. 89) and support from the family is essential.

Trief, Sandberg, Dimmock, Forken, and Weinstock (2013) explored relationship challenges experienced by people with type 1 diabetes and their partner. Sixteen adults aged 21 and over with a minimum duration of type 1 diabetes of two years agreed to participate. Again, the fear of hypoglycemia was voiced by both the person with diabetes and their partner, as well as future complications and the thought of having children and passing it on. The positive focused on the support of the partner without diabetes and the improvements that technology has

made in their life and relationship. However, some partners also felt that improved technology (e.g. insulin pumps) actually caused them to be somewhat excluded from care that they were a significant part of prior to the introduction of the technology (Trief et al., 2013). For example, partners may not know how to program the insulin pump or address issues, causing them to withdraw from care.

Watts, O'Hara, and Trigg (2010) examined the relationship between person and illness in a study that used in-depth interviews with four participants with type 1 diabetes: David, aged 67, diagnosed at 30; Sarah, aged 23, diagnosed at eight; 60-year old Mark diagnosed at 28; and Kate, a 20-year old female diagnosed at six. Each of these interviews were analyzed separately in an attempt to recognize the individuality of each person's journey. The authors use the discussion as a way of describing diabetes as a relationship: David ignores diabetes, which is described as David and his diabetes being estranged; Sarah seemed to want more control at some times, but not at others, which was described as a dysfunctional relationship; Mark saw his relationship with diabetes as a battle, he has been worn down by the conflict and sees death daily; Kate saw the relationship as one of getting on together, however, she cautioned to not allow the relationship with diabetes to take over your life. Watts, O'Hara, and Trigg (2010) thought the strongest message from this study was that the concept of adherence underplays the context or the 'rest of life issues' (p. 504); recognizing the need for attainment of personal goals may take precedence over physical goals. Their parting comment is that "Type 1 diabetes is not just a physical condition, but also a profoundly social and psychological one, and this leads us to conclude that access to insulin should probably come hand-in-hand with access to personal, emotional and psychological support" (Watts et al., 2010, p. 504).

Summary of the Literature

This review of the literature about living with type 1 diabetes has revealed several commonalities across the lifespan, including: seeking normalcy in the midst of dealing with a chronic disease that demands constant vigilance; the need for support from others such as teachers, parents, partners, friends, and health care providers; the recognition that health care providers can be a source of discouragement as opposed to a source of support; the prevalence of emotional feelings of fear, frustration, and guilt (i.e. fear of hypoglycemia, fear of future complications; frustration with being mistaken for type 2 and that type 2 gets more attention; frustration with access to technology; and guilt for not managing perfectly); and finally a feeling of being stigmatized, whether, feeling different as a child that has to treat a hypoglycemic incident in the middle of play or the adult that is afraid to tell an employer he/she has diabetes for fear of losing their job. It is interesting that many of the feelings exist across the lifespan. This study adds to this body of knowledge by learning if the same commonalities exist for the person who has lived with diabetes for 4 decades or more. The next chapter will describe the research design, methods and procedures used in this study.

CHAPTER THREE: RESEARCH DESIGN, METHOD, AND PROCEDURES

This chapter describes the research process used to answer the purpose and questions outlined in Chapter One. The chapter is divided in the following sections: study design, sampling, data collection, data analysis, scientific quality, limitations, and ethical considerations.

Study Design - Interpretive Description

This study lent itself well to a qualitative approach, as the aim was to seek answers about the "'what', 'how', or 'why'" of the phenomenon of living 40 years or more with type 1 diabetes (Green & Thorogood, 2009, p. 45). The phenomenon was illuminated through the personal stories of the participants. Through the method of interpretive description, the stories were described and then interpreted into something meaningful for clinical practice. Thorne et al. (2004) suggests that "what is known, whether by virtue of formal research or of clinical interpretation, should be considered foundational forestructure to a new inquiry" (p. 173). Thus, interpretation was aided by the analytic framework of the exiting knowledge (literature review) and the clinical and personal knowledge of the researcher; a diabetes educator who also has a husband who has lived with type 1 diabetes for 55 years. Interpretive description provides a method of qualitative inquiry that borrows from the areas of phenomenology, ethnography, and grounded theory. The method does not prescribe specific steps but rather provides guidance on what to avoid when working out a design logic (Thorne, 2016, p. 41). The intention of using this method was to develop meaningful interpretations of the phenomena which could be applied within the practice of nursing. It is hoped that this interpretive description will pass

> "the 'thoughtful clinicians test,' in which those that have expert knowledge of the phenomenon in a particular way find that the claims are plausible and confirmatory of

'clinical hunches' at the same time as they illuminate new relationships and understandings" (Thorne, Reimer-Kirkham, & O'Flynn-Magee, 2004, p. 8).

Sample/Data Collection

Data saturation refers to repetitive patterns in data or receiving redundant information leading to the belief that the research is complete because no new data is being revealed (Polit & Beck, 2017). Thorne (2016) suggests saturation is not possible when exploring a clinical phenomenon; that there is the possibility of "infinite experiential variation" (p. 107). Rather, she suggests making a case for setting "arbitrary sample limits" (p. 108). For this study, the researcher sought a sample size of six to ten participants. Six participants were the minimum number of interviews that would allow for common aspects to be discerned across them and to provide an opportunity for "meaningful clinical description" (Thorne, 2016, p. 105). As there are no apparent statistics available outlining the number of people in who have had type 1 diabetes for 40 years or more, it was difficult to determine the number of participants available. Six to ten participants seemed to be a practical number; however, there was no guarantee the minimum would be reached. In the end eight participants agreed to be included in the study. Table 1 provides some information about the demographics of the participants.

Table 1

Participant Demographics in the Living Well with Long-Term Type 1 Diabetes Study

Age	Sex	Age of diagnosis (years)	Duration of diabetes (years)	Employed
50	female	10	40	✓
48	male	8	40	✓
62	female	19	42	retired
50	male	8	42	✓
52	male	10	42	✓
62	male	13	49	retired
63	female	11	51	retired
56	male	3	52	✓

Data collection occurred through the use of semi-structured, individual interviews with eight people who had lived with diabetes for 40 years or more. A convenience sample of participants were recruited through: the placing of a poster in strategic places (Appendix B), such as doctors clinics and pharmacies; letters of invitation distributed to appropriate clients (those having had type 1 diabetes for 40 years or longer) by a Nurse Manager of a Diabetes Research Group (Appendix C); and an email invitation (Appendix D) sent by the Regional Executive Director of the Canadian Diabetes Association. A snowball approach was also used in that participants or others expressing interest in the project were offered letters of recruitment to distribute to acquaintances who met the criteria. Participants then contacted the researcher by phone or email.

Prior to beginning the interviews, the purpose of the study and the research questions were reviewed with the participants. The consent form was reviewed with the participant emphasizing the assurance of confidentiality and the right to withdraw at any time until the data had been combined and it is no longer possible to identify individual responses (see Appendix G).

Each participant was interviewed in-person for one hour and 15 minutes to one hour and 30 minutes in a location that was mutually agreed upon. The list of interview questions and prompts are provided in Appendix E. A debriefing session occurred immediately following each interview (Appendix F). All interviews were audio-recorded using a digital recording device and were transcribed verbatim. The researcher transcribed the first 2 interviews and a transcriptionist was hired to transcribe the following 6 interviews. The audio recording was deleted following transcription and the transcribed data was stored on a password protected computer.

Field notes and reflexive journaling were completed immediately following each interview. Field notes allowed for the researcher to outline observations that would not be readily apparent through the interview transcript such as what the researcher has "heard, seen, thought or experienced" (Streubert & Rinaldi Carpenter, 2011, p. 42). Also, a reflexive journal was kept as a way to identify (and bracket) potential researcher bias and related influence on the data collection and analysis. Jootun, McGhee, and Marland (2009) suggest, "reflecting on the process of one's research and trying to understand how one's own values and views may influence findings adds credibility to the research" (p. 42). As part of the reflexive journal the researcher tracked an internal dialogue on "'what I know' and 'how I know it'" (Jootun, McGhee, & Marland, 2009 p. 42).

Data Analysis

Although interpretive description (ID) does not offer a 'cookbook approach' in that there are "very few explicit or prescriptive guidelines", there are some common steps for analyzing data (Thorne, 2016, p. 41). Thorne suggests that a sequence of steps to draw upon may be useful, but to recognize that the steps inform rather than prescribe analysis (Thorne, 2016, p. 111). ID uses concurrent data collection and analysis. As a result, data analysis began after

transcription of the first interview. Only slight modifications to the interview questions were made following the first interview, analysis of the related transcript, and in consultation with the thesis supervisor. Losses related to diabetes were identified right from the first interview. Thus the following prompt was added after the question on challenges related to diabetes: Has diabetes stolen anything from your life?

Transcribed interviews were read and re-read several times, allowing the researcher to become immersed in the data and to begin the coding process. A preliminary code book was developed in consultation with the supervisory committee. Once the code book was refined, the remaining transcripts were coded. Analysis of the data was accomplished using an iterative approach for categories that have similar patterns, themes or meanings. The software program NVivo™ was used to assist in organizing the data. The process of data analysis occurred over several months and in consultation with the Supervisory Committee. Four main themes emerged, which are described in detail in Chapter Four.

Scientific Quality

Rigor is often expressed as trustworthiness in qualitative research, which refers to the confidence the researchers can have in their data (Polit & Beck, 2017). Lincoln and Guba's framework (as cited in Polit & Beck, 2017, pp. 559-560) was used to determine rigour. The four criteria in this framework are credibility, dependability, confirmability, and transferability.

Credibility

Several methods were employed to ensure credibility. The supervisors for the project reviewed the coding and were involved through discussions of theme development and other aspects of the analysis. The reflexive journal assisted with bracketing, which is described as "putting aside one's own beliefs, not making judgments about what one has observed or heard,

and remaining open to data as they are revealed" (Streubert & Rinaldi Carpenter, 2011, p. 27). This was an important consideration as the researcher is both a Diabetes Educator and the spouse of someone with long term diabetes. As such, there was potential that the researcher could impose her own feelings into the study. By bracketing using a reflexive journal, the researcher identified personal experiences that could influence or colour data collection or analysis (LoBiondo-Wood & Haber, 2005).

The researcher also promoted credibility by member checking the final themes with the participants. All participants were given an opportunity to review the themes. Four participants chose to review the themes and provide feedback. Thick description with the inclusion of interviewee quotes was also incorporated into the Findings Chapter thus promoting credibility. The final measure of credibility is visible in the Discussions Chapter when the findings are discussed in light of other published research (Shenton, 2004).

Dependability

A research log was maintained during the duration of the research. The research log outlined the activities that occurred and the methodological decisions made throughout the project. The presence of a research log provides a map of the processes of the study.

Confirmability

An audit trail was maintained to support confirmability. The audit trail included how decisions were made such as how the data was transformed into codes and then into themes (Letts et al., 2007). NVivo™ was used to organize data (labeling text, coding and retrieving data), but did not replace reading, thinking about, and analyzing data (Bringer, Johnston, & Brackenridge, 2004).

Transferability

Due to the small sample size it is difficult to determine whether the study results are transferrable. However, the participants are described in terms of demographics which may enhance transferability (Letts et al., 2007).

Authenticity

Authenticity was achieved by using descriptive wording in the final report that mirrors the participants experience as explained to the researcher. Field notes during the study helped the researcher maintain authenticity as she tracked non-verbal cues, and setting within the interview.

Limitations

The small sample size limits the ability of this study to be transferrable to other similar populations. All participants were Caucasian, knowledgeable about type 1 diabetes, and with the exception of one participant, were quite connected with the health care system (e.g. identified a health care team that they accessed). None of the participants had any significant diabetes complications. As seven of the eight participants came from referral through the CDA or through the Nurse Manager of a Research Unit, it could be argued that this group represented those people with type 1 diabetes who stay connected and supported in their care. It is difficult to know if this is representative of most people who have had type 1 diabetes for 40 years or more.

Ethical Considerations

Ethical approval was received through the Trinity Western University Research Ethics Board. A consent form was developed and signed by the participants with a copy provided to the participant and a copy for the researcher's records (Appendix G). As diabetes is a chronic

disease and predisposes the person to many complications such as blindness, amputations, and heart disease, there was a potential for participants to be economically marginalized due to disability and/or institutionalized. None of the participants appeared to have this as an issue, but all meetings were at a mutually decided on location to support accessibility for the participant.

All participants freely chose to be interviewed. The researcher did not have any prior contact with the participants regarding this research opportunity. Due to the type 1 diabetes community being small, and the researcher being a diabetes educator in the past, as well as a volunteer for the CDA, the researcher was acquainted with or knew of the person through mutually acquaintances for 6 of the 8 participants. However, the researcher had not been an educator for any of the participants. The participants voluntarily contacted the researcher. Although the researcher did not ask the participants specifically where they had learned about the project, it was the researchers impression that most either heard of it through CDA or through the Nurse Manager at the Diabetes Research Unit. Only one participant was referred through a mutual acquaintance of the researcher.

Confidentiality of the participants was maintained by not linking names to the information presented. The participants are identified by numbers which are used throughout the transcripts and in this thesis. The researcher is the only link between the numbers and the names of the participants. The data is stored on a password protected computer and printed transcripts are in a locked cabinet. Audio-recordings were destroyed after transcription. The data will be kept in a secure place for 5 years, after which time it will be destroyed. Access to the data will be restricted to this researcher and the supervisory committee.

Chapter Summary

Interpretive description was explicitly developed for nursing. Thorne et al. (1997) recognized that the traditional qualitative methods nurses were using were reflective of philosophies that were different that nursing. Interpretive description provided a way to learn from and use the previous qualitative methods but also to depart from them where necessary and not be accused of "sacrificing the theoretical or methodological integrity" (p. 169). This method worked well for discovering the "'what', 'how', or 'why'" of the phenomenon of living 40 years or more with type 1 diabetes (Green & Thorogood, 2009, p. 45). Through the scaffolding or lens of the literature review and the expertise of the researcher, the information provided by the participants illuminated interpretive reflections that can be used and verified by others in the diabetes field. However, the method also provided direction for checks and balances to assist in maintaining the scientific quality such as keeping a reflexive journal, so that the professional and personal knowledge of the researcher did not overshadow or lead to interpretations that were coloured by the researcher's experience. The researcher is part of the process and thus cannot remove all of her bias's completely, however, through the reflexive journal, she can make her subjectivity apparent to the reader.

As with all research, there are limitations. This study provides a glimpse into living 40 plus years with type 1 diabetes for eight participants who are fairly homogenous, in that they are all Caucasian, all except one have a health care team, and none are experiencing significant diabetes complications. However, they have lived with the disease for 40 plus years and their thoughts and impressions are valuable. It is anticipated that nurses working with those with type 1 diabetes will find the interpretation of their experiences helpful to their practice. The next chapter will describe the findings from these participant interviews.

CHAPTER FOUR: FINDINGS

Introduction

The purpose of this study was to learn about living well with type 1 diabetes from participants who had lived long term with the disease. Tension between the many aspects of caring for diabetes and living a full life were noted. Participants described living between two dichotomies – one which facilitated living well with diabetes and the other constantly challenging living well with diabetes. Table 2 outlines the themes and sub-themes that were identified through analysis.

Table 2

Themes and Sub-themes in the Living Well with Long-Term Type 1 Diabetes Study

Themes	Sub-themes
Accommodating and Battling the Disease	*Routine* *Losses and fears* *Unrelenting*
Convenience and Constraint of Technology and Treatment	*Technology/treatment as convenience* *Technology/treatment as task master*
Self Reliance and Reliance on Others	*Family support* *Medical management and self management* *System dependence*
External and Personal Knowledge	*Knowledge seeking* *Lack of knowledge of others*

These themes are further described and interpreted in the following paragraphs. An initial section sets the stage with descriptions about the participants' introduction to diabetes (diagnosis). Direct quotes are used to contextualize themes. These exemplars are used throughout this Findings chapter to offer "illumination of commonalities and elaboration of some of the kinds of variations" in the individual stories (Thorne, 2016, p. 207). Showing the common

and the particular within the study stays true to the method of interpretive description, recognizing the value of individual responses along with the shared experiences.

Diagnosis

Um, upon admission to hospital, my blood sugar was 32 and immediately, you know, my life changed forever...(#2)

All of the diabetes stories began with diagnosis. Although diagnosis was never described as traumatic, it was described as a significant and memorable event in each of the interviewees' lives. Even the participant diagnosed at 3 years of age spoke about feeling very ill, how frightened his parents were because they initially thought he had leukemia, and about the experience of having his first needle. Most can remember what they were doing at the time of diagnosis and the time of year.

Over 40 years ago it was common practice to admit the person newly diagnosed with type 1 diabetes to the hospital for treatment and this was the collective tale from the interviewees. The participant diagnosed as a young adult found this difficult as she had just started working and thus was not paid for her time away from her job. Another described this initial hospitalization as his first time being away from home as a child. Only one participant described being diagnosed without being admitted to hospital and his was a unique story. His brother, at age 11, was showing the classic signs of diabetes - thirst, frequency, weight loss - and was subsequently diagnosed with diabetes. Upon his brother's diagnosis, three of his siblings and himself were taken for a glucose tolerance test and it was determined the participant was hyperglycemic. Interestingly, he was placed on a 'diabetic diet' for several months before starting insulin. Thus, he was diagnosed pre-symptoms and was never hospitalized.

Diagnosis began the diabetes journey. As the stories continued it became clear that the participants' relationship with diabetes varied from compatible agreement, to conflict, to an uneasy truce. As such, diabetes seized a very real role in each participant's life.

Theme 1: Accommodating and Battling the Disease

Each participant described diabetes as integrated into their lives, but also shared about times when they railed against it, clearly elaborating on the tension of living with type 1 diabetes long term. While the daily activities of managing diabetes became routine, those very activities, along with the disease itself, led to fears and losses in their lives. As well, the participants shared that there are no holidays from this disease; it is unrelenting.

1.1 Routine

...practice as much as you can taking good care of yourself, whatever the circumstances are, always make sure that your diabetes is in good control. Whatever, whether things are going well or not so well for you, ...this is just one of those constant things like eating and going to the bathroom

Advice to the newly diagnosed child (#5)

After 40 years, diabetes was described as a routine part of life and, as such, needed to be accommodated into life in the same way as other daily activities. One participant suggested, "I just look at it as a sort of routine...it's, it's one of those uncontrollable things, so I don't waste any emotion on it, just move on" (#5).

A positive mindset was described as a facilitator for integrating diabetes into the routine of life. This was described as a 'can-do' attitude; not hiding the disease, not flaunting it, but making the best of it. Participants felt they were fortunate that diabetes was their disability and not another disease, "...of all the disabilities I could've had, (with) diabetes you're guaranteed

three square meals a day, you know you gotta look at those things right?" (#3). Downward comparison to other conditions was also not uncommon, "Because, um, ohh, I hate to say it this way, I sometimes think there's a lot worse people out there" (#2). Another participant shared he never has a bad day because he recognizes those who are ‘worse than him’. Two of the participants felt proud of the fact that they had received perfect attendance awards at their job and saw that as evidence of dealing well with diabetes.

Living in balance or practicing moderation was described as an attitude for successful diabetes management. For example, "living well is to not let it get...to you too much and yet not ignore it. So finding the balance" (#6), and from another participant, "...always trying to be in balance, moderation, you know, this is sort of an oxymoron but extreme moderation, you know. Don’t over expend in too many areas at once" (#3).

In concert with a positive attitude, several participants indicated that living with diabetes had actually benefitted them in life. Some shared that diabetes influenced their career choice or the knowledge and skills gained through their journey with diabetes helped them advance within their chosen career. Diabetes was credited with helping the child with diabetes to think logically and grow up fast. Many of the participants indicated that diabetes was instrumental in causing them to live a healthier lifestyle. One participant stated it this way, "diabetes has helped me...has provided the impetus for me for try to maintain myself physically, to stay in good shape, and not abuse my body" (#5), and another suggested,

> I’m probably far healthier than I would have been if I didn’t have it. I eat really healthy, my whole grains, my fresh fruits and veggies. I am far more aware of what's going into my mouth than people around me are (#4).

The ability of each participant to build diabetes into the fabric of their lives speaks to their success in living well with type 1 diabetes for 40 plus years. Wrapping the care and management of diabetes within a positive outlook on life was shared as a secret to success. However, the years were not without losses and fears.

1.2 Losses and Fears

if you can live through your adolescence, the rest gets easier

Advice to child with diabetes (#3)

One of the first losses identified by the participants was an early and ongoing awareness of mortality. One interviewee felt it was impossible to get away from recognition of his own mortality, due to negative media messaging, especially by diabetes non-profit organizations when soliciting donations,

> All my life I'm saying you're going to have a heart attack, you're going to die from a heart attack, you're going to ...be blind, you're going to lose your toes, and all that sort of stuff, so again, I have a very positive outlook but that's being, you're being bombarded on a regular basis (#8).

One spoke about living dangerously as an adolescent because he believed he would not live past 40 years of age. Another shared a poignant story from his childhood, unintentionally hearing about his limited lifespan,

> ...I was at an appointment with my mom with Dr. M and he was talking to somebody in the hallway and I remember him saying with type 1 diabetes his prognosis is probably about forty years. I was, I was like ten, nine, I'm thinking you know that's not a very long life somehow (#7).

One of the women spoke about people using threats as a way to keep her focused on managing her diabetes, "I was warned by people that I was going to be blind by the time I was

twenty-five. I would be dead by the time I was thirty and I would never have children" (#4). Mortality was also very real to two of the participants who had lost parents early in their lives as a result of diabetes.

Each of the ages and stages of life came with their own losses and fears related to living with diabetes. The first memories were closely aligned with accommodating daily injections, which were frequently described as a psychological hurdle. In the early years, the needles were glass syringes that needed to be boiled and sharpened. Dislike of needles or needle phobia was described,"... I was petrified and I seriously mean petrified of needles... when I started with the shots they almost had to hold me down" (#6). One spoke about hiding under the bed when a nurse came to do his blood sugar. Another described having "nightmares about poking myself, because I used to be a... skinny little runt (#3). He switched to the pump later in life to reduce the number of times he had to give a needle. After 40 plus years of type 1 diabetes, participants expressed that they still "hate needles" (#7).

Childhood events such as Halloween, birthday parties, and sleepovers were described as limited or non-existent due to diabetes. Some people chose not to drink alcohol because of diabetes, and one shared this limited her social activities as a young adult. Two participants spoke about diabetes limiting involvement in sports in school, "I used to be a great sprinter, but every time I'd run a sprint I'd get a hypoglycemic… immediately afterwards...So I decided, and I was very good, and I decided I had to quit" (#3).

As children, several participants indicated they had felt stigma related to diabetes. Two participants spoke about being treated badly as children because they had diabetes, "Well, kids used to laugh at me. Halloween or something you'd bring a can of apple juice or something instead...no such thing as diet drinks" (#1); and "I can remember clearly, you know, my school at

Valentine's Day, everybody got a valentines, everybody, I got nothing. Christmas time, you know cards are given out from all the students, nothing" (#7). This participant went on to say that he can meet classmates as an adult today and one of the first comments is that he is 'that fellow with the disease'.

Other incidences of stigma included not being invited to birthday parties, being accused of being teacher's pet when a teacher purchased a drink for the participant when she had a low blood sugar, being scolded by a flight attendant for taking insulin at her seat, and being told 'you can't do that' or 'you can't have that'. One participant joked that he was going to write a book titled "You Can't Do This, You're Diabetic" (#5).

Even those participants who stated they had not experienced stigma related stories that could be construed as stigma. For example: not being allowed to take sick days from work to see her specialist but having to take vacation days; being patted down at the airport because the pump can't go through the scanner, and having an airport official refuse to touch the pump; and being 'observed' carefully by a policeman when taking insulin in a restaurant.

One participant related, "The boyfriend I had in high school... his mother warned him not to get serious with me because I would never be able to have children and I would be dead by the time I was thirty" (#4). That participant has gone on to marry and have two children. She stated she was at a social function with those same parents many years later and that she wanted to go up to them and say "Boo."

Adolescence was commonly described as a difficult time for diabetes care and management. Not only were there hormonal changes and growth spurts that played havoc with blood sugars, but this was also described as the time when you are trying to assert your independence and move somewhat away from parental control. As described by one participant,

who was diagnosed in his teens, "I'm a fairly assertive person and … (diabetes) didn't help me break free from, you know, constraints around me, become more independent. So it inhibited my independence considerably" (#3). In the same vein, the participant who was diagnosed at 3 years of age wondered if perhaps he adjusted better to the disease than those who had to learn to adjust at an older age.

Adolescence is also the time that teens begin to experiment with alcohol and drugs. As one participant shared:

> ...as an adolescent you want to, you know, you want to do stuff, you want to become intoxicated, you want to smoke dope, all this stuff is problematic. ...So you have to learn how to do that and still maintain, still stay alive and so it's very difficult when you're an adolescent. So the discovery was tough and then the adolescent years were very, very tough because, you know, (you are) just happy to be alive basically (#3).

Participants described times of rebellion in terms of diabetes management. One participant talked about getting "mad" at her parents and getting back at them by eating candy. Some made up the records they took to the doctor. For example,

> When I was first diagnosed, we were testing our urine with drops of urine and drops of water in a test tube and putting a pill in there, so when you'd go to diabetes camp you either use someone else's urine or you add more water just to get the colour change right... we were only cheating ourselves (#8).

Another participant spoke about faking his sugar logs and having a doctor call him on it:

> So he says to me one day, this might get a little bit graphic just so you know, there was a swear word. I remember I was in his office, and he says 'so how you doing?' I said 'I'm doing good' he goes 'yeah, the sugars good?' well I'm like 'yeah'. He says your logs

> look really good but your A1C is SHIT. And I says ‘I’m stunned’ and he says 'listen to me if you want to effing kill yourself, don’t waste your time doing it then, just do it then’ (#7).

He described this incident as his wake up call, the turning point when he began to look after his diabetes.

As a young adult, several life experiences interfered with living well with diabetes. The women described pregnancy as an age and stage when diabetes took priority in their lives. Unlike adolescence though, this was the time when the women took charge, putting all their efforts into managing the disease well. This was the highest motivation in their lives, to put the life of their unborn child first and foremost, which meant having diabetes take centre stage. One participant described planning the conception and being "vigilant" and "almost scientific." Good diabetes control during pregnancy was paramount to these women. One described testing her blood sugars, on average eight times a day and another stated, "you’re so concerned to be as perfect as you can possibly be. And I probably was the most, the best during those two pregnancies" (#6).

However, losses were expressed around having children as well. One participant shared he did not have children because he did not want to pass on diabetes. Another had a tubal ligation after having one child. She had experienced a stillbirth prior to the live birth and felt blessed to have one child. However, later on she wished she could have had a baby with her second husband. She felt diabetes had influenced her decision to have a tubal ligation.

The immediacy of life choices as a young adult, with career, education, and young family, also impacted the management of diabetes. One participant shared that when his children

were young, he was going to school and had a full time job. He described the interruptions in sleep and the general busyness of life as a loss to good diabetes control.

Although some participants felt diabetes had actually benefited their career, others felt it was an impediment to career choices,

> You know, it has hindered me a lot in my life's work...as you can see I play piano and I used to play guitar, and that kinda thing. And, I'm decent at it. I wanted to travel and make money playing different places. But, most of that's in the U.S...And I couldn't, you know, I couldn't go there because they didn't have any health care (#1).

Several participants identified travel as something that diabetes has limited. Travel imposes a lot of considerations such as: what is available medically? do I need to worry about keeping my insulin cold? and do I want to travel alone and juggle all of the diabetes management? One participant suggested he may have been a more adventurous traveler without diabetes.

The aging adult was also not immune to losses and fears related to diabetes management. Participants shared they now are dealing with further chronic diseases such as arthritis, which causes them to not be as active, which in turn impacts diabetes management. As well, normal aging processes such as menopause make the balancing of blood sugars less achievable.

As noted, each stage of life was impacted by the losses and fears related to having diabetes. Many of those losses and fears were related to diabetes management. All participants were aware of the importance of managing the disease. Sometimes the burden of management itself led to choices that represented losses, such as career, travel and having children. Sometimes the interference of other aspects of life led to losses in control of the diabetes, such as the busyness of life and the aging process. Sometimes there was outright rebellion against the

disease such as when some adolescents chose to fabricate their results. However, in the midst of the losses and fears, it was very apparent that diabetes itself, never goes away, is a constant in their life, and could be described as unrelenting.

1.3 Unrelenting

What would you tell them? I guess there would be that part about coming to that realization that it is gonna be there for the rest of your life...

Advice to a newly diagnosed child (#5)

The 24/7 nature of diabetes is unrelenting; there are no holidays from the disease. One participant shared her frustration this way, "just this week while we're here on holidays I said to my husband I'm kind of resentful ... of the pump, I have to go it's empty, I have to go change it, like I'm sick of it" (#6). She went on to describe an experiment in relinquishing control for a bit of a 'holiday'. She had gone to the doctor one day and said she wanted to quit caring for diabetes. The doctor said he wished he could give her a holiday. He suggested that she let someone else make the decisions for one day. So, she said to her husband, 'you make the decisions today - you keep track of my blood sugars, you carb count, and you determine my insulin'. He said sure, he thought he could do that. After breakfast, she asked, what did I have for breakfast? What was my blood sugar? How much insulin do I take? He shrugged his shoulders, and she realized that he hadn't been paying attention. She could not get a holiday from diabetes.

Although diabetes was incorporated into life for the participants, even the routine was challenging. For example, when going out for supper at a friend's house, the person with type 1 diabetes has to remember to take fast acting sugar, a blood glucose meter and strips, insulin, an insulin delivery device, and make sure the glucose meter is charged. When they get to the house

they have to consider how long it will be before they eat, and whether they need anything extra while they wait. If they have an alcoholic drink, they have to think about how that will impact their sugars. When supper comes, they have to consider what they will be eating and balance it with their insulin delivery. They have to know if there will be dessert as they need to take all of this into consideration when coping with the duties of living with diabetes. One participant described it like this:

> I carry dex tabs with me all the time, try to, you know? It's that extra, there's always that extra bit of stuff you have to remember, you know, so my wife is very patient because I always take the longest to get out the door because I've got to grab all my stuff, you know...It's not like just grabbing my wallet and my cell phone and go, I grab my wallet and my cell phone, do I need my meter, is my (meter) charged...And where are we going, does the insulin need to remain cold, do I need to bring something along to try and keep it a little cooler...Uh, blood glucose meter, do I have enough strips, uh, you know (#5).

The unrelenting responsibility of diabetes is linked closely to trying to manage fluctuating blood sugars. One participant clearly identified diabetes as an adversary,

> I want you to know it was not an easy fight that I fight every day, there is no day that I wake up and think that I'll give insulin tomorrow or I'll check sugars tomorrow, every hour of every day or every minute of every day I'm concerned thinking about what my sugars are at, if I'm bouncing, when the next low is going to be or when the next high is going to be (#7).

Daily activities have to be accounted for and if there are adjustments in routine, the person with diabetes has to consider how that affects them. One participant spoke about riding on the golf cart and waiting until the third hole to start golfing, as his blood sugar was low. The

same participant spoke about the challenge of losing weight. He was trying to lose weight but he had several nights with lows. He had to get up and treat with food, thus sabotaging his weight loss plans.

All participants discussed the difficulty in maintaining stable blood sugars. In fact, several commented that stable blood sugars were an impossibility for the person with type 1 diabetes, "I have had low sugar before, you know, we all, every diabetic does...If they say they don't they're lying to you" (#1); "'Cause I mean, at the end of the day, there is no perfect...formula for smooth control all the time, you're gonna end up bouncing" (#2); and "it's funny to hear people, oh I'm a diabetic I have no problems, I'm like well then you're lucky, you're lying, but you're lucky" (#7).

Fluctuating blood sugars affected all aspects of life. Participants described high blood sugars as affecting both their concentration and their emotions. One participant described it to his daughter as a hormone, similar to when she has her menstrual cycle - when the hormone insulin is not leveling the blood sugars, emotions can cycle out of control.

> you know, women have that time of the month where emotions are up and down, flaring, and you go from, you know, calm to cry-baby in like ten minutes. And that's me every day because insulin's a hormone. So my sugars are out of whack and it does happen, I just came out of a two-day low blood sugar where, you know, ya you get emotional, you get sad, you get depressed, you get angry, you get frustrated, you yell at people, it's really a mixed bag, ...because my hormones are out of whack every day of the week, there's no one day where it's like okay, yeah, it's good let's go (#7).

Accommodations for fluctuating blood sugars include testing often, modifying activities, telling people about the condition, and having fast acting sugar on hand at all times. But even the

best-laid plans can go awry. One participant had juice in the staff room fridge for use when he had a low blood sugar and another staffer drank it, resulting in him not having a fast acting sugar available for his low blood sugar. When one participant was a teen, another teen played a trick on him and switched locks on his locker, leading to an emergency situation when the teen with diabetes could not get into the locker for his fast acting sugar. Another talked about cycling and forgetting his fast acting sugar. He had a low blood sugar on the trail and had to approach several hikers and ask for help. This constant tension between independence and accommodating the disease is troubling for the participants. One participant described it as embarrassing, "I have a low sugar, you feel embarrassed, you know, if I have a high sugar I feel embarrassed, because you're not the same person" (#7).

Traumatic hypoglycemic events were not uncommon in this group. One participant took insulin as was his habit in the evening, even though his blood sugar was low. His wife had to call the ambulance. He was told afterwards that he was minutes away from death. The participant that was diagnosed as a young adult remembers her first hypoglycemic event in the hospital. She had a pass from the hospital to go to an event on New Year's Eve and before she went, she experienced her first low blood sugar. She shared,

> 'cause we had tickets to go somewhere and, um, I was allowed to go out for 2 hours, and I had the worst low ever. And it was my first experience with an extreme low. And I just bawled, because, I just thought, oh, ya, 'cause I had never had a low. So, I did not go out, I did not go out that day (#2).

The same participant lost her license as a result of hypoglycemia - shearing off a fire hydrant during the incident. She states she never drives now without testing her blood sugar first, "I will never get behind the wheel without poking (testing blood sugar). Ever! I mean,

even if it's just and hour and a half between the time that I've tested, had breakfast, showered, now I'm going to drive? I'll poke" (#2).

Fluctuating blood sugars have had an impact on the job for a number of the participants. One stated that if he is working with a customer, he cannot walk away to do his blood sugar. Another spoke about just being promoted to team leader and having to cancel a meeting as she was having a low blood sugar and was not capable of leading the meeting. A third spoke about having to tell a supervisor during an interview for a new job that she was having a low blood sugar and was not at her best to continue the interview.

All spoke about the factors in everyday life that affect blood sugars negatively such as stress, common illnesses, increased activity, and hot weather. One participant described a traumatic low blood sugar following activity on a hot day in vivid detail:

> Warm summer day about three years ago, I had hula hooped in the park that morning. After lunch I am going to go (shopping)...I'm in the car and I'm thinking yeah it's really hot out but I'm sweating...I think I might be low. So I check my blood sugar and sure enough I am low so I call him (husband) and I say I just checked my blood sugar and I'm low so I'm not driving for about twenty minutes. I'm just sitting here. We use the stalker app, the find my iphone app so we can find where each other is if we wanted to check, so I knew, I figured he might be looking at me and wondering what the heck I'm doing sitting in a parking lot. So 'I'm just calling to let you know I'm going to be sitting here for a little while' 'okay, alright, thanks, you know what, just give me a call before you're ready to start driving again', I said 'maybe I'll go hang at ...(store) for a while and look at the animals, it's air-conditioned in there' and I didn't want to start my car. So, anyways I call him again, okay, now I'm going to head over to (grocery store), 'okay'. I get to

> (store), there's only a few things I need to pick up…, I get in there and I'm just about done my grocery shopping and I start to sweat like a teamster and I'm thinking holy crap, my blood sugar is dropping. Oh I'll just check out, get my groceries into my car and then I'll treat, then I'll wait a little while and then I'll drive home. Well I got my groceries into my car, took the cart to the cart realm and I'm trying to extract now all carts, I don't know why. The (store) park person stops and asks me what I'm trying to do, what I'm trying to accomplish, excuse me. And I looked at him, then I just slurred at him, I couldn't speak. ...I remember putting my head in my hands and he says to me, miss can you tell me where you are? And I look up at the great big (store) sign and I say (store) but it's really slurred. Miss, do you have a car here? And all I do is turn and point at my car. I point at my car. There's another shopper approaching with a small child. He stops her, he asks if she has a cell phone and asks her to call 911, that part I don't remember, my husband collected that data later... Now my husband is watching me on the stalker app on the iphone and noticed that I had been in the parking lot for ten minutes. He's been watching me not move so when I turn to point to my car I see his vehicle pull up and I recognize the grill. And I started to cry because I knew that...I was so low now that I was not able to treat myself, okay. So (husband) gets me into the vehicle and gives me about five dextrose and he gets me sitting there and he went back then to the cart person and the woman with her small child. And so he went and explained that I am diabetic, and I was having a hypoglycemic event, and that thank you so much for looking after her and intervening (#4).

She then went on to describe how she felt after that experience through a discussion with her son:

> ...I am bitter when I walk into the house, so angry that this has happened and that this happened in public and that people are going to think I'm an idiot and that I'm not capable and dad's going to think that I can't be unattended ever now. I'm talking to (son) now; 'Mom, mom, mom, no, stop beating yourself up, no mom it's not like that' (#4).

This episode depicts how difficult it is for the person with diabetes to experience the lack of control during a hypoglycemia event that cannot be managed without help.

The participants clearly described diabetes as a constant task master. The words battle and fight were used, and the sneak attacks of severe hypoglycemic events were described in detail. Although the activities of managing diabetes are routine, they also require constant diligence. Advances in technology and treatment over the years have assisted the person with type 1 diabetes in being armed for the battle. However, as can be seen in the next section, technology can be both a support and a frustration.

Theme 2: Convenience and Constraint of Technology and Treatment

Forty years of advances in technology and treatment of type 1 diabetes were discussed by the participants. All but one remembers reusable glass syringes. All remember being on one injection a day. All remember checking urine for sugar. The amount of change in the treatment and surveillance of type 1 diabetes in the past 40 years has been dramatic. Although the treatment and technology changes were welcomed and embraced by the participants, they also created another layer of expectations for the person with type 1 diabetes.

2.1 Technology/Treatment as Convenience

> *Get on an insulin pump ASAP and learn carb counting.*
>
> *Advice to a newly diagnosed child (#6)*

One participant described the discovery of insulin as a bit of a "serendipitous event", discovered "a bit ahead of its time, so science had to catch up" (#3). The scientific 'catching up' included the introduction of synthetic insulin and differing ways to deliver insulin such as the pen and the pump. Many remember needles that were large and painful, so disposable needles that became finer and shorter were a welcome addition to their box of tools.

Every participant described blood testing as a significant scientific breakthrough since his or her diagnosis. Glucose testing historically started with dropping blood on testing strips and comparing the strip to a colour chart, which was very subjective, to large testing machines, to the small compact machines of today.

In the words of one participant, "the biggest breakthrough, biggest breakthrough, blood testing. Ya, that to me was, like I wanted to celebrate that. Because it gave me the power to self-manage and understand the results" (#2). Another suggested,

> and then that also was when we started with the finger blood sugar checking, which to me has been the biggest change in the fifty some odd years… I love what I have now with the pump and I love all these new insulins but I could not live, I don't think, without blood sugar testing because urine testing was ridiculous (#6).

All of the participants were diagnosed when urine testing was the norm and they all commented on this form of testing as being an almost useless activity. For example,

> up until then it was just urine tests and, and sorry I should confess, those weren't fun, I skipped out of those every time I possibly could, if no one bugged me about them I didn't…That was not, not fun. Um, and quite often when I did check there was usually sugar in my urine. But you're just on one shot a day...Yeah. Okay, so you're not going to have a potato at dinner time, or like what? Like what are you gonna (do) (#4)?

Another shared, "urinalysis testing and ketone testing… the results back then were horrible, they were five hours old so you had no idea if you were doing good sugar wise or not" (#7).

Innovations continued over the years. Three of the participants were on an insulin pump. One participant has invested in a continuous glucose monitor, but is not on a pump. Both of these tools were described as facilitators for living well with diabetes. The following participant explains why convenience is so important to living well with diabetes,

> And convenience is, is important with diabetes because it makes the disease less of an issue if you can have all of these things that are convenient around you. You know, insulin pens and you don't need to sit in a restaurant and draw insulin out of a vial and make a spectacle of yourself. ...And so you know the decision to, well (do) I have to go to the bathroom now or can I just sit here and enjoy this conversation. I just take my insulin. So the pen's been a huge breakthrough and even blood glucose monitoring. I mean, it's so small and efficient and quiet and you know, you can do those things…in public places without anybody even really noticing...They think you're checking your phone (#5).

Another described the flexibility the new innovations have afforded her,

> now there are so many varieties of short acting insulins and long acting insulins and I take four shots for sure each day, but my goodness if somebody brings a cake into the office at two o'clock in the afternoon and I want a piece, I can have a piece, if I don't feel like eating lunch at noon, I don't have to eat lunch at noon. It can wait til one o'clock or I can eat lunch at eleven, like, I find there's so much more flexibility and options (#3).

One participant shared that when he was younger he would try to adjust the insulin to accommodate treats in his diet, but because of the less effective insulin than we have now, he

often experienced, what he described as "epic fails." Now, with the newer insulin he can accommodate treats and still maintain control over his blood sugars.

As technology and treatment changed over the years, diabetes became a self managed disease rather than a medically managed disease. The convenience of the newer treatments and technology made managing diabetes more achievable. However, the new treatments and technology added another layer onto the constancy of the disease, as can be seen in the next section on the constraint of technology and treatment.

2.2 Technology/Treatment as Task Master

The drawback to newer technology and treatments was the cost associated with them, both in time and money. Sometimes those costs dictated what the participant would choose, affecting their ability to live well with the disease. For example, two of the retirees are currently on insulin pump therapy and have been for years. A new pump will be needed soon and both are considering going off pump therapy due to the expense, even though the pump has provided good control for many years.

> Pretty soon I'm going to need a new pump. That's 7500 bucks. I don't really have 7500 bucks. ...it's more and more and more expensive all the time. So, that is my biggest regret, 'cause I, I'm kinda considering going off pump therapy... But, I, I've, pump therapy has become a part of me (#2).

The tension between purchasing supplies and other activities in life are very real: "...I feel guilty that I am going on a trip to the east coast, because I, I, I do need a pump, but I think I deserve the trip" (#2). When asked 'if diabetes has given you anything', one participant replied: "It's given me an added expense line on my annual budget" (#5). Another participant replied to the question 'what helps you live well with diabetes?' with "...I'd say technology. And having money. You

need both" (#6). Participants described health plans through work and wondered how people manage without drug plans:

> Luckily I have a very, very, very good uh, drug plan from work...I pay five dollars per, per prescription and that's it...So normally it would cost about $300 a month, I'm paying maybe $20 a month, so and some people don't have access, many people don't have access to things like that (#8).

Blood glucose meters, as mentioned earlier, were described as a necessity for self-management. When they first came on the market, they were expensive and two participants stated their families just could not afford them. Even today, the blood testing strips are expensive, so the cost to the person with diabetes, if they wish to test several times per day, becomes significant. Added costs include the medications that are necessary for the prevention of complications, such as blood pressure and cholesterol medications.

Technology and newer treatments have provided tools to make living with diabetes a much easier experience today than in the past. Conversely technology becomes a task master, as blood testing a minimum of four times a day becomes the norm. The expense of the technology and treatments were also described as a barrier to living well with the disease. However, the participants shared how grateful they were for the technology and newer treatments and find they do facilitate living well with diabetes. The newer technology and treatments have assisted the person with type 1 diabetes to live independently with the disease. However, parents, spouses, other family members, and medical caregivers provide a supportive role in managing the disease as well.

Theme 3: Self Reliance and Reliance on Others

Although type 1 diabetes is primarily a self managed disease, each of the participants recognized the other supports in their lives. All but one of the participants were diagnosed as a child or adolescent and thus the nuclear family in the childhood home had a great impact on the management of diabetes. Today, many of the participants still credit family as an important source of support in managing diabetes. As well, although medical management has transitioned into self management, the participants continue to recognize the support of their medical team. They do, however, note that the health system itself has created some barriers to living well with diabetes.

3.1 Family Support

Don't hover...mistakes will happen... your child has the diabetes, you don't.

Advice to the family of a newly diagnosed child (#3)

The most significant support identified by the participants were family. Parents, in most cases, were described as the first and greatest aide in learning to live with diabetes. Participants shared that their parents sacrificed as a result of their child's diabetes. One participant recalled having a conversation with her mother about the many times her mother got up daily to sterilize her child's syringes because, at the time of diagnosis, there were no disposable syringes. She said her mother vividly remembers thinking: "... not again, have to do this, I'm tired, I don't....then she sorta said she talked to herself and said this is ridiculous, they are going to live with it forever, I just have to do this till they're gone" (#6). Other examples of parental support included: a parent who worked until 4 a.m. and then got up to give insulin to his child at 7 a.m.; and a mother who made arrangements to come to where their child was having a sleepover to give her insulin, making it possible for the child to go for a sleepover. One participant lost his

mother when he was age 15. He remembers thinking, "...mom and I worked it out together, and there was always a lot of hugging, she held me close, made sure I gave it, and at fifteen, you're like, yeah this is all mine now" (#7). One participant credits his parents for supporting his "owning" of the disease from the outset, "but the most important thing they gave me ...right from the very framing it, in a, this is yours, you control it...And it's setting that tone for everything else to come" (#8).

As adults, the participants continued to indicate that family has a supporting role in living well with diabetes, especially spousal support. Support from the spouse was often described as being educated about diabetes and offering reminders when needed, "considering, consider how you feel, what should you do, stopping for meal times, that kind of thing" (#6). One participant described her husband as having a sixth sense about low blood sugars,

> My husband has some crazy sixth sense, 7am on a Saturday morning he's been up already for an hour, I'm still being a teenager at heart and sleeping. And he'll feel like something isn't right and he'll come upstairs and check on me in the bedroom, and sure enough I'm sweating. He'll try to wake me, I'm not waking, so he sticks dextrose in my mouth, checks me again in five or ten minutes. He is amazing (#3).

One participant was raised in a home with a strong faith in God. For years his family prayed for his healing. Although he has not been healed, he attributes living well with diabetes to his strong faith, the foundation of which was built within his birth family. Although he doesn't know why he has diabetes, he fully believes God will heal him, either on this earth or in heaven. God is his most important support. This motivates him to live well with diabetes.

Family was described as the base of support when learning about diabetes and continues to be a support into adulthood. Parents were the first teachers and helpers of the child or

adolescent learning how to manage diabetes. However, these participants also described living through the years when diabetes was primarily medically managed and witnessed firsthand the transition to self management.

3.2 Medical Management and Self Management

It's yours. You own it.

Advice to a newly diagnosed child (#8)

Diabetes care in the early years was described as medically managed rather than self - managed. This meant that the physician most often took the primary role. A shift in philosophy began to occur in the late 1970s when self-management and a health care team approach took precedence. As explained by one participant, "your results weren't dis(cussed), you weren't part of the team, ...I learned …about the team approach later on" (#2). The core team was described by the participants as the general practitioner, the endocrinologist, an optometrist or ophthalmologist, a nurse educator, and a dietitian. Other team members included podiatrists, pharmacists, massage therapists, and physiotherapists. One participant included his personal trainer as a member of his health care team. The participants considered themselves as having the central role in the team. When asked to enumerate the team, one participant listed himself first as "the number one person who should be in control. And the other people are the supports" (#8). Another participant suggested,

> I feel quite honored because I feel like I'm in the middle of this group of doctors who are doing everything to keep me going and they encourage me to keep going and not to stop....I'm like the quarterback because I'm the guy they're protecting in the middle (#7).

Since diabetes is chronic, oftentimes the participants described the relationship with their team as closer than a typical client-health care provider. This relationship, in some cases, has extended over decades. As one participant described it,

> Ask me about how I'm doing with things in life, I'm going to be your patient for 25-35 maybe 40 years, get to know me, get to know your patients. I have one doctor, my renal specialist, Dr. O, he's like that. He's this old fashioned hippie, big bushy beard, he likes Stanley Kubrick, he's had raccoons, we sit and talk, you know. I like that and I think that when you go into a doctor's office and you feel like you're being spoken to, not as a number to the doctor, you feel, I come out of my clinic feeling better, like I want to do better, I want to hear better from the doctors. Other doctors in the past, (were) like 'okay yeah, here you go, here you go, here you go, take care' and it's always like 'that was a waste of my time'. Everybody likes to have the acknowledgment of accomplishment, everybody likes that, whether it's health life, work life, everyone wants acknowledgement and when I see Dr. O, he chit chats, so how are your daughters doing? He knows their names (#7).

One participant spoke about a particularly traumatic low blood sugar for which she got admitted to hospital. She cried when her specialist came into the room, "So, anyway, Dr. L was there. And, he, I, I looked at him, and I bawled like a baby. I, 'cause I still had, I was a mess. And ...just, he just held me" (#2). This personal touch was what she needed at the time.

As noted, health care providers offer an important supporting role for the participants with type 1 diabetes. But how they assumed that role varied. Some diabetes specialists were described as knowledgeable and supportive about living with diabetes. For example,

> I suppose, I mean I don't know, (name of diabetes educator), I'd swear somewhere in the back of her brain she's a diabetic because when I talk to her about things she's like yeah, she understands it. She's my focus back, she can explain things to me, she can talk to me

> as if she already knows. It's a great relationship I have with her, it's always been kind of sporadic but when I'm with her it's like, yeah, she gets it (#7).

However, participants also reflected that it is impossible to learn diabetes from a book – you have to live it. So, in several cases, participants suggested that the diabetes educator or specialist should not be able to take that role unless they themselves have diabetes. For example, one participant suggested,

> if you took the book away from them, how much (do) they actually know, zero. They read a book, …and it's a practice makes perfect disease. So, if you have no personal practice with it, dealing with it, you never learn (#1).

Another participant was more direct,

> well first of all I wish they all had diabetes. I wish they all had acute type1 diabetes. That would be the first thing I wish on all of them...They all get the disease, if you don't have the disease you can't be in this profession. You know? Endocrinologist, you wanna make $800,000 a year, you're going to have to take insulin every day. That's just one of the qualifications to get through this door, that's what I would wish on them (#3).

The suggestion of healthcare providers having diabetes was about the provider having empathy for all the person with diabetes has to experience. Other participants mentioned empathy as well, although not in the context of the provider having the disease. They suggested that healthcare providers should be constantly aware of the never ending demands of the disease; that treatment options may need to be thought of "outside of the box"; and to not always be "on your case" or demanding of different behaviour.

The shift from medical management to self management was described as a positive by all of the participants. However, the medical system itself continued to make demands on the person, causing a dependence that many of the participants resented.

3.3 System Dependence

I would say get, get a, get a human being as a GP, not just a doctor, get a human being and then try to get a good medical team around you and do what they say, learn as much as you can as early on as you can so you can be your own physician.

Advice to a newly diagnosed child (#8)

In spite of the advances in technology and treatment that have made it possible for all of the participants to be self managed rather than medically managed, there were expressions of frustration with the medical system. Annoyance was expressed about the number of doctors' appointments and the way the system imposes greatly on their life. One participant, when asked 'What has diabetes given you?' responded, "Oh, it's given me... lots of doctors' appointments" (#5). The participant diagnosed as a young adult found it stressful to have to go for lab work in the morning because she would miss work, "I remember my heart just pounding because I was stuck at the lab, ...and going, well you know they are going to be watching me in the workplace, so ...that caused me a lot of stress" (#2).

Another participant expressed annoyance at attending doctor's appointments to learn nothing,

> There's the endocrinologist who is basically useless, they give you your numbers every six months. I tell mine, I said, you know, why do I come to see you in (city) here, what the hell am I doing? I got approached by three panhandlers while I was parking my car here, one of them is trying to vandalize it right now, you know, why am I coming to see

> you? And she says well that's the only way I can get paid. I said well ...isn't that ever stupid, eh? It is. So I got to go to (city) and back so she gets paid. I said, put two visits down. Cause I, I'm talkative today, put two visits down and I'm bitchy, you don't help me with anything (#3).

Frustration was also expressed about health care providers who do not recognize the expertise of the person with type 1 diabetes. A participant was in the hospital with an infection and her blood sugars were, as she described, 'through the freaking roof'. She was in a teaching hospital and every day the doctors would come around with their residents and talk at the end of the bed. She describes how every morning she would request to manage her own diabetes,

> so every morning when they were there I would explain 'guys can I please do my own insulin, can I please manage my diabetes properly'? Finally, must have been about the fourth morning, it was the same group every morning. One of the doctors turns and looks at me and he says, he asks me a few questions about diabetes, I answered them all appropriately. And he looks at the group and he says 'why are we not letting her manage her diabetes, look at these blood sugars we're running here, this is ridiculous' (#4).

Another participant shared,

> I do remember, uh, one newer doc coming in…and she started lecturing me on nutrition and stuff like that and I said, I just said to her 'wait a minute I've been living with this, at the time for thirty plus years. I know what I'm talking, I know about nutrition' (#8).

Another participant relayed a story about calling 911 because he was feeling unwell while driving. He did not want the ambulance dispatched, but it was and he was asked to pull over. He asked the dispatcher to have the attendants bring fast acting insulin, as he felt his symptoms were due to a high blood sugar. However, because chest pain was one of his

symptoms, he had called 911. The ambulance arrived with no insulin. The participant had also called his wife and she arrived with insulin whereby he was able to treat his blood sugar, resulting in the disappearance of the symptoms. He went to emergency because of the earlier chest pain. During a seven hour wait he had his blood drawn, "I said I'm going to let you take my blood but you know how ridiculous this is, by the time you analyze this I'll be sitting with my slippers on by my fireplace at home with my blood sugar perfect" (#3). Finally he was seen by a doctor and was able to tell his story, "the doctor says, I tell him a little bit about, he says don't ever come to emergency again... he says you know exactly what you're doing" (#3).

The health care system, with its rules and bureaucracy, has been described as a barrier to living well with diabetes. Numerous medical appointments that, at times, appear unnecessary and lack of recognition of the participants' expertise in diabetes management were both expressed as frustrations for the participants. However, health care providers within the system were some of the first diabetes educators for the participants.

Theme 4: External and Personal Knowledge

All of the participants expressed different ways of seeking knowledge, including how it had transitioned from face to face sessions with diabetes educators in the beginning to self motivated knowledge seeking through the internet, through taking courses, and through relationships with health professionals. As they were increasing and augmenting their knowledge, they also noted they had to educate others. Participants shared that many people around them lack diabetes knowledge, including the difference between type 1 and type 2 Diabetes and not understanding the unrelenting demands of the disease. The lack of knowledge was noted in friends, relatives and health care professionals.

4.1 Knowledge Seeking

I would assure them that this is manageable, it's going to right now seem very overwhelming and there's going to be a lot of information coming at you, it's going to be okay, pay attention, pay attention to the information you're given, know that it's going to be okay.

Advice to family of a newly diagnosed child (#4)

Learning how to manage diabetes initially occurred through face to face diabetes education with health professionals or, in many cases, with the parent of the newly diagnosed child. The participants recognized the need for and acknowledged the positive aspects of in-person diabetes education when initially diagnosed and even for some years afterward, but the longer they lived with the disease, the less desire they expressed for that type of education. One participant described the in-person formal diabetes education as, "you get to the place where you sort of stop, I wouldn't say you stop learning but you stop ...you know, your back is against the chair now instead of leaning forward like it was all those years" (#3).

Two of the participants are health professionals and had been certified in diabetes education. However, one chose not to renew his certification. He shared,

> and I didn't maintain it because I found that the people that I felt I could talk to, because now I was a certified diabetes educator, they didn't, they weren't necessarily as engaged with me until I told them I had type 1 diabetes. ...Then they started to listen. …So, so the credentials didn't mean anything...But the fact that I had diabetes, then it suddenly now meant something (#5).

Knowledge seeking did not cease as the participant aged, but rather different education avenues were used such as the internet, conferences, and Canadian Diabetes Association (CDA) webinars. A couple of the participants were heavily involved with the CDA in the early years of

their diabetes and were instrumental in planning diabetes conferences. In fact, the CDA was identified as an important source for learning about diabetes in the early years, including camp, family days and parent sessions. One of the participants involved with diabetes camp described it as a venue where a lot of children/adolescents learned independence. Although he felt camp was overall a positive, he did note that camp could also be a place where bad habits were learned. He described teenage girls learning informally from other campers about taking less insulin in order to lose weight.

Participants expressed interest in innovations and research that would improve living with the disease. They sought out new information primarily through checking with the endocrinologist about 'what's new' or researching the internet. A couple of the participants had ongoing relationships with one or more diabetes educator, whom they felt they could 'touch base' with informally through texts or email.

All of the participants expressed they felt knowledgeable about their disease and that the time of sitting down with a diabetes educator was in the past. Rather, now they were much more self directed in their knowledge seeking, which is synchronous with the concept of self management. However, as will be noted in the next section, they were often confronted by others who had limited knowledge about diabetes.

4.2 Lack of Knowledge of Others

> *... try to advance the knowledge and the lifestyle of people with diabetes to enhance other peoples opportunities behind you. And you will benefit from those experiences as I have...*
>
> *Advice to a newly diagnosed child (#3)*

Dealing with misconceptions and outright erroneous information of family, friends and health care providers was commented on by several participants. For example, one participant

spoke about a co-worker offering to get his insulin when he had a low blood sugar. Another spoke about family members believing that type 1 diabetes can be cured through alternative medicines, "There are some family members out there who still believe diabetes can be cured if I take this vitamin or consume more cinnamon or see this reflexologist...Their freaking alternative practitioners and vitamin pills are not going to cure anything" (#4).

Examples of people not understanding simple things, such as that both sugar and honey are simple sugar were shared, "I remember my grandmother saying, I was having tea with her, and she offered me some sugar and I said ‘well you know sugar’s not good for the diabetic’ so ‘well here’s some honey, it’s natural, it’s not sugar’" (#8). Or what a carbohydrate is, "I’m surprised when I used to volunteer and teach, for lack of a better term, diabetes 101, and how many people didn’t understand what a carbohydrate was. Dudes, come on, this is second nature" (#8).

Frustration was expressed about people not understanding the difference between type 1 and type 2 diabetes,

> I get tired and I love my friends for this, and my family, I get articles sent to me, through Facebook or my dad will call me and ‘oh saw this in the news about a cure’, and I’m like dad, it’s type 2 (#7).
>
> I think the general population, well you know this too, has no clue of what it’s like. So I don’t know how you correct that because they just all think it’s just fat uncle joe, just stop eating and start exercising and it's so different with type 1, I mean it’s totally different (#6).

As indicated, there was mention of the general lack of knowledge of others about type 1 Diabetes and how to manage it. Participants identified this as a barrier to living well with type 1

Diabetes. Alternative medicine as a cure, lack of basic understanding of physiology, and the confusion between type 1 and type 2 diabetes were the specifics that were shared.

Chapter Summary

Eight participants with 40 to 52 years of experience living with type 1 diabetes shared their thoughts and experiences on how to live well with the disease. The impact of the diagnosis of diabetes was identified as a turning point in their lives and they described stages in the 40+ years when it was more of a challenge to live well with the disease than at other times. They all described times of accommodating and times of battling the disease.

Each participant integrated diabetes into the routine of their life, which along with a positive life attitude, facilitated living well with the disease. Living in balance and recognizing that it was achievable to live well with diabetes were identified as a mindset that helped with successful diabetes management. A number of the participants identified positive benefits diabetes had given them, such as developing skills and fostering healthy lifestyles. However, integrating the disease into their life did not pre-empt the fears and losses associated with the disease.

The concept of mortality became a reality for them at a younger age as they were bombarded with messages about the damage diabetes could do to them. It seems the recognition that they would not live as long as their friends was common and, in one case in particular, led the participant to experimenting dangerously as an adolescent.

Daily injections were identified as an initial fear that is now only tolerated as a necessity of life. Childhood was fraught with losses such as Halloween activities, lack of sleepovers, not being invited to birthday parties, or being invited and not allowed to partake like other children. Adolescence was a difficult time, as diabetes made them more dependent at a time when they

were trying to assert independence. Risky behaviour often prevailed during this time, including rebellion against diabetes. Young adulthood provided challenges to diabetes control as the women traversed pregnancies made more difficult due to diabetes, and the business of education, career, and starting a family pushed diabetes into the background, resulting in less control of the disease. Aging also contributed to loss of diabetes control as other chronic diseases took precedence, physical activity was reduced, and the physiology of aging itself interfered with control (e.g., menopause).

Stigma was also described, whether overt, such as deliberate shunning on Valentines Day, to subtle, such as not being invited to birthday parties. Other losses included choices that were made to try and accommodate diabetes such as not travelling, not having children, not choosing the career of their dreams, and dropping out of activities they enjoyed.

Diabetes was described as unrelenting, with no holidays from the daily pressure of keeping blood sugars under control. All the participants expressed that fluctuating blood sugars are a fact of life with diabetes, and trying to keep blood sugars balanced is a battle or fight that is constant. Daily life is impacted by high blood sugars that were described as affecting concentration and emotions, and low blood sugars, which could be life threatening. Traumatic hypoglycemic events were shared by a number of the participants.

Technology and newer treatments, especially blood glucose testing were lauded as making life better for the person with diabetes, improving wellbeing, and allowing the person to self-manage. The convenience of these new innovations allowed for a flexibility and transportability that made controlling the disease much more achievable. However, these same improvements were also outlined as barriers to living well, contributing to the unrelenting 24/7 nature of the disease. Blood testing provided the data for treatment decisions, but it also meant

testing occurs many times a day, equipment has to travel with the person, and he/she must always be aware of what the technology needs (e.g. charging, more strips, refilling). As well, the expense related to technology and newer treatments was described as a challenge for living well with diabetes. Participants expressed that they may have to choose between the financial expense of treatment that has worked well for them and other activities in life.

Although self-reliance or self management of diabetes was primary, all participants also shared experiences about their reliance on the support of others. Parents were often the first line of support for the participants. They were the first teachers, and sacrificed to make the child/adolescent's life better. Family continued to be a support in the future, mostly in the form of spouses who supported with reminders and accommodations for the disease.

Reliance on medical personnel has continued to this day, however disease management has evolved from primarily medical management to primarily self management. Since self management has become the norm, most participants describe their care providers as a team, with themselves as team leader. Participants also spoke about the unusual long term relationship with health professionals, sometimes thirty years or more. The medical personnel who see the person with type 1 diabetes as a person with a full life were appreciated more than those who saw the person as a ‘number’. There were stories of the doctors or diabetes educators who knew the names of the person's family, knew their interests, and knew them as a person. Those were the health care providers who generated a desire to 'do better' with their diabetes management.

Although self management was described as the current norm in diabetes care, the participants shared that, in some cases the system had not caught up to that philosophy. Numerous doctor's appointments that were not felt to be useful were a frustration. Situations

were also described that involved the protocols or policies of the system making it impossible for the person to self manage, for example when admitted to hospital.

Finally, the participants shared how they increased their personal knowledge of diabetes and their frustration at the lack of general knowledge about diabetes. Although each participant had at least some formal diabetes education within the health care system, none are seeking that type of education now. These participants want information on new innovations or research on better treatment methods or a cure. Knowledge seeking is through the internet, asking an endocrinologist at a regular appointment, or informally touching base with diabetes educators through email or text.

Frustration was expressed about the lack of knowledge of the general public, including family and friends, about type 1 diabetes. There was discussion about: the general lumping together of type 1 and type 2 diabetes when they are two different diseases; alternative medicines, and how well-meaning relatives and friends frequently provide information on the latest 'cure all'; and lack of general knowledge about the basics, such as the fact that insulin reduces blood sugar. These examples of lack of general knowledge were described as frustrating for the participants.

In this chapter, the stories of the participants who have lived 40 plus years with type 1 diabetes have been interpreted into themes and contextualized with the participants' own words. The next chapter, Discussion, will be the venue to examine, reflect and reinterpret the themes "within the context of other literature" to determine what the study "means" (Thorne, 2016, p. 215).

CHAPTER FIVE: DISCUSSION

The discussion chapter provides an opportunity to examine this study in relation to other research. This layer of interpretation allows the findings to be placed within the context of past research, either providing support for earlier findings, noting contrasting results with past research, or illuminating new insights.

Previous research into living long term with type 1 diabetes tends to be sparse, with an extensive literature search revealing no articles that specifically address this population. However, research exists that addresses some of the ages and stages of diabetes that are comparable to what was learned through this study. Research results that resonate with the participants' experiences include: the unremitting responsibility of diabetes that coincides with the concept of diabetes distress; the development of collegial relationships with health care providers leading to improved management; and the lack of general community knowledge about diabetes, especially the difference between type 1 and type 2. No research studies were found on the losses experienced by those with type 1 diabetes and the burden that technology places on the person with type 1 diabetes. Finally, this population has essentially chosen to exit from formal diabetes education and there seems to be little to no research on how, or even if there is a need, to reconnect them.

Ages and Stages of Type 1 Diabetes

There are a number of studies that examine the ages and stages of living with diabetes - primarily focusing on the stages of childhood to young adulthood. Because the participants from this study have lived through and experienced those ages and stages, they were able to comment on each.

The literature on the experience of type 1 diabetes in childhood and adolescence introduces the concept of desiring to be ‘normal’ (Babler & Strickland, 2015b, p. 89; Freeborn et al., 2013; Huus & Enskär, 2007; Marshall et al., 2009; Spencer et al., 2013). However, this desire to be ‘normal’ does not end with adolescence; it carries on into young adulthood and beyond (Balfe et al., 2013; Ingadottir & Halldorsdottir, 2008). The current study extends this concept even further, noting that the participants continue to seek normalcy by integrating diabetes care into the routine throughout their lives. However, participants also noted that diabetes interferes with the routine or the norm, due to sneak attacks of hypoglycemic events and the demands of vigilant care. In the same way that Huus and Enskär (2007) describe the life experience of the adolescent with diabetes as a "pendulum swinging between normal and being different" (p. 29), the participants – having lived with diabetes for 40+ years – suggested they oscillate between the factors that facilitate living well with diabetes and those that challenge living well with diabetes.

Many of the ages and stages described by the literature as problematic were validated by the participants of this study as stages of difficulty in coping with diabetes. Adolescence, for example, was described by the participants as fraught with difficulties, often related to the seeking of independence from parents-something also noted in the Babler and Strickland (2016) study. Young adulthood was described by some of the participants as a time of abdication of some of the responsibility of managing diabetes as other life activities such as education, career and family took precedence; this supported the findings in the Balfe et al. (2013) study. Where past research and this research diverge, however, is discussion of the adult entering their 5th and 6th decade of life. The difficulties in managing type 1 diabetes as concurrent chronic diseases appear such as arthritis and adult onset asthma were described by the participants as taking

precedence at times over diabetes, thus, causing the management of diabetes to be less than optimum.

Stigma and Loss

Participants described experiences of stigma. However, this was described mostly in terms of the past - for example not being invited to birthday parties as a child. Interestingly, events that could be construed as stigma such as not being allowed to take a sick day from work for specialist appointments, or being told 'you can't have that, you have diabetes', were not seen as stigma by the participants. This finding is different from the Browne et al. (2014) study from Australia that identified blatant stigma in their study of adults with type 1 diabetes. Further research would be needed to determine if, perhaps, this could be explained as related to cultural differences between Canadian and Australian participants.

Although stigma was not viewed as a substantial barrier to living well with diabetes, loss was a recurring theme. The participants identified travel, not having children, not choosing a specific career, and dropping out of activities they enjoyed, as losses that were all directly related to diabetes. Existing research does not address the losses that the person with long term type 1 diabetes has encountered. A significant loss identified by the participants was the loss of the young person’s sense of invulnerability. All of the participants spoke of recognising their own mortality early. In fact, many spoke of how the message of early mortality was imposed on them by friends, family, health care providers, and media. At the time this group of participants was diagnosed, life expectancy for a person with diabetes was reduced by 27 years (Goodkin, as cited in Miller, Secrest, Sharma, Songer, & Orchard, 2012) and this may have contributed to this finding. As new innovations have occurred in the diabetes field, life expectancy has improved. For example, in their prospective, study Miller et al. (2012) found that life expectancy is reduced

only 4-6 years for those born in the 1960s and 1970s. More research is needed to determine whether this early awareness of mortality is experienced more acutely by those who were diagnosed when life expectancy was significantly reduced.

Diabetes Distress

The participants indicated that the unrelenting nature of type 1 diabetes was a challenge to living well. Schwartz et al. (2017) suggests that diabetes management can be "the equivalent of a part time job…and may eventually overwhelm patients' capacity of handling the diabetes workload" (p. 35). This constant vigilance can be an assault to the person's mental health. Depression has been increasingly recognized in people with diabetes, with approximately 30% of all people with diabetes experiencing clinically relevant depression and 10% having a major depressive disorder (Robinson, Luthra, & Vallis, 2013). Recently experts in diabetes and mental health have been suggesting that the symptoms that lead to a depression diagnosis, in many cases, may not be depression but are in fact diabetes distress (Esbitt, Tanenbaum, & Gonzalez, 2013; Robinson et al., 2013; Strandberg, Graue, Wentzel-Larsen, Peyrot, & Rokne, 2014; Sturt, Dennick, Due-Christensen, & McCarthy, 2015; Vallis et al., 2016).

The term diabetes distress has been around for more than two decades (Polonsky et al., 1995) but has only recently "achieved a sharper focus in clinical practice" (Sturt et al., 2015, p. # needed). Diabetes distress is defined as "the despondency and emotional turmoil related specifically to having the condition, the need for continual monitoring and treatment, persistent concerns about complications and the potential erosion of personal and professional relationships" (Robinson et al., 2013, p. 89). The measures used to determine a major depressive disorder do not account for life stressors "that may be causally related to depressive symptoms" and thus are not sensitive to diabetes distress (Esbitt et al., 2013, p. 28). Esbitt et al. (2013), in

his chapter titled “Disentangling Clinical Depression from Diabetes-Specific Distress: Making Sense of the Mess We’ve Made”, suggests that if the depression is actually subclinical diabetes distress or if the depression is secondary to diabetes distress, antidepressants are not going to be effective.

Numerous expressions of diabetes distress were expressed by the participants including: descriptions of diabetes being a fight or battle; feeling as if they wanted a holiday from diabetes, but recognizing there were no holidays; needle phobia and ongoing dislike of needles; the trauma of severe hypoglycemia; the frustration of constantly fluctuating blood sugars; the expense of the disease; and the constant responsibility of managing the disease, with all its component parts (e.g. diet, testing, exercise, medical appointments). It appears that the length of time a person has diabetes may not mitigate the distress of dealing with it. This is an important finding in light of newer studies indicating that distinguishing between major depressive disorder, depressive symptoms, and diabetes distress is very important because, of the three conditions, “diabetes distress may be most strongly related to adverse diabetes outcomes” (Robinson et al., 2013, p. 89; Strandberg et al., 2014).

Two well validated scales for measuring diabetes distress have been developed; the Problem Areas in Diabetes Scale (PAID) and the Diabetes Distress Scale (DDS) (Esbitt et al., 2013; Polonsky et al., 1995; Sturt et al., 2015). Sturt et al. (2015) reviewed the evidence for diabetes distress in type 1 diabetes using both the PAID and DDS and determined diabetes distress is elevated in 20-30% of those with type 1 diabetes. Another study examined diabetes distress in 305 adults with type 1 diabetes in the U.S. and then followed with a confirmatory study with another 109 Canadian participants (Fisher et al., 2015). The authors in this study, determined the DDS was not specific to type 1 diabetes and thus developed a new measure– the

T1-DDS. Seven major sources of diabetes distress were identified: powerlessness, which related to the fluctuations in blood sugar and the difficulty in managing those fluctuations; management and eating, which highlighted the food restrictions and worries about monitoring; hypoglycemia, which focused on the fear of the traumatic lows that can lead to embarrassment and risk; negative social perceptions, which referred to other people treating them differently and worries about the way employers perceive them; family/friend distress, which refers to the family and friends who try to police them or, alternatively, who take no interest in their diabetes; and finally physician distress, which relates to not receiving appropriate support from the physician. Over 40% of the participants experienced moderate diabetes distress using this new measure (Fisher et al., 2015). Powerlessness received the highest item rating, with management/eating and hypoglycemia having the next highest levels, (Fisher et al., 2015, p. 7), which underscore the unremitting demands of diabetes care.

In spite of the relentless responsibility of type 1 diabetes, all of the participants in this study exhibited and stated that a positive attitude helps them live well with the disease. This supports Stucky et al.'s (2014) findings, through the multinational DAWN2 study, that "having a positive outlook and sense of resilience in the midst of having diabetes" (p. 2466) was a facilitator for adapting to diabetes.

Technology as a Burden

Technology, although a benefit to diabetes self-management, was also identified by the participants as a burden. Technology is a fact of life in type 1 diabetes management today, perhaps more so than in any other chronic disease (Gonder-Frederick, Shepard, Grabman, & Ritterband, 2016). Although technology has improved living with diabetes in many ways, there is little recognition in the research of the life burden that the technology imposes. This is an area

of research that needs further exploration, both for current and future technology use. As stated by Gonder-Frederick et al. (2016), "the hope for the future is that the development of diabetes technology will occur more in tandem with the development of psychological and human factor research" (p. 585).

Relationships with Health Professionals

Participants indicated the relationship with health care professionals could be a source of support or another source of stress. Because of the chronic nature of type 1 diabetes, the relationship with health care professionals may extend over decades. Participants expressed a desire to be approached in a collegial manner by health professionals; they wanted their care providers to acknowledge they did most of the work of diabetes care and thus were experts in managing their own disease. Doctor's appointments that seemed to serve no purpose were described as frustrating. Often participants described health professionals as judgemental who did not recognize the moment by moment responsibility of living with type 1 diabetes. Several participants went so far as to suggest that health care providers working with people with diabetes should have the disease, with one suggesting it is a "practice makes perfect" disease, asking rhetorically, if you don't have practice how can you advise?

Other studies have also emphasized the need for the health care provider to treat the person in a non-judgemental way and to recognize them as an expert in the management of their own diabetes (Richards et al., 2006). A consensus report developed by a number of diabetes experts convened by the American Diabetes Association recognized the multidimensionality of diabetes management – that management cannot by extricated from the individual's context (Marrero et al., 2013). The authors identify several recommendations for health care providers that support a collaborative model "where patients and clinicians relate as equals"(Marrero et al.,

2013, p. 465). The concept of judgement is also addressed in this consensus paper, as the authors suggest that laboratory tests be viewed as “feedback instead of judgement” (p. 465).

Health care provider empathy was important to the participants, including the recognition of the day-to-day challenges of dealing with type 1 diabetes. Health care providers often approach sub-optimal blood glucose control by focusing on diabetes management and trying to increase the person’s skills or knowledge about the disease (Schwartz et al., 2017, p. 40). Schwartz et al. (2017) suggests another approach would be to talk less about diabetes and its management and more about the patient’s life, although that may seem "counterintuitive" (p. 40. Trust and a therapeutic relationship can be nurtured through this approach, ultimately resulting in better diabetes management. A challenge is that in this hurried world of health care, time is at a premium, and the time needed to nurture relationships may be seen as expendable. As suggested by Schwartz et al. (2017), physicians cannot afford to spend time on relationship building in a "fee for service environment that rewards volume over quality" (p. 40).

Diabetes Education

Classic diabetes education (in-person with a nurse and/or dietitian) was not something participants in this study sought out. Rather, they sought out (and found useful) education that could fit into their lifestyle, which included the internet, quick emails or texts to others, or asking questions to the endocrinologist during a regularly scheduled visit. These participants did not stop learning, although after 40 years of living with the condition they no longer felt the need for the classic diabetes education. It was intimated that they felt this type of diabetes education was more geared to people in the beginning stages of learning about diabetes. No research was found regarding how to reach this particular audience for ongoing diabetes education. In some ways this audience is lost to diabetes education system, having ‘dropped out’ many years ago. Further

research is needed to determine how to meet the educational needs of those with long term type 1 diabetes.

Lack of Community Knowledge

Participants in this study commented on the lack of knowledge about type 1 diabetes in the general community. The DAWN2 study revealed that the respondents to the survey felt that "the experience of support was found to be lower, especially for type 1 diabetes" within community and work environments (Vallis et al., 2016, p. 240). A lack of understanding was also noted about the difference between type 1 and type 2 diabetes (Vallis et al., 2016). Recommendations from the DAWN2 study included a "public education campaign to increase awareness of and support for people living with diabetes, particularly to clarify the differences between type 1 and type 2 diabetes" (p. 240). Findings from this study align with findings from the DAWN2 study in this way.

Chapter Summary

Rich information was shared by the eight participants of this study. The information on the ages and stages of diabetes fit well within the context of past research; the difficulties in living with type 1 diabetes as an adolescent and young adult were expressed. The process of 'normalizing' diabetes seems to be never ending for these participants. They described fitting the management of type 1 diabetes into their daily routine, similar to brushing teeth. Some stigma was described, but the group overall did not feel stigmatized, such as was described in the Australia study (Browne et al., 2014). Though these participants expressed similar experiences to those in the Browne et al. (2014) study, they did not refer to these as stigma; they did not feel stigmatized. Instead, "loss" was a stronger theme for these participants—something identified in this study as a gap in the literature. A particularly poignant loss was the participants'

experiences of their early recognition of mortality. Diabetes distress was encompassed in the descriptions the participants shared relating to the unceasing demands of diabetes management. Little research has been done on diabetes distress in the type 1 diabetes population, and none exists on those living long term with diabetes. Although technology has been recognized in research articles for the benefits it has brought to the self-management of diabetes, there is scant research on the impact that technology has on quality of life for the person with type 1 diabetes. The participants shared their ideas regarding qualities that foster a good health professional relationship, and some that hinder it. Interpersonal communication that shows the professional's interest in the person beyond diabetes was highlighted, and research has supported this finding. They also noted ways in which diabetes education is primarily self-directed. Finally, lack of community knowledge about diabetes was noted to be, at the very least, an annoyance factor for the participants of this study, and at the most, dangerous misinformation. This aligns well with findings from the DAWN2 study, which supports the need for increased community education on type 1 diabetes (Vallis et al., 2016). Chapter Six outlines the recommendations for health professionals based on this study.

CHAPTER SIX: CONCLUSIONS AND RECOMMENDATIONS

The methodology of Interpretive Description was created for nurses by nurses, with the primary purpose to provide meaningful knowledge "in a world of practical application" (Thorne, 2016, p. 229). Although the method was meant for nurses, the participants from this study provided information on practical implications for health care providers as a whole. Accordingly, the recommendations will be reported from a health care team approach. This resonates well with the participants as many described a health care team approach in relation to their diabetes care, a team that was directed by the participants, and which includes nurses.

Interpretations and recommendations cannot, in good conscience, be viewed independently of considerations of good research. The scientific quality in relation to this research, based on Lincoln and Guba's framework (as cited in Polit & Beck, 2017, pp. 559-560), was discussed in Chapter 3: Methodology. Thorne (2016) suggests moving beyond typical evaluation criteria to include moral defensibility, disciplinary relevance, pragmatic obligation, contextual awareness, and probable truth. Prior to describing the recommendations for practice, each of these criteria will be considered in the context of the current study. This will be followed by recommendations for practice and suggestions for further research resulting from the interpretation of participant discussions.

Beyond Evaluation Criteria

Because qualitative research is expected to influence practice, it makes sense to return to the initial research question to determine whether the data collection and "interpretive strategies ...follow logically from that question" (Thorne, 2016, p. 233). The research question in this study was: What do persons living with type 1 diabetes for forty years or more perceive as

facilitators and barriers to living well with diabetes? And the main questions guiding this study were:

1. How do persons living with long term type 1 diabetes define “living well” with diabetes?
2. What do persons with long term type 1 diabetes perceive as facilitators to living well with diabetes across their lifespan?
3. What do persons with long term type 1 diabetes perceive as barriers to living well with diabetes across their lifespan?
4. How might health care providers support “living well” with long term type 1diabetes?

Each of these questions were addressed through the study.

Moral Defensibility

It is important to examine how the research findings may benefit people with long term type 1 diabetes. These findings are not just interesting stories, but provide a deeper understanding of the challenges of living with long-term diabetes. This deeper understanding by care providers may lead to improved care approaches and a higher quality of life for those experiencing this disease. Those with long term type 1 diabetes did not seem to have a "voice" in the current research literature. This project provided that voice, and the interpretations of the findings led to recommendations for improving type 1 diabetes care and education for those living long term with the disease.

Disciplinary Relevance

The number of people being diagnosed with type 1 diabetes is increasing, the treatment modalities continue to improve, and the life expectancy gap for people with type 1 diabetes is narrowing towards the life expectancy of the broader population. As the population of people living with type 1 diabetes continues to grow, so will the need for strategies to provide optimal

care. The development of care approaches that take patients' own experiences into account can provide a more meaningful discourse for care providers. Thus, the practical implications on how to best serve this population will continue to grow, making this research relevant to practice.

Pragmatic Obligation

Pragmatic obligation refers to the possibility that the study may have an impact on practice. Accordingly, it is important to recognize the limitations when suggesting the findings may transfer to a more general knowledge. This study was limited to eight individuals with long term type 1 diabetes who had similar characteristics. Repetition of the study with a more diverse group would assist in making the findings more generalizable. However, from the perspective of pragmatic obligation the researcher examined the findings within the context of other research and "'as if' they might be applied in practice" prior to setting the recommendations for practice down within this chapter (Thorne, 2016, p. 237).

Contextual Awareness

The researcher identified her contextual biases through a reflexive journal throughout the study, and attempted to bracket them. However, as Thorne states, "perspectives are inevitably bounded by their historical context as well as by their disciplinary perspective" and "we cannot see what we cannot see" -- making it clear that it is impossible to extricate the researcher from the research (Thorne, 2016, p. 237). However, it is hoped that the expertise of the researcher as a health professional having worked in diabetes education and the spouse of a person with long term diabetes would add to the richness of the study, while also recognizing the inherent possibility of bias.

Probable Truth

Thorne (2016) reminds us that qualitative research cannot provide absolute truth. Though as researchers we desire to produce credible results, it is imperative that we accept the limitations on validity within qualitative inquiry. However, qualitative inquiry does provide us with meaning from people's experiences. This study has been undertaken to find meaning that has practical application for those living long term with type 1 diabetes.

Implications for Practice and Further Research

All eight participants had a rich history of living with type 1 diabetes for 40 years or more. Participants were able to share their practical wisdom during the course of the study. These discussions revealed a number of areas with practical implications including: relationships between health care providers and persons with long term type 1 diabetes; special considerations for those living with long term type 1 diabetes, such as diabetes distress, losses related to diabetes, and technology burnout; and how to meet the educational needs of this group along with how to access the educational resource that this group represents. Overall, research is limited with this population and several areas for potential future research were identified through this study.

Relationships with Health Care Providers

As emphasized by the participants, type 1 diabetes is a long term disease, primarily managed by the person with the disease. Because the nature of long-term type 1 diabetes is chronic in the truest sense, the relationship between a health provider and the person with diabetes may extend over decades. It has been suggested by these participants that such a relationship should be deeper than what lab values reflect. That is, the health care provider in the relationship should: 1) recognize that the person with the disease is the expert on their own

diabetes; 2) be aware that the context of the person's life affects their diabetes management, and therefore should have conversations beyond current diabetes control; and, 3) have a relationship that reflects collegiality and problem solving, rather than a hierarchical relationship with the health care provider as the 'expert'.

Special Considerations for those Living with Long Term Type 1 Diabetes

Living with long term type 1 diabetes has challenges that are unique to this population. Some practical considerations for health care providers caring for this population are listed below.

Diabetes distress. Although research into diabetes distress and type 1 diabetes is relatively new (Fisher et al., 2015; Sturt et al., 2015; Vallis et al., 2016), there is some evidence indicating that people with type 1 diabetes are more at risk of diabetes distress than those with Type 2 diabetes. It appears that the length of having the disease may not mitigate the distress, as these participants shared numerous examples of diabetes distress. There also appears to be a correlation between diabetes distress and poorer diabetes outcomes (Robinson et al., 2013). Thus, it seems to make sense to be screening for diabetes distress and addressing the results with those with type 1 diabetes. There are several validated screening tools such as the Problem Area in Diabetes Scale, the Diabetes Distress Scale and the T1-Diabetes Distress Scale for measuring diabetes distress that take little time to complete (Esbitt et al., 2013; Fisher et al., 2015; Polonsky et al., 1995). Esbitt et al. (2013) suggests that waiting room time could possibly be used for completing brief self-report assessments.

The danger of screening is that the health care provider may feel ill-equipped to assist with areas of distress. Esbitt et al. (2013) points out that "talking openly about the distress related to the challenge of diabetes does not require special mental health training; empathic

listening, engagement in thoughtful and supportive dialogue, and the use of reflective comments are important skills for all members of the health care team" (p. 41). However, further training in managing diabetes distress could also be beneficial for the health care provider as well as being aware of other resources in the community to whom the person can be referred.

Losses related to type 1 diabetes. Numerous losses related to type 1 diabetes were outlined by the participants such as choosing to travel less due to the complexities of traveling with diabetes, not having children, not choosing a specific career (e.g., music career that would include irregular hours and travel), and dropping out of activities they enjoyed. An early recognition of mortality was also a loss this group experienced. No research on the losses related to type 1 diabetes was found in the literature search. This is a subject that could benefit from further exploration. Are the losses more prevalent for this population - those having lived long term with type 1 diabetes? Or has the newer generation of those with type 1 diabetes experienced these losses as well? How have these losses impacted quality of life? How have these losses impacted diabetes management? Further research could unravel some of these queries.

Aging and type 1 diabetes. As we age, the appearance of chronic disease seems to become somewhat inevitable. Having type 1 diabetes did not exempt these participants from other chronic diseases such as arthritis and adult-onset asthma. Participants suggested that diabetes management sometimes suffered as another chronic disease took precedence over their attention. Coordination of care by health care providers that takes the whole person into consideration would be of benefit during this time. For example, having multiple doctor's appointments or education appointments can cause the individual to make choices as to which

appointments take precedence as a busy life cannot accommodate all. Coordination of the appointments to maximize the person's time would be of benefit.

Technology as benefit or burden. Technology was identified by the participants as a benefit that made it possible for them to take on the management of type 1 diabetes. The introduction of self-blood glucose testing was identified by a number of the participants as the most important technological advance during their time of having type 1 diabetes. However, they also indicated the burden that technology imposed - adding to the financial burden and the unrelenting demands of diabetes.

Adoption of technology for diabetes has been slow, with most people with type 1 diabetes adopting self-blood glucose monitoring (99%) thirty some years after the initiation of this technology (Gonder-Frederick et al., 2016). Although this technology has reached almost all of those with type 1 diabetes, other technologies such as the insulin pump and continuous glucose monitoring are not being adopted at the same rate. As suggested by Gonder-Frederick et al. (2016), adoption of technology is not just a function of the person's understanding the benefit or objective utility, but rather needs to take into account "subjective perceptions" (p. 578) such as the time constraints affiliated with the technology.

Participants in this study identified two barriers to adoption of technology: cost and convenience. Two actions can be identified from these barriers. First, lobbying needs to occur to make technology available to people with diabetes at an affordable cost. Health care providers can join their voice with organizations such as Diabetes Canada and the Juvenile Diabetes Research Foundation to lobby government to provide support for those with type 1 diabetes to incorporate technology into their management. For example, eight provinces in Canada cover the cost of an insulin pump for those between the ages of 17 and 25 (depending on the province)

(Canadian Diabetes Association, 2015, p. 31). One wonders what happens when the person reaches the age of the limit of coverage – must they give up the pump due to cost? This question was asked by two of the participants who are going to require replacement pumps but are living on retirement income. A technology solution, the insulin pump, has worked well for them for many years but may now become cost prohibitive. Many health care providers may be unaware of the limitations of coverage and could have a strong voice in advocating for improved availability of these technologies. Furthermore, technology research needs to incorporate human factor research. As new technologies are developed, participants with type 1 diabetes need to be included to provide insights about the psychosocial barriers that may impede adoption of the newer technology.

Diabetes Education

Two implications arose from discussions about diabetes education with the participants: 1) that the participants are no longer involved in formal diabetes education, and 2) that those with long term type 1 diabetes have experience that could benefit the newly diagnosed.

Formal diabetes education. Two of the participants had been certified diabetes educators in the past. One is now retired and the other did not feel the credentials made him more attractive to the person with diabetes - rather the fact that he had diabetes made him a more credible source of information, so he let his certification lapse. None of the group has a formal relationship with diabetes education now, though they had learned about diabetes at the beginning of their journey through the classic face to face diabetes education. All of the participants continue to seek information about type 1 diabetes, especially by querying new developments via internet searches, asking the endocrinologist, or through informal relationships with diabetes educators.

It is difficult to know whether this group needs to be or should be supported by formal diabetes education. None of the participants seemed to desire it. However, it seems as if this group, those with long term type 1diabetes, are somewhat lost to diabetes education, only plugging back into the system during a crisis such as a hospital admission. More research is required to determine how best to meet the educational needs of this population. As most indicated the internet was often a source of information, it would seem logical to have them connected to local diabetes education through websites, chat rooms, and even text messaging.

Tapping into the expertise. The participants in this study were able to share expertise in diabetes management that had extended forty plus years. During the discussion they shared numerous examples of wisdom they would share with the person learning to deal with a new type 1 diabetes diagnosis.

Several instances of health coaches have been integrated into diabetes health centres as pilot projects (Foundation Pour La Santé Medavie Health Foundation, Canadian Diabetes Association, & New Brunswick, 2014; McGowan, 2017). However, the focus is on type 2 diabetes and/or preventing diabetes. More research is needed to consider how to integrate the wisdom that persons with long term type 1 diabetes have into supporting the person newly diagnosed with the disease.

Chapter Summary

The information provided by eight individuals with type 1 diabetes for a duration of 40 years or more has been developed into implications for practice. Four themes were identified that identify the barrier and facilitators to living well with the disease. The barriers and facilitators were, to some extent, two sides of the same coin. They described ways in which they regularly accommodate *and* battle the disease, how technology *and* treatment can be both a

convenience and a constraint, how they move between self-reliance *and* reliance on others, and how they draw from external *and* personal knowledge in order to live well with type 1 diabetes. The themes were then developed into implications for practice for the health care team working with people with long term type 1 diabetes. Each recommendation was considered through the lens of moral defensibility, disciplinary relevance, pragmatic obligation, contextual awareness, and probable truth. Although the limitations of the study (a small sample and fairly homogenous respondents) need to be recognized, it also should be noted that the strength of the study was providing a voice for this particular population, which does not seem to be present in existing literature. Further research with this population would strengthen the implications for practice. Specifically, further research is needed on diabetes distress, losses experienced due to diabetes, how to meet their educational needs, and how to tap into their expertise for the benefit of those with type 1 following them.

Conclusion

Living well for the long term with type 1 diabetes is a multifaceted and difficult task. Eight participants willingly shared their journey with diabetes and expressed times of triumph and times of difficulty. Type 1 diabetes is a demanding disease, but these participants described facing the challenge with an overall positive attitude. This is not a disease that can be separated from the stuff of living and each participant made that clear. It is an unavoidable part of them, and they daily try to keep it where it belongs, a part of life, but not all of life. Their rich stories and insights are valuable for health care professionals and for others wanting to learn how to live well with type 1 diabetes.

References

Ahrén, B. (2015). Hepato-incretin function of GLP-1: Novel concept and target in Type 1 Diabetes. *Diabetes, 64*(3), 715-717.

Babler, E., & Strickland, C. J. (2015a). Moving the journey towards independence: Adolescents transitioning to successful diabetes self-management. *Journal of Pediatric Nursing, 30*(5), 648-660.

Babler, E., & Strickland, C. J. (2015b). Normalizing adolescent experiences living with Type 1 Diabetes. *The Diabetes Educator, 41*(3), 351-360.

Babler, E., & Strickland, C. J. (2016). Helping adolescents with Type 1 Diabetes 'figure it out'. *Journal Of Pediatric Nursing, 31*(2), 123-131. doi:10.1016/j.pedn.2015.10.007

Balfe, M., Doyle, F., Smith, D., Sreenan, S., Brugha, R., Hevey, D., & Conroy, R. (2013). What's distressing about having Type 1 Diabetes? A qualitative study of young adults' perspectives. *BMC Endocrine Disorders, 13*, 25-25. doi:10.1186/1472-6823-13-25

Bliss, M., & Purkis, R. (1982). *The discovery of insulin.* Chicago: University of Chicago Press.

Bringer, J. D., Johnston, L. H., & Brackenridge, C. H. (2004). Maximizing transparency in a doctoral thesis 1: The complexities of writing about the use of QSR* NVIVO within a grounded theory study. *Qualitative Research, 4*(2), 247-265.

Browne, J. L., Ventura, A., Mosely, K., & Speight, J. (2014). 'I'm not a druggie, I'm just a diabetic': A qualitative study of stigma from the perspective of adults with Type 1 Diabetes. *BMJ Open, 4*(7), e005625-e005625. doi:10.1136/bmjopen-2014-005625

Bruni, A., Gala-Lopez, B., Pepper, A. R., Abualhassan, N. S., & Shapiro, A. (2014). Islet cell transplantation for the treatment of Type 1 Diabetes: Recent advances and future challenges. *Diabetes Metab Syndr Obes, 7*, 211-223.

Burke, H., & Dowling, M. (2007). Living with diabetes: Adolescents' perspectives. *Journal of Diabetes Nursing, 11*(3), 4.

Canadian Diabetes Association. (2015). *Report on diabetes: Driving change*. Retrieved from http://www.diabetes.ca/getmedia/5a7070f0-77ad-41ad-9e95-ec1bc56ebf85/2015-report-on-diabetes-driving-change-english.pdf.aspx

Distiller, L. A., Cranston, I., & Mazze, R. (2016). First clinical experience with FreeStyle Libre Pro Flash Glucose Monitoring (FGM) characterizing glycemic control with ambulatory glucose profile (AGP) analysis in South Africa. *Journal of Diabetes Science and Technology*, 1932296816648165.

Eknoyan, G., & Nagy, J. (2005). A history of diabetes mellitus or how a disease of the kidneys evolved into a kidney disease. *Advances in Chronic Kidney Disease, 12*(2), 223-229.

Esbitt, S. A., Tanenbaum, M. L., & Gonzalez, J. S. (2013). Disentangling clinical depression from diabetes-specific distress: Making sense of the mess we've made. In C. E. Lloyd, F. Pouwer, & N. Hermanns (Eds.), *Screening for depression and other psychological problems in diabetes* (pp. 27-46). London: Springer.

Fisher, L., Polonsky, W. H., Hessler, D. M., Masharani, U., Blumer, I., Peters, A. L., . . . Bowyer, V. (2015). Understanding the sources of diabetes distress in adults with Type 1 Diabetes. *Journal of Diabetes and its Complications, 29*(4), 572-577.

Foundation Pour La Santé Medavie Health Foundation, Canadian Diabetes Association, & New Brunswick. (2014). *Live well! Bien vivre! Mid-project report. November 2012-February 2014*. Retrieved from http://medaviehealthfoundation.ca/wp-content/uploads/2012/11/live-well-bien-vivre-mid-project-report-low-res.pdf

Freeborn, D., Dyches, T., Roper, S. O., & Mandleco, B. (2013). Identifying challenges of living with Type 1 Diabetes: Child and youth perspectives. *Journal of Clinical Nursing, 22*(13/14), 1890-1898 1899p. doi:10.1111/jocn.12046

Funnell, M. M. (2006). The diabetes attitudes, wishes, and needs (DAWN) study. *Clinical Diabetes, 24*(4), 154-155.

Gannoni, A. F., & Shute, R. H. (2010). Parental and child perspectives on adaptation to childhood chronic illness: A qualitative study. *Clinical Child Psychology and Psychiatry 15*(1), 39-53.

Goldenberg, R., & Punthakee, Z. (2013) Canadian Diabetes Association 2013 clinical practice guidelines for the prevention and management of diabetes in Canada: Definition, classification and diagnosis of diabetes, prediabetes and metabolic syndrome. *Can J Diabetes 2013:37(suppl 1),* S8-S11.

Gomes, D. M., & do Espírito Santo, P. d. S. M. F. (2015). Experiences and perceptions of teens with Type 1 Diabetes mellitus. *Journal of Nursing UFPE / Revista de Enfermagem UFPE, 9*(2), 582-591. doi:10.5205/reuol.7028-60723-1-SM.0902201513

Gonder-Frederick, L. A., Shepard, J. A., Grabman, J. H., & Ritterband, L. M. (2016). Psychology, technology, and diabetes management. *American Psychologist, 71*(7), 577.

Green, J., & Thorogood, N. (2009). *Qualitative methods for health research* (2nd ed.). Los Angeles, CA: Sage.

Hagger, V., Hendrieckx, C., Sturt, J., Skinner, T. C., & Speight, J. (2016). Diabetes distress among adolescents with Type 1 Diabetes: A systematic review. *Current Diabetes Reports, 16*(1), 9. doi:10.1007/s11892-015-0694-2

Huus, K., & Enskär, K. (2007). Adolescents' experience of living with diabetes. *Paediatric Nursing, 19*(3), 29-31.

Ingadottir, B., & Halldorsdottir, S. (2008). To discipline a "dog": The essential structure of mastering diabetes. *Qualitative Health Research, 18*(5), 606-619.

Jaser, S. S., Patel, N., Xu, M., Tamborlane, W. V., & Grey, M. (2016). Stress and coping predicts adjustment and glycemic control in adolescents with Type 1 Diabetes. *Annals of Behavioral Medicine*, 1-9.

Jones, A., Olsen, M. Z., Perrild, H. J. D., & Willaing, I. (2016). The psychological impact of living with diabetes: Descriptive findings from the DAWN2 study in Denmark. *Primary Care Diabetes, 10*(1), 83-86. doi:10.1016/j.pcd.2015.03.008

Jootun, D., McGhee, G., & Marland, G. R. (2009). Reflexivity: Promoting rigour in qualitative research. *Nursing Standard, 23*(23), 42-46.

Karlsson, A., Arman, M., & Wikblad, K. (2008). Teenagers with Type 1 Diabetes—a phenomenological study of the transition towards autonomy in self-management. *International Journal of Nursing Studies, 45*(4), 562-570.

Kay, C., Davies, J., Gamsu, D., & Jarman, M. (2009). An exploration of the experiences of young women living with Type 1 Diabetes. *Journal of Health Psychology, 14*(2), 242-250. doi:10.1177/1359105308100208

Letts, L., Wilkins, S., Law, M., Stewart, D., Bosch, J., & Westmorland, M. (2007). Guidelines for critical review form: Qualitative studies (Version 2.0). *McMaster University Occupational Therapy Evidence-Based Practice Research Group*.

LoBiondo-Wood, G., & Haber, H. (2005). *Nursing research in Canada: Methods, critical appraisal and utilization (*1st ed.*).* Toronto, ONT.: Elsevier Canada.

Marrero, D. G., Ard, J., Delamater, A. M., Peragallo-Dittko, V., Mayer-Davis, E. J., Nwankwo, R., & Fisher, E. B. (2013). Twenty-first century behavioral medicine: A context for empowering clinicians and patients with diabetes. *Diabetes Care, 36*(2), 463-470.

Marshall, M., Carter, B., Rose, K., & Brotherton, A. (2009). Living with Type 1 Diabetes: Perceptions of children and their parents. *Journal of Clinical Nursing, 18*(12), 1703-1710. doi:10.1111/j.1365-2702.2008.02737.x

McGowan, P. (2017). The role and effectiveness of diabetes coaches in British Columbia. *The Diabetes Communicator, Winter 2017*, 22-23.

Miller, R. G., Secrest, A. M., Sharma, R. K., Songer, T. J., & Orchard, T. J. (2012). Improvements in the life expectancy of Type 1 Diabetes: The Pittsburgh Epidemiology of Diabetes Complications Study Cohort. *Diabetes, 61*(11), 2987-2992.

Nathan, D. M., & DCCT/EDIC Research Group. (2014). The diabetes control and complications trial/epidemiology of diabetes interventions and complications study at 30 years: Overview. *Diabetes Care, 37*(1), 9-16.

Paterson, B., & Thorne, S. (2000). Developmental evolution of expertise in diabetes self-management. *Clinical Nursing Research, 9*(4), 402-419.

Pelletier, C., Dai, S., Roberts, K., & Bienek, A. (2012). *Chapter 5: Diabetes in children and youth*. Ottawa, ONT: Government of Canada. Retrieved from http://www.phac-aspc.gc.ca/cd-mc/publications/diabetes-diabete/facts-figures-faits-chiffres-2011/chap5-eng.php

Polit, D. F., & Beck, C. T. (2017). *Nursing research: Generating and assessing evidence for nursing practice* (10th ed.). Philadelphia, PA: Wolters Kluwer.

Polonsky, K. S. (2012). The past 200 years in diabetes. *New England Journal of Medicine, 367*(14), 1332-1340.

Polonsky, W. H., Anderson, B. J., Lohrer, P. A., Welch, G., Jacobson, A. M., Aponte, J. E., & Schwartz, C. E. (1995). Assessment of diabetes-related distress. *Diabetes Care, 18*(6), 754-760.

Richards, G., Morris, M., Booker, S., & Johnson, A. (2006). What do people with Type 1 Diabetes find helpful in health professionals? Results from a focus group study. *Practical Diabetes International, 23*(6), 249-252.

Rintala, T. M., Paavilainen, E., & Åstedt-Kurki, P. (2013). Everyday life of a family with diabetes as described by adults with Type 1 Diabetes. *European Diabetes Nursing, 10*(3), 86-90. doi:10.1002/edn.234

Robinson, D. J., Luthra, M., & Vallis, M. (2013). Canadian Diabetes Association 2013 clinical practice guidelines for the prevention and management of diabetes in Canada: Diabetes and mental health. *Can J Diabetes, 37*(suppl1), S87-S92. Retrieved from http://guidelines.diabetes.ca/?_ga=1.55197611.1057007269.1381262736

Samson, J. (2006). Exploring young people's perceptions of living with Type 1 Diabetes. *Journal of Diabetes Nursing, 10*(9), 7.

Scholes, C., Mandleco, B., Roper, S., Dearing, K., Dyches, T., & Freeborn, D. (2013). A qualitative study of young people's perspectives of living with Type 1 Diabetes: Do perceptions vary by levels of metabolic control? *Journal of Advanced Nursing, 69*(6), 1235-1247 1213p. doi:10.1111/j.1365-2648.2012.06111.x

Schwartz, D. D., Stewart, S. D., Aikens, J. E., Bussell, J. K., Osborn, C. Y., & Safford, M. M. (2017). Seeing the person, not the illness: Promoting diabetes medication adherence through patient-centered collaboration. *Clinical Diabetes, 35*(1), 35-42.

Shenton, A. K. (2004). Strategies for ensuring trustworthiness in qualitative research projects. *Education For Information, 22*(2), 63-75.

Sparud-Lundin, C., Öhrn, I., & Danielson, E. (2010). Redefining relationships and identity in young adults with Type 1 Diabetes. *Journal of Advanced Nursing, 66*(1), 128-138. doi:10.1111/j.1365-2648.2009.05166.x

Spencer, J. E., Cooper, H. C., & Milton, B. (2013). The lived experiences of young people (13-16 years) with Type 1 Diabetes mellitus and their parents--a qualitative phenomenological study. *Diabetic Medicine: A Journal Of The British Diabetic Association, 30*(1), e17-e24. doi:10.1111/dme.12021

Strandberg, R. B., Graue, M., Wentzel-Larsen, T., Peyrot, M., & Rokne, B. (2014). Relationships of diabetes-specific emotional distress, depression, anxiety, and overall well-being with HbA 1c in adult persons with Type 1 Diabetes. *Journal of Psychosomatic Research, 77*(3), 174-179.

Streubert, H. J., & Rinaldi Carpenter, D. (2011). *Qualitative research in nursing: Advancing the humanistic imperative* (5th ed.). Philadelphia, PA: Lippincott.

Stuckey, H. L., Mullan-Jensen, C. B., Reach, G., Kovacs Burns, K., Piana, N., Vallis, M., . . . Peyrot, M. (2014). Personal accounts of the negative and adaptive psychosocial experiences of people with diabetes in the second Diabetes Attitudes, Wishes and Needs (DAWN2) Study. *Diabetes Care, 37*(9), 2466-2474. doi:10.2337/dc13-2536

Sturt, J., Dennick, K., Due-Christensen, M., & McCarthy, K. (2015). The detection and management of diabetes distress in people with Type 1 Diabetes. *Current Diabetes Reports, 15*(11), 1-14.

Thorne, S. (2016). *Interpretive description: Qualitative research for applied practice* (Vol. 2). New York: Routledge.

Thorne, S., Reimer Kirkham, S, & MacDonald-Emes, J. (1997). Focus on qualitative methods. Interpretive description: A noncategorical qualitative alternative for developing nursing knowledge. *Research in Nursing & Health, 20*(2), 169-177.

Thorne, S., Reimer Kirkham, S., & O'Flynn-Magee, K. (2004). The analytic challenge in interpretive description. *International Journal of Qualitative Methods, 3*(1), 1-11.

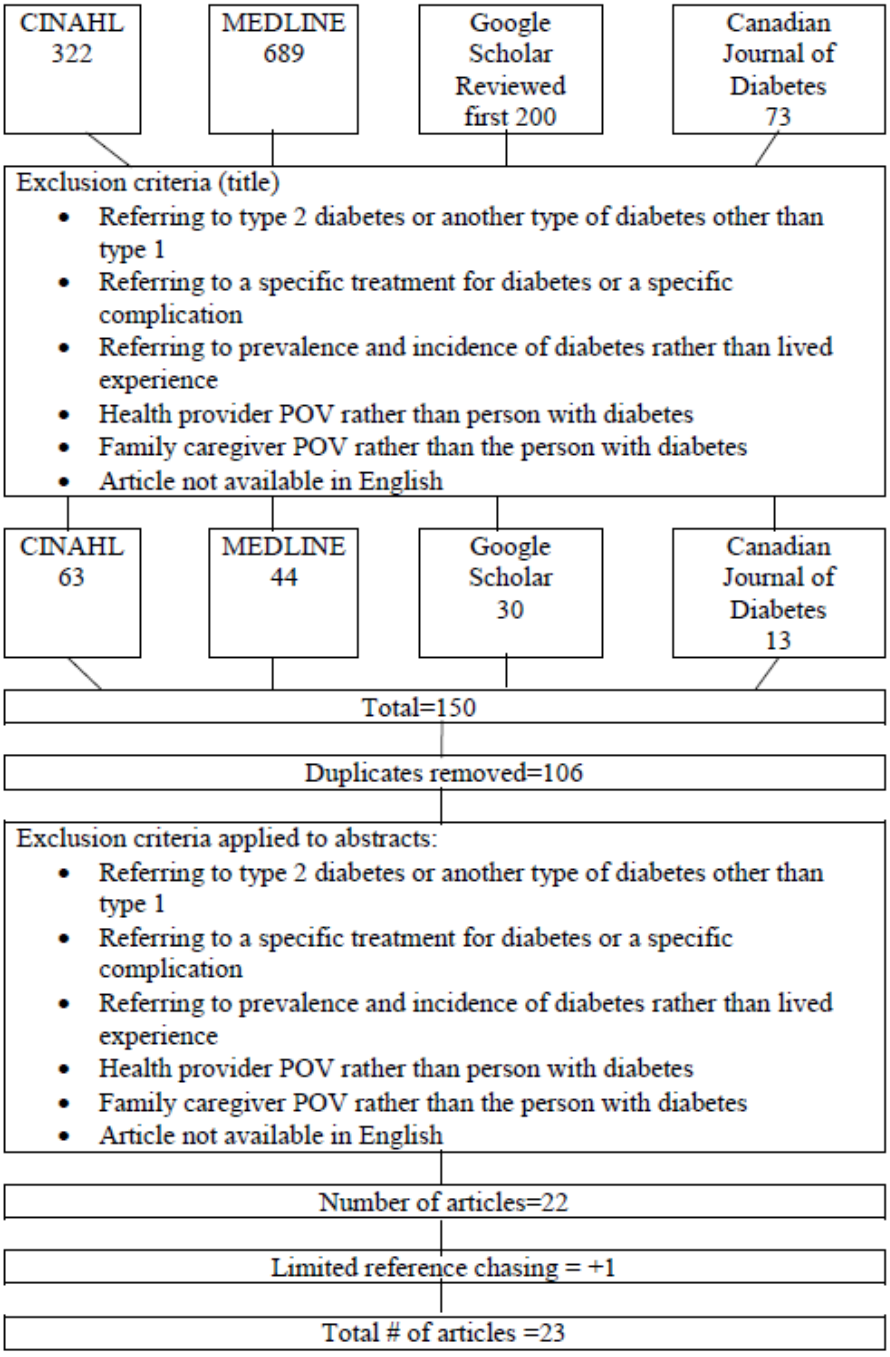
Trief, P. M., Sandberg, J. G., Dimmock, J. A., Forken, P. J., & Weinstock, R. S. (2013). Personal and relationship challenges of adults with Type 1 Diabetes: A qualitative focus group study. *Diabetes Care, 36*(9), 2483-2488. doi:10.2337/dc12-1718

Vallis, M., Burns, K. K., Hollahan, D., Ross, S., & Hahn, J. (2016). Diabetes attitudes, wishes and needs second study (DAWN2): Understanding diabetes-related psychosocial outcomes for Canadians with diabetes. *Canadian Journal Of Diabetes, 40*(3), 234-241. doi:10.1016/j.jcjd.2015.11.002

Watts, S., O'Hara, L., & Trigg, R. (2010). Living with Type 1 Diabetes: A by-person qualitative exploration. *Psychology and Health, 25*(4), 491-506. doi:10.1080/08870440802688588

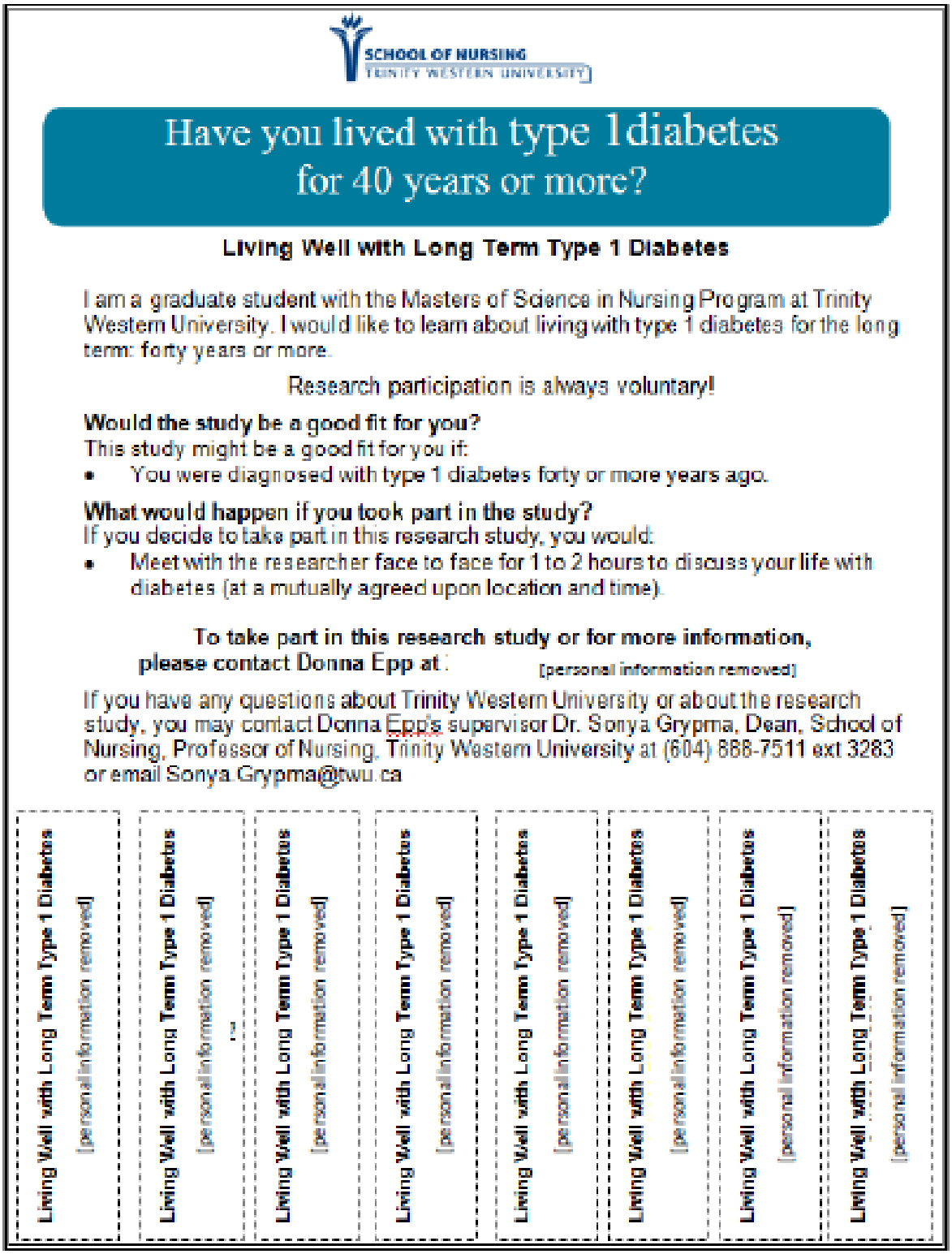
Appendix A – Literature Search Decision Tree

Search terms: "type 1 Diabetes" OR "diabetes mellitus, type 1" AND "life experience" OR "living with"
Limiter: years 2000 to present
Search engines: CINAHL, MEDLINE, Google Scholar, and the Canadian Journal of Diabetes.



*Four 2016 articles were added to the Literature section of the paper following the development of the Findings Chapter and prior to the development of the Discussion Chapter.

Appendix B - Recruitment Poster



SCHOOL OF NURSING
TRINITY WESTERN UNIVERSITY

Have you lived with type 1diabetes for 40 years or more?

Living Well with Long Term Type 1 Diabetes

I am a graduate student with the Masters of Science in Nursing Program at Trinity Western University. I would like to learn about living with type 1 diabetes for the long term: forty years or more.

Research participation is always voluntary!

Would the study be a good fit for you?
This study might be a good fit for you if:

- You were diagnosed with type 1 diabetes forty or more years ago.

What would happen if you took part in the study?
If you decide to take part in this research study, you would:

- Meet with the researcher face to face for 1 to 2 hours to discuss your life with diabetes (at a mutually agreed upon location and time).

To take part in this research study or for more information, please contact Donna Epp at : [personal information removed]

If you have any questions about Trinity Western University or about the research study, you may contact Donna Epp's supervisor Dr. Sonya Grypma, Dean, School of Nursing, Professor of Nursing, Trinity Western University at (604) 888-7511 ext 3283 or email Sonya.Grypma@twu.ca

Living Well with Long Term Type 1 Diabetes [personal information removed]

Living Well with Long Term Type 1 Diabetes [personal information removed]

Living Well with Long Term Type 1 Diabetes [personal information removed]

Living Well with Long Term Type 1 Diabetes [personal information removed]

Living Well with Long Term Type 1 Diabetes [personal information removed]

Living Well with Long Term Type 1 Diabetes [personal information removed]

Living Well with Long Term Type 1 Diabetes [personal information removed]

Living Well with Long Term Type 1 Diabetes [personal information removed]

Appendix C - Recruitment Letter

On TWU letterhead

Living Well with Long Term Type 1 Diabetes

Date

The person who provided you with this letter believes you may be interested in taking part in the research study **Living Well With Long Term with Type 1 Diabetes.** This study is being conducted by Donna Epp, RN, BScN, CDE as a component of her Master of Nursing education at Trinity Western University.

What is the study about?

The purpose of this study is to learn about what it is like to live with type 1 diabetes for forty years or more; what has helped you live well and what has hindered you living well.

Would the study be a good fit for you?

This study might be a good fit for you if you were diagnosed with type 1 diabetes forty or more years ago.

If you participate, what will you be asked to do?

If you agree to be in this study, you will be asked to take part in a 1 to 2-hour interview on living long term with diabetes. The time and place of the interview will occur will be mutually agreed upon between yourself and the researcher. The interview will be audio taped and the researcher may take notes during the interview. Once the researcher has completed analysis of all the data, she may ask for your thoughts on the results that have come out of the interviews.

How can you join this study?

If you would like to be a part of this study or have further questions, please contact Donna Epp [personal information removed]

If you have concerns about the study or would like to know more about Trinity Western University, please contact my supervisor Dr. Sonya Grypma, Trinity Western University at (604) 888-7511 ext 3283 or email Sonya.Grypma@twu.ca

Participation is completely voluntary. Thank you for considering this opportunity to take part in this study.

Donna Epp
Principal Investigator

Appendix D - Email for Canadian Diabetes Association Listserve

Subject line: Seeking participants for research study

Living Well with Long Term Type 1 Diabetes

You are receiving this email because you are a member of the Canadian Diabetes Association and live in a catchment area of 250 kilometres surrounding Brandon MB.

Donna Epp, a Master of Science in Nursing student at Trinity Western University is seeking participants for her research study. This study is about learning what it is like to live for forty years or more with **type 1 diabetes**; what has helped you live well and what has hindered you living well. You would be eligible for this study if you were diagnosed with type 1 diabetes 40 or more years ago.

If you agree to be in this study, you will be asked to take part in a 1 to 2-hour interview on living long term with diabetes. Once the researcher has completed analysis of all the data, she may ask for your thoughts on the results that have come out of the interviews.

If you are interested in participating or have any questions about the study, please email [personal information removed]

If you have questions about the study or about Trinity Western University, please contact my supervisor Dr. Sonya Grypma, Trinity Western University at (604) 888-7511 ext 3283 or email Sonya.Grypma@twu.ca

Participation is completely voluntary. Thank you for considering this opportunity to take part in this study.

Donna Epp

Principal Investigator

Appendix E - Interview Questions and Prompts

1. Tell me about the experience of being diagnosed with type 1 diabetes.
   Prompts:
   How old were you?
   Do you remember what was happening at the time?
   How did your family react?
   How did you feel about it?
   When did it sink in diabetes wasn't going to go away?
2. What does “living well” with diabetes look like in your life?
   Prompts:
   Can you describe one time or experience when you considered yourself to be living well with diabetes?
3. If you think back over the years, when did diabetes challenge you the most and why?
   Prompts:
   What was happening at that time?
   Has diabetes stolen anything from your life?
4. Now think back over the years and tell when diabetes was not a challenge or even a time when you felt diabetes was a positive in your life and why?
   Prompts:
   What was happening at that time?
   Has diabetes added anything positive to your life?
5. How has your experience of living with diabetes changed over the years?
   Prompts:
   What was it like to live as a child with diabetes? An adolescent? A young adult? A middle aged adult? An older adult?
6. What do you wish your health care providers knew about what it's like to live with diabetes?
7. What do you wish your family members knew about living with diabetes?
8. What has been your experience with diabetes education?
   Prompts:
   Have you ever gone?
   What kept you going? Or, why did you stop going?
9. How could diabetes education meet your needs at this age? In the future?
10. What has been your experience with the medical system? The good? And the not so good?
11. Knowing what you know now, what advice would you give to children, their family, the school, and community members re: what to expect from diabetes?
12. What do you wish you had known earlier?
13. Is there anything we haven't talked about that you would like to share about living with diabetes for so many years?

Appendix F - Debriefing Script

Living Well With Long Term Type 1 Diabetes

Principal Investigator: Donna Epp, Thesis, Masters of Nursing Student, School of Nursing, Graduate Program, Trinity Western University.
[personal information removed]

This research is part of a Thesis Capstone Project for the Master of Science in Nursing Degree.

Thank you so much for your participation in this study.

Is there anything you would like to say about what it was like to participate in this interview?

What do you think you gained from this experience?

Your participation is very important to this study to help us understand living well with long term type 1 diabetes.

Do you have any other question?

Appendix G - Consent Form

Living Well with Long Term Type 1 Diabetes

Principal Investigator: Donna Epp, RN, BScN, CDE, Thesis research for Masters of Science in Nursing Program, Trinity Western University, [personal information removed].

Supervisor: Dr. Sonya Grypma, Dean, School of Nursing, Professor of Nursing. Trinity Western University at (604) 888-7511 ext 3283 or email Sonya.Grypma@twu.ca

This research is part of a Capstone Project submitted in partial fulfillment of the requirements for the degree of Masters of Science in Nursing at Trinity Western University.

Purpose

The purpose of this study is to explore the experience of living with type 1diabetes for forty years or more; what has helped you live well and what has hindered you living well.

Procedures

If you agree to be in this study, you will be asked to take part in a 1 to 2-hour interview on living long term with diabetes. The time and place of the interview will be mutually agreed upon between yourself and the researcher. The interview will be audio taped and the researcher may take notes during the interview. Once the researcher has completed analysis of all the data, she may ask for your thoughts on the results that have come out of the interviews. This may take up to 30 minutes.

Potential Risks and Discomforts

It is not anticipated that there will be any risks or discomforts with this project. There is the potential you may become uncomfortable speaking about difficulties related to diabetes management.

Potential Benefits to Participants and/or Society

There are no benefits to you participating in this study. Your participation may benefit others by increasing their understanding of what it is like to live long term with a chronic illness.

Confidentiality

Any information that is obtained in connection with this study and that can be identified with you will remain confidential and will be disclosed only with your permission or as required by law. Data will be collected anonymously and names will not be linked with any information.

The data from this study will be kept private. In any report made public we will not include any information that will make it possible to identify you. The results of this study may be published in professional or lay journals, but your name and identity will not be revealed. Research records will be kept in a locked file; only the researcher and her thesis committee will have access to the records. The audio-recordings of the interview will be deleted after the interview has been transcribed. All of the documents related to this project will be shredded and all computer files will be deleted after 5 years.

Appendix G - Consent Form (continued)

Consent

Taking part in this study is completely voluntary. You may decide to not answer questions or discontinue the interview at any time. If you decide to take part, you are free to withdraw any time until the data has been combined and it is no longer possible to identify your responses from others. If you decide not to participate, there will be no penalty to you.

Contact for Information about the Study

If you have questions or desire further information with respect to this study, you may contact Donna Epp at [personal information removed]. You can also contact Donna Epp's supervisor, Dr. Sonya Grypma, Trinity Western University at (604) 888-7511 ext 3283 or email Sonya.Grypma@twu.ca

Contact for Concerns about the Rights of the Subjects

If you have any concerns regarding your treatment or rights as a research participant, you may contact Ms. Sue Funk in the Office of Research, Trinity Western University at 604-513-2142 or sue.funk@twu.ca

Signatures

Your signature below indicates that you have had your questions about the study answered to your satisfaction and 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.

Your Signature _____ Date _____

Your Name (printed) _____