

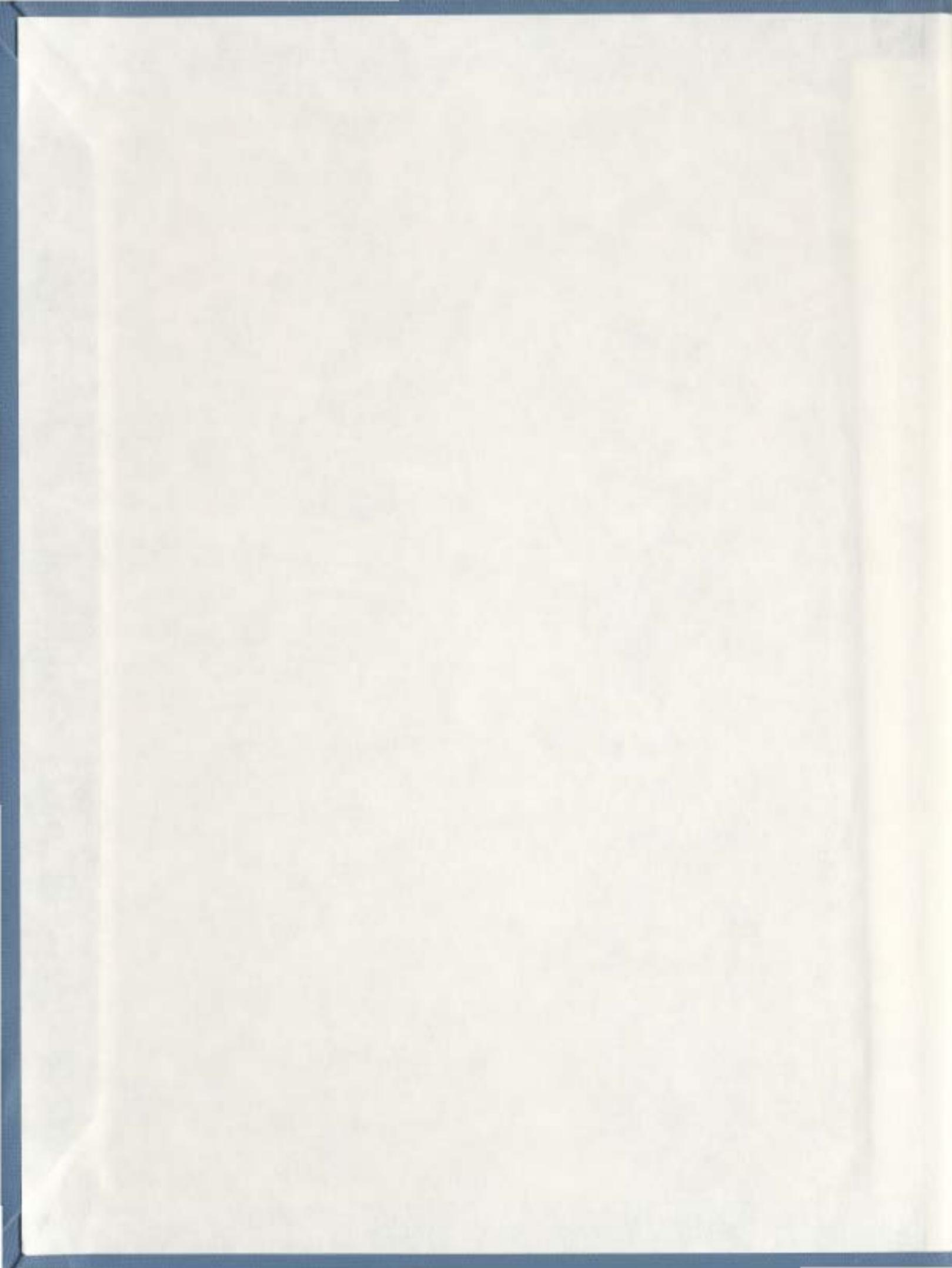
THE LIVED EXPERIENCE OF TYPE 1 DIABETES  
IN ADULTHOOD:  
A PHENOMENOLOGICAL STUDY

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ANNE LEMESSURIER LILLY







THE LIVED EXPERIENCE OF TYPE 1 DIABETES IN ADULTHOOD:  
A PHENOMENOLOGICAL STUDY

by

Anne LeMessurier Lilly, B.N., R.N.

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School of Graduate Studies  
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## **ABSTRACT**

Type 1 diabetes in adulthood permeates every aspect of life. While previous research has been carried out on the experience of living with type 1 diabetes, none of it has been written from the perspective of a nurse researcher with type 1 diabetes, who was one of the participants in this phenomenological study. van Manen's (1997) method of inquiry was used to explore the meaning of the lived experience of type 1 diabetes in adulthood. Unstructured interviews were conducted with five women and three men. Eight themes were identified from data analysis: (1) constant vigilance, (2) struggling for stability, (3) striving for freedom, (4) surviving perceived noncompliance, (5) the lived experience of blood glucose fluctuations, (6) enduring sustained uncertainty, (7) family support: sustaining or smothering, and (8) being alone with diabetes. These findings go beyond previous research in that they reveal a discerning insight into the depth of the ongoing impact of type 1 diabetes on the lives of these eight adults. In addition, the findings highlight the ways in which these adults meet the challenges of type 1 diabetes with perseverance, courage, and pride in their achievements, and how they continuously strive to live happy and productive lives.

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## DEDICATION

I dedicate this thesis with deepest love to my wonderful parents, the late George LeMessurier and the late Kathleen (Norris) LeMessurier, and to my wonderful husband Noel Lilly. Mom and Dad, your belief in me gave me hope. Your positive attitude helped me to accept the challenge. Your strength became my strength. I owe my long, productive, and happy life with type 1 diabetes to your unconditional love, your humour, and your constant, empowering support. Mom and Dad, all my life you have said, "Yes, you can do it!" and you were right! And to my husband Noel, who with great love, gentle strength, humour, and selfless acceptance carried on with me along the path that had been laid. Thank you all from the bottom of my heart. It is your thesis as much as it is mine.

## TRIBUTE

This study is a tribute to my participants, the seven women and men who opened their hearts and told their stories to me. It is a celebration of their strength, hope, humour, and discipline, of conquering their vulnerability and fear. It is a celebration of their ability to overcome incredible odds day-to-day. We owe these women and men our deepest respect. They have learned not just to survive, but to live, and in doing so have shown us the unquenchable power of the human spirit.

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## CHAPTER 1

### Introduction

Type 1 diabetes is an incurable lifelong disease that usually occurs at a young age, affecting approximately 10 percent of persons with diabetes. It is a complex, chronic disease that affects an individual's total life situation – cognitive, physical, emotional, social, and spiritual dimensions. The treatment regimen is rigid and demanding, and it requires sustained lifestyle changes and constant diligence in order to maintain any level of diabetes control (Brennan, 1996; Canadian Diabetes Association, 1997; Joseph & Patterson, 1994; Lundman & Norberg, 1993; Tillotson & Smith, 1996; Wikblad, 1991).

This thesis is a phenomenological study of the meaning of living with type 1 diabetes in adulthood. This research study comes out of my thirty-two years of clinical practice with adults who have type 1 diabetes and my own personal experience of living with this disease for thirty-eight years. I have observed that long-term adaptation to type 1 diabetes is a goal that many adults fail to achieve. I have heard statements such as: *"I have a touch of diabetes; I don't need to do much about it"*. Knowing personally that this is far from the truth, many questions arose as I compared the experience of these adults with mine. Do such statements indicate a lack of commitment to controlling the disease? Are these adults denying the seriousness of type 1 diabetes or do they not understand how uncontrolled diabetes can adversely affect their health and quality of life? I know

personally that you can live well with this disease. It really bothered me to see so many persons living in fear with a poor quality of life and little hope for the future. I wanted to gain insight into the reasons for this low adherence to the daily diabetes regimen.

This thesis is different in that it reveals an insiders' view of type 1 diabetes. It is related by a person who has not only lived most of her life with type 1 diabetes but also has a keen interest in the lived experience of other adults with this disease. I approach this research from that place. It is about who we persons with type 1 diabetes really are, and what it is truly like to live with this disease every second of your life.

## **Background**

In 1997, a new classification and set of diagnostic criteria for diabetes was proposed for Canada, based on the international work of experts in diabetes (Meltzer et al., 1998). The terms "insulin-dependent diabetes mellitus (IDDM)" and "non-insulin-dependent diabetes mellitus (NIDDM)" were eliminated, and the terms "type 1" and "type 2" were retained. The former terms caused a great deal of confusion as they were based on the treatment of the disease rather than the pathogenesis. The use of insulin does not classify the patient; persons with any forms of diabetes may require insulin at various stages of their disease (Meltzer et al.). A distinguishing characteristic of type 1 diabetes is that it involves

pancreatic beta-cell destruction leading to an absolute insulin deficiency and a susceptibility to ketoacidosis. It may be the result of an autoimmune process but the actual etiology of the beta-cell destruction is unknown (Meltzer et al.). While the pathophysiology of type 1 diabetes involves more than the absence of insulin (Buse, Weyer, & Maggs, 2002), persons with this disease are dependent on injections of exogenous insulin (Canadian Diabetes Association, 1997; Goldman & Maclean, 1998; Hernandez, 1996; Maldonato, Bloise, Ceci, Fraticelli, & Fallucca, 1995). Persons with type 1 diabetes are required to self-manage a complex daily regimen of multiple insulin injections, blood glucose monitoring, regular exercise, and an individualized, calorie-reduced meal plan in an effort to stabilize continuously fluctuating blood glucose levels (Nichol, 1999; Paterson & Thorne, 2000b; Price, 1993; Wikblad, 1991). This self-care management regimen involves major and permanent lifestyle changes which affect every aspect of daily living, a fact which has far-reaching implications for adults living with type 1 diabetes (Fitzgerald, Anderson, & Davis, 1995; Hwu, 1995; Jacobson, 1996; Kyngäs & Hentinen, 1995; Lundman & Norberg, 1993; Mitchell & Lawton, 2000; Paterson & Sloan, 1994; Polonsky et al., 1995; Tillotson & Smith, 1996; Toljamo & Hentinen, 2001; Willoughby, Kee, & Demi, 2000). Type 1 diabetes is different from many other chronic diseases in that it is largely invisible to others and it is constantly changing. Adults with this disease must be continually

vigilant and make innumerable decisions every day about control of the disease (Joseph & Patterson, 1994; Rubin, 2002).

Diabetes self care is very costly and requires substantial time and effort (Aalto, Uutela, & Aro, 1997; Fitzgerald et al., 1995; Paterson & Sloan, 1994). Adults with type 1 diabetes have a life-long expectation of risk and live with a great deal of uncertainty (Beeney, Bakry, & Dunn, 1996; Maclean & Goldman, 2000; Price, 1993; Ryan, Todd, Estey, Cook, & Pick, 2002). The ever-present risk of developing debilitating and life-threatening complications can cause fear, and in some cases, a preoccupation with a shorter life expectancy (Beeney et al.; Hernandez, 1995; Jacobson, 1996; Lundman, Asplund, & Norberg, 1990; Lundman & Norberg, 1993; Maldonato et al., 1995; Polonsky et al., 1995; Tillotson & Smith, 1996). The knowledge required by adults with type 1 diabetes is extensive and complex. It is essential that they understand and manipulate the many factors affecting control of a disease that not only affects them uniquely as individuals but also requires twenty-four hour a day management (Brennan, 1996; Canadian Diabetes Association, 1997; Fitzgerald et al., 1995; Joseph & Patterson, 1994; Lundman & Norberg, 1993; Paterson & Sloan, 1994; Tillotson & Smith, 1996; Wikblad, 1991). In order to be successful, adults with type 1 diabetes must feel a sense of personal control over the disease, and not feel they are being controlled by it (Hernandez, Bradish, Rodger, & Rybansky,

1999; Maclean, 1991; Maclean & Goldman, 2000; Mitchell & Lawton, 2000; Paterson & Sloan, 1994; Paterson & Thorne, 2000a; Price, 1993; Vallis, 2001).

Education is essential for helping adults with type 1 diabetes to take responsibility for managing their disease (Canadian Diabetes Association, 1997; Goldman & Maclean, 1998; Maclean & Goldman, 2000; Paterson & Sloan, 1994; Price, 1993). The knowledge requirement for adults with type 1 diabetes is overwhelming; this burden is magnified by the expectation that these adults immediately apply this information in changing lifelong habits and adopting drastic lifestyle changes (Beeney et al., 1996). It is not surprising that the resulting emotional upheaval can affect their readiness to learn (Hwu, 1995; Jacobson, 1996; Paterson & Thorne, 2000a).

Diabetes mellitus is acknowledged as a potentially immense public health problem. It is estimated that it affects 1.2 to 1.4 million Canadians aged 12 and over, that is, 1 in 13 persons in Canada (Canadian Diabetes Association, 1997; Diabetes Division, Health Canada, 1999). Of these numbers, less than 70% or approximately 800,000 are diagnosed cases. The incidence of diabetes among aboriginal people is triple that found in the general population. The incidence of diabetes increases with age. The overall prevalence of self-reported diabetes is increasing, but of the 60,000 new cases of diabetes diagnosed every year in Canada, no differentiation of type 1 and type 2 diabetes is made. The age of onset of diabetes indicates a small proportion prior to age 40 (~ 32%); this

percentage is consistent with the early age of onset of type 1 diabetes in a minority of persons with the disease. The majority of persons with diabetes have type 2 in which there is a later age of onset. The most recent estimate is that by the year 2010, there will be three million Canadians with diabetes. The World Health Organization (WHO) estimates that there will be 300 million people with diabetes worldwide by 2025 (Canadian Diabetes Association; Diabetes Division, Health Canada).

There is increased morbidity with diabetes. It is a major cause of heart disease, and a leading cause of blindness, kidney failure, and limb amputations. People with diabetes have a perception of poorer general health, more days of disability than the general population, and a much higher need for health care services. Newfoundland is one of three provinces in Canada with higher rates of hospitalizations for diabetes (Diabetes Division, Health Canada, 1999).

Diabetes is underrepresented in morbidity and mortality statistics. It is ranked as the seventh leading cause of death in Canada, but the number of deaths attributed to diabetes is five times the current figures. The reason is that diabetes is not given as the underlying cause of death in cases relating to death from the complications of diabetes. Newfoundland shows the highest diabetes mortality rate in all of Canada (Diabetes Division, Health Canada, 1999).

In economic terms, the health care costs of diabetes for individuals and for the Health Care System are enormous. For individuals with diabetes,

financial costs can be more than \$5,000 per year. The Health Care System in Canada spends at least nine billion dollars annually on treating people with diabetes and its complications (Canadian Diabetes Association, 1997; Diabetes Division, Health Canada, 1999).

These are staggering statistics for everyone involved with diabetes, but the psychosocial aspects of living with the reality of these statistics are missing. What do they mean to persons who have this disease? Statistics do not provide an estimation of how type 1 diabetes can deprive individuals and families of their hopes and dreams (Newbern, 1990).

### **Rationale**

The impact of type 1 diabetes on adults affected with the disease is profound because of the major disruptions in lifestyle and functional health, and the severe consequences of poor diabetes control. Failure to follow the diabetes regimen increases the risk of severe complications and premature death. There are gaps between clinician-recommended regimens and actual patient practices, with low and variable patient compliance rates, ranging from 10% to 94% (Simons, 1992; Tillotson & Smith, 1996). Despite the many and varied education programs for type 1 diabetes, long-term adherence to the daily diabetes regimen is low (Hernandez, 1995). Adults with type 1 diabetes are constantly being given a mixed message. They are told not only to take charge of themselves but also

to comply or adhere to their prescribed regimen. Hernandez questions how these adults comprehend or deal with these conflicting demands as they try to live with their diabetes. Further, she criticizes the adherence framework as being inadequate in understanding what it is like for persons to live with diabetes.

What are the reasons for this low adherence to the daily diabetes regimen? Could the reason be the health care provider's approach and teaching methods - is there too much emphasis being placed on physiological control while disregarding the psychosocial well-being of adults with type 1 diabetes? Is the focus on the disease itself and not on the persons with type 1 diabetes and their perspectives as adults? Do current teaching and management methods reflect a basic lack of understanding of what it is like for adults to live with this chronic disease? How can these adults be helped to deal with the reality of a serious illness, and take up the challenge and the responsibility for managing their disease, without resorting to denial and despair?

The psychosocial aspects of the disease must be addressed if the diagnosis of type 1 diabetes is to be accepted and the management plan followed because “. . . complex personal and social meanings comprise the experience of diabetes” (Goldman & Maclean, 1998, p. 747). This vital issue can only be addressed if the health care providers who care for these adults can achieve an awareness and an understanding of the importance of psychosocial issues to persons with diabetes (Aalto et al., 1997; Beeney et al., 1996; Brennan,

1996; Fitzgerald et al., 1995; Goldman & Maclean; Hernandez, 1995; Jacobson, 1996; Joseph & Patterson, 1994; Lundman & Norberg, 1993; Maldonato et al., 1995; Polonsky et al., 1995; Tillotson & Smith, 1996). When health care providers achieve deeper insight into the essence of the experience of type 1 diabetes, from the perspective of individuals with the disease, changes can be made. This knowledge can help health care providers to develop appropriate therapeutic interventions, in teaching and support programs, to meet the psychosocial needs of adults with type 1 diabetes and to enhance their quality of life (Hartrick, 1998; Hernandez, 1995; Mitchell & Lawton, 2000).

There is a growing body of knowledge concerning diabetes, some of which attempts to recognize the experience of adults with type 1 diabetes by focusing on aspects of management, adjustment, and self-care (Aalto et al., 1997; Bonnet, Gagnayre, & d'Ivernois, 2001; Golin, DiMatteo, Leake, Duan, & Gelberg, 2001; Hartrick, 1998; Hernandez, 1996; Jones, 1990; Lloyd, Dyer, Lancashire, Harris, Daniels, & Barnett, 1999; Maclean, 1991; Paterson & Thorne, 2000b; Price, 1993; Strauss, 1996; Vallis, 1998). However, more research focusing on the lived experience of type 1 diabetes is required in order to provide a greater understanding of persons' experiences of living with this complex disease.

### **Purpose**

Many health care providers do not know and understand the reality of the experience of living with type 1 diabetes. Many theorists and diabetes specialists do not know what this experience is like. Diabetes educators and education programs can be more responsive if they have an increased understanding of this insiders' view of what it is truly like to live with type 1 diabetes.

The purpose of this study was to explore and describe the experience of living with type 1 diabetes in adulthood, thus contributing to current knowledge and adding new insights into this experience. Understanding the lived experience of adults with type 1 diabetes will lay the groundwork for future focused studies based on selected aspects of this phenomenon. Such studies have the potential for improving the care of adults with this disease.

### **Research Question**

This study addressed the following research question: What is the meaning of the experience of living with type 1 diabetes in adulthood?

## CHAPTER 2

### Literature Review

A comprehensive literature review was carried out to locate research on the meaning of the lived experience of type 1 diabetes in adulthood. Computer searches were conducted on CINAHL, MEDLINE, ERIC, PUBMED, and PSYCHINFO databases. Reference lists of appropriate articles and books were examined for studies that focused on this lived experience. Most of the retrieved articles related to type 1 diabetes while a few related to type 2 diabetes. There was a variety of research methods employed, qualitative, quantitative, as well as a combination of both methodologies.

The actual lived experience of type 1 diabetes, from the perspective of adults with this disease, has received some attention in the literature. However, none of the research was presented from the vantage point of researcher as participant, as an “insider” to the actual phenomenon.

Many health care providers treat diabetes, and persons with it, using the biomedical approach and evidence-based medicine, with evidence coming from a focus on the outcomes of physiological measures. Research on type 1 diabetes comes mainly from these paradigms. But it is the *person* who has diabetes. It is the person who must try to live with the biomedical approach while still seeking autonomy and a quality of life. Many disease-oriented groups are advocating for empowerment of patients. This viewpoint clashes with biomedical

or “physicians’ knowledge”. These groups bring into consideration the “insider view” and the “patient as expert”, and critique the possibility of health professionals being able to have empathy for patients living with a certain condition. The review of the literature is set within this context.

This review of the literature has been organized under three headings that include key findings from research on type 1 diabetes in adulthood:

(1) implications of the Diabetes Control and Complications Trial (DCCT), (2) the experience of living with type 1 diabetes, and (3) compliance and adherence.

Each major category has been divided into subheadings that should further clarify the broad scope of the research literature appropriate to this study.

### **Implications of the Diabetes Control and Complications Trial (DCCT)**

In research addressing the experience of living with type 1 diabetes, the importance of relationships with health care professionals has been a focus. These relationships have been profoundly influenced by the results of the DCCT (Diabetes Control and Complications Trial Research Group, 1996) because these results have influenced the practise of diabetes care and the approach to persons with type 1 diabetes. The results of the DCCT present evidence that endorses the biomedical approach because the outcomes of this trial are based on physiological measures.

The DCCT followed over 1400 persons with type 1 diabetes for an average of 6.5 years. The results of this trial, which were released in 1993, were significant. They demonstrated a reduction in the development and progression of the long-term physical complications of type 1 diabetes, if normal glycemia was achieved through intensive therapy. Intensive therapy included multiple daily injections of insulin or continuous subcutaneous insulin infusion, self-monitoring of blood glucose four times per day, diabetes diet, planned activity/exercise, monthly clinic visits, frequent telephone contact with the treatment team, frequent blood tests to check HBA<sub>1c</sub> and other blood levels, urine tests, retinal examinations, and electrocardiograms every two years. One of the conclusions reached by this study was that even though intensive therapy is more expensive than conventional therapy, there should be cost saving in the long term due to prevention and/or delay in the occurrence of complications (Diabetes Control and Complications Trial Research Group, 1995).

Health care professionals have supported the importance and value of these findings, and have therefore sought the most efficient methods of translating the results of the DCCT into practice. Consequently, a number of studies have investigated current diabetes treatment practices, as well as health care professionals' attitudes toward diabetes care. The significant results of these studies suggest that the psychosocial needs of persons with type 1

diabetes are being overlooked by the intensified push for tighter diabetes control. These studies will be addressed below.

Most physicians have adhered to the recommendations of the DCCT, with a focus on strict compliance with the treatment regimen, their goal being good glucose control and prevention of complications (Havas, 1999; Helseth, Susman, Crabtree, & O'Connor, 1999; Hernandez, 1996; Hunt, Arar, & Larme, 1998; Jones et al., 2001; Nichol, 1999). Another study found that general practitioners were putting more focus on the physiological rather than the psychosocial aspects of diabetes (Beeney et al., 1996). They significantly overestimated physiological complications as a concern for their clients with diabetes at diagnosis, possibly influenced by the results of the DCCT. Their clients reported the need for more emotional support in order to help them meet their diabetes information needs. These clients indicated a preference for diabetes educators and courses over physicians' teaching. Other researchers have discovered that it is not diabetes educators, but the primary care physician (who may be a diabetes specialist), who is the first and often the principal medical contact for persons with diabetes (Harris, Meltzer, & Zinman, 1998; Meltzer et al., 1998).

Another significant finding of the DCCT indicates that with intensive management, the lowering of blood glucose levels to normal causes an increased incidence of severe hypoglycemia (Drass & Feldman, 1996; Hernandez et al., 1999; Rubin, 2002). A serious consequence of recurrent

hypoglycemia is treatment nonadherence because of the psychological and physical discomforts of these episodes (Strauss, 1996). Although these findings have profound physical, cognitive, social, and emotional implications for persons with type 1 diabetes, they have not been given much attention.

One of the limitations of the DCCT is that it focused on insulin therapy for optimal glycemic control while ignoring some of the other glucoregulatory hormones. This raises “. . . the important question of whether it is realistic to expect that near-normalization of glycemia can be routinely and easily achieved in most patients with exogenous insulin replacement alone” (Buse et al., 2002, p.137).

### **The Experience of Living With Diabetes**

The focus of the DCCT provides a sharp contrast to the actual experience of living with type 1 diabetes. Some nurse researchers have investigated the personal meaning of diabetes in an attempt to understand the “insiders view”. A number of references have been found that present insights into what adults live through in their daily struggle with type 1 diabetes. These studies used qualitative research methods. A summary of each study, with a comparison of the similarities and differences of the findings will be presented first. Then, the findings on various other aspects of living with type 1 diabetes will be presented

using the subheadings: (a) quality of life, (b) autonomy, (c) the impact of health care professionals, and (d) diabetes management / diabetes education.

Hernandez (1995) used grounded theory to investigate the experience of living with type 1 diabetes in adulthood. She postulated that the emphasis on diabetes control implied domination of clients and suggested the need for collaborative alliances that broke down current hierarchical relationships. Her findings provided support for the need to move to a new paradigm in diabetes education described as integration, to replace the traditional compliance / adherence paradigm. Integration occurred when the personal and diabetic selves merged in such a way that persons became experts in their own diabetes care (Hernandez, 1996).

The findings of Paterson and Sloan's (1994) phenomenological study parallel the findings of Hernandez (1996) in that their participants had become experts in diabetes self-care management. Paterson and Sloan investigated the decision-making of persons with long-standing type 1 diabetes. These participants moved through a developmental progression entailing risks as well as confrontation with health care professionals. They took an active role in diabetes management that gave them a feeling of control when they felt restricted by the disease and betrayed by disinterested health care professionals. They became experts in self-care by knowing the body,

anticipating problems, establishing collaborative relationships with health care professionals, and fostering the support of family and friends.

Price (1993) developed a Diabetes Self-Management Model (DSMM) from the findings of her grounded theory study on the actual experience of adapting to the diabetes regimen. Similar to Paterson and Sloan's (1994) findings, this learning evolved over time, and involved problem solving and a definition of control different from that of health care professionals. Price's dynamic model affirmed the effort and stress of learning diabetes self-management. The importance of individualized treatment regimens, developed from personal experiences and harmonized with persons' values and expectations of how life should be lived, was also affirmed by the DSMM.

Hartrick (1998) conducted a phenomenological study to gain insight into an insider's perspective of how type 1 diabetes is meaningfully experienced. Hartrick's goal was to help nurses to use the insights gained to practice more holistically. The findings revealed complex and multifaceted meanings of diabetes in participants' lives. Similar to the findings of Hernandez (1995), Paterson and Sloan (1994), and Price (1993), Hartrick discovered that the meaning of type 1 diabetes in people's lives was unique and personal, and that this meaning had evolved over time. This personal knowledge influenced the choices they made about diabetes management. Hartrick's findings, concerning the power of health professionals and the difficulty of integrating the diabetes

regimen into everyday life, support previous findings. Hartrick presented new insights in her description of diabetes as loss and gain, and diabetes as being culturally influenced in that these persons do not meet the North American cultural value of being healthy; they are considered to be different.

Maclean and Goldman (2000) reviewed and synthesized sixty qualitative research studies conducted on the psychosocial aspects of diabetes. They summarized feelings expressed about life with diabetes under six themes, some of which were similar to the findings of other reviewed studies. These themes were: loss of spontaneity, anger, unpredictability, endlessness, and disruption to sexuality. Maclean and Goldman's discussion of the results of this review emphasized the personal meanings of adjusting to diabetes, and the personal knowledge gained from experimentation. Persons with diabetes individualized their management choices. The low priority given to participants' psychological responses by health professionals, and their need for emotional support was also highlighted in this review. Persons with diabetes preferred health professionals who respected their viewpoint and were willing to work collaboratively with them, not ones who judged them as being irresponsible and lacking in self-control.

A meta-analysis of published research and theses' pertaining to the lived experience of diabetes was conducted by Paterson, Thorne, and Dewis (1998). Forty-three qualitative research studies were reviewed using meta-ethnography

in a comparative analysis of findings. The goal of this meta-analysis was to discover the totality of the experience of living with and managing diabetes. The findings revealed that balance was the definitive metaphor of the lived experience of diabetes. Persons with this disease learned balance through a developmental process in which they utilized both their personal experience and experimentation in managing their diabetes. They strove for a normal life by focusing on wellness, empowerment, and balance instead of control. The authors proposed that these findings bring new meaning to behaviours often regarded as being noncompliant. They felt that judgements regarding noncompliance were not appropriate because persons with diabetes were balancing and developing their own expertise. They recommended that health care professionals apply these findings in their approach to persons with type 1 diabetes.

As part of a larger project, Finfgeld (2000) conducted a grounded theory study to examine the role of courage in young adults with long term health concerns, including those with insulin-dependent diabetes. Becoming courageous and maintaining courage was found to be a progressive-regressive continuum. Courage was learned over time and developed when persons had to struggle to manage a threat, such as a chronic health concern. During this learning process, persons utilized cognitive thinking strategies involving discernment, or the ability to moderate extremes of rigidity and irresponsibility,

values clarification, and greater sensitivity to the positive aspects of life. Their courageous behaviour was characterized by altruism, by pushing to transcend health problems, and by being humble in not identifying themselves as courageous. In order to maintain and promote the development of courage, persons used hope, self-confidence, and personal values to help them. Other factors such as role models, recognition from others, the advocacy of others through encouragement and humour, and the support and validation of health care providers was important. Two outcomes of being courageous were thriving or living life fully, and personal integrity in which feelings of pride and dignity were experienced.

Collectively, these studies reveal a deeper insight into living with diabetes. Findings suggest that taking a more holistic view of the total lives of persons with diabetes is important, and can be accomplished by showing respect for their courage and ingenuity in seeking balance, rather than trying to control them. More studies need to be conducted on ways to bridge the gap between biomedical and holistic approaches because both approaches are important in helping persons live healthy and productive lives with diabetes.

### ***Quality of Life***

Quality of life is a recurring psychosocial concept in the research literature. Quality of life is an ability to experience health despite illness

(Lundman et al., 1990). Quality of life is very subjective and should be judged by personal values and beliefs (McLeod, 1998; Vallis, 1998). Because of the all-encompassing nature of the diabetes lifestyle and its ongoing threat to quality of life, this area of research gives valuable insights into the lived experience of diabetes.

A number of studies have been done to investigate quality of life with diabetes. Persons with diabetes have reported a lower quality of life and lower health status than the healthy population (Aalto et al., 1997). A self-report survey measured diabetes-related emotional distress in type 1 diabetes, and reported that those with the highest total scores found the frustrations of the disease and its treatment regimen to be overwhelming (Polonsky et al., 1995). DeCoster (2003) reported that the non-pathological emotions of fear, anxiety, guilt, irritation, anger, and sadness were experienced by persons with diabetes and could present a coping challenge. Low levels of subjective health and quality of life were related to the threat of acute and long-term complications (DeCoster; Hendricks & Hendricks, 1998; Lundman & Norberg, 1993; Lundman et al., 1990). A systematic review of thirty-six studies that examined the impact of psychosocial outcomes following education, self-management, and psychological interventions found that psychological interventions improved depression, and self-management interventions improved quality of life (Steed, Cooke, & Newman, 2003).

Under certain conditions, some persons with diabetes will achieve a relatively good quality of life despite this disease. Most participants reported general feelings of well being providing no severe complications had developed (Lundman et al., 1990). In another study, personal choice helped participants to achieve a quality of life; they were able to distance themselves from the restrictions of living with diabetes by choosing to take a break from strict control at times, and by exercising selective restraint in order to keep life spontaneous and enjoyable (Mitchell & Lawton, 2000). In a similar study, health was more closely related to mental well-being than optimal blood sugar levels; quality of life was associated with experiencing feelings of psychological well-being despite living with a demanding disease; persons lived well with type 1 diabetes if they had successful problem solving and emotional coping strategies (Finfgeld, 2000; Lundman & Norberg, 1993).

### ***Autonomy***

Natural psychological drives in adulthood are free will and self-determination (Vallis, 2001), both of which are characteristics of autonomy (Lutz, 1994; Thompson, 1995). The reality of the lived experience of adults with type 1 diabetes is that their autonomy is compromised not only by the demands of diabetes management but also by the actual and potential threats of the disease itself. A number of studies have been carried out to investigate the meaning of

autonomy to persons with diabetes. Autonomy has been considered in a psychosocial sense, as a component of the sense of identity, and in terms of empowerment. These aspects of autonomy will be discussed in this section.

The psychosocial aspect of autonomy has been explored by many researchers who felt it was important to understand how individuals balanced the excessive self-care demands of the diabetes lifestyle with their need for self-direction in their lives (Goldman & Maclean, 1998; Maclean, 1991; Mitchell & Lawton, 2000; Reichard, 1996; Vallis, 2001; Wikblad, 1991). In the context of the diabetes treatment regimen, autonomy and adherence are conflicting terms; aiming for adherence to stringent rules can set the stage for failure as it involves choosing a life of complex restrictions, a frustrating experience for health care providers and patients because there is no provision made for choice and self-direction (Strauss, 1996; Vallis; Weiss & Hutchinson, 2000). Several researchers, who explored experimentation with the diabetes lifestyle, discovered that seeking autonomy was one aspect of experimentation. Individuals who used experimentation shared a goal of fitting diabetes into their individual lifestyles, and of harmonizing it with their values and expectations of how life should be lived (Mitchell & Lawton, 2000; Paterson & Thorne, 2000b). In another study, Price (1993) compared experimentation to the role of a scientist who carries out detective work and pattern recognition, while Paterson and Thorne (2000a) discovered that participants, when faced with an unfamiliar

situation, solved the problem by using management principles and logical patterns of thinking resembling those of beginning health care professionals.

Other researchers have investigated autonomy as a major component of the sense of identity. The diagnosis of diabetes is an assault on the self; therefore the challenge of diabetes management is to redefine one's identity so that diabetes is integrated in a positive manner (Goldman & Maclean, 1998). The process of redefining one's identity has been described as reconfiguring the sense of self to incorporate the new self with a chronic illness (Maclean & Goldman, 2000). Patients have a need to be in control because their sense of self is the same whether ill or well, and their sense of self should be valued (Newbern, 1990).

Autonomy has been researched in terms of empowerment, that is, enabling the person with diabetes to effectively make decisions relating to self-management of the disease. True empowerment for persons with diabetes enables them to live the life they would have chosen if they did not have diabetes (Reichard, 1996). In the area of diet-related self-care, empowerment acknowledges the right of individuals with diabetes to make their own decisions about diet, even if that decision is to do nothing to adhere to the prescribed diet. Participants have shown enhanced well being in the areas of self-esteem and a sense of belonging in social situations, when they made deliberate autonomous choice regarding dietary flexibility (Maclean, 1991). Spousal help can have an

impact on the autonomy of persons with diabetes in that they have a need to counter the demands of diabetes care and the concerns of their spouses with their own needs for autonomy and self-esteem (Baily & Kahn, 1993).

Several researchers proposed that health care professionals can have a negative impact on the autonomy of adults with diabetes. When health care professionals attempt to control and modify their behaviour, these adults feel threatened; they will respond with resistance as they feel their personal free will and authority being taken away, reasoning that the best way to resist this threat is to oppose. These researchers recommend that health care professionals recognize the autonomy of the individual - that diabetes is theirs to manage (Mitchell & Lawton, 2000; Vallis, 2001). Weiss and Hutchinson (2000) recommend that health care providers collaborate with each person with diabetes to develop an individualized treatment plan that is most helpful and beneficial to his/her health.

### ***The Impact of Health Care Professionals***

The chronic and ever-changing nature of type 1 diabetes necessitates interactions with health care professionals for management of the disease. Persons with diabetes require regular assessment by physicians regarding their daily, and long-term blood glucose levels, adjustment of insulin dosages, and early diagnosis and treatment of complications. Certified diabetes educators

have a specialist role in supporting and teaching persons with diabetes. While diabetes nurse educators can modify insulin dosages in order to improve blood glucose levels, diabetes dietician educators can help persons with diabetes to adjust and modify their dietary intake. All diabetes educators have a very important role in diabetes education, and advocacy. As necessary, other members of the health care team are utilized to meet individual needs. The way in which persons with type 1 diabetes perceived these interactions had a profound impact on their lived experience of the disease in their daily lives.

At the time of diagnosis, participants in Maclean and Goldman's (2000) study reported being dependent on health care professionals for guidance in integrating and applying all the new information they were being taught. They also sought support from health care professionals in dealing with the emotional ramifications of the disease and the shock of diagnosis. As participants became more familiar with the disease and its treatment, their need for constant reassurance decreased but they still consulted with health care professionals as needed to control their disease.

Health care professionals' perspectives regarding diabetes management frequently differed from those of participants, leading to frustration on both sides. The goals of health care professionals for strict observance of the diabetes regimen have not always recognized and met participants' own needs and lifestyles. Paterson and Sloan (1994) discovered that the expectations and goals

for diabetes management are set by health care professionals who believe that permanent diabetes control is attainable only if persons with diabetes adhere to every aspect of the treatment regimen. Participants came to discover that not only were these goals unattainable at all times, but also that health care professionals did not understand or listen to them about their body's unique responses, treating them as "textbook cases". In a study of two hundred nurses, their perceptions of primary patient problems in diabetes management were acceptance of diabetes, knowledge deficits, and noncompliance (McDonald, Tilley, & Havstad, 1999). In another study, persons with diabetes used experimentation in diabetes control because it helped them to sort out why they had difficulty controlling erratic blood glucose levels, especially hypoglycemia and its aftermath, and it helped them to deal with the restrictions and the rigid diabetes lifestyle (Maclean & Goldman, 2000). Experimentation helped some persons gain more control over their diabetes treatment regimen when they felt restricted by the disease and discouraged by the attitudes of health care professionals who implied that they were "cheating" because their blood glucose levels were erratic despite following the prescribed course of care; they explained that using experimentation was an abandonment of the health care professionals' perceptions and a taking on a "survivor mentality" (Paterson & Sloan, 1994).

There is an obvious moral tone to the varied discussions of health care professionals' domination and patients' conformity or nonconformity. It is illustrated in the inappropriate, personal language used to describe persons with diabetes and their behaviour, in the intimidation used by some health care providers to force persons to comply, and in blaming and shaming persons with diabetes, all of which are reported in the following studies. A number of researchers have investigated the consequences of this moralistic attitude to persons with diabetes and their care. Luftey and Wishner (1999) found that inappropriate words such as negligence, refusal, and deviation were used by authoritative medical practitioners to describe patient non-conformity to the treatment regimen, and inappropriate characterizations such as bad, difficult, disobedient, unreliable and uncooperative were used to describe those who do not conform. In another article, Strauss (1996) postulated that when some practitioners used threat of consequences as a motivator for following the diabetes regimen, it was counterproductive – patients came to believe that the recommended treatment regimen had no value. Benner, Janson-Bjerklie, Ferketich, and Becker (1994) found that an attitude of moral responsibility exists in which an individual with a chronic illness is expected to be not only responsible for being healthy by controlling the body with the mind and the will, but also responsible for refraining from burdening others with his/her illness; this view sets up a high likelihood for blaming the person with the chronic disease.

A number of researchers reported the responses of persons with diabetes, the recipients of these negative attitudes. Participants articulated that they did not want judgements or intrusions in their lives - they did not like to be pushed, prodded, nagged, punished, or watched by health care practitioners (Mitchell & Lawton, 2000). They wanted health care professionals to help them with their diabetes by listening supportively as they told their own stories of their experience of living with the disease (Goldman & Maclean, 1998). They wanted health care professionals to give them diabetes education on disease control, to support them as they coped with the emotional aspects of living with diabetes, and to show an appreciation for their need to find their own balance between rigid diabetes control and a manageable lifestyle (Maclean & Goldman, 2000).

When referring to diabetes control, the emphasis is on control of the disease while the experience of diabetes is that of the person with it. Some researchers have found that there is a problem with these concepts. Paterson and Thorne (2000b) determined that some physicians frequently blame persons with diabetes for negative outcomes and want to control them while others display a negative attitude toward persons who use experimentation or show rebellion, describing them as irrational. Other researchers have discovered that repeated non-success in living up to health care providers' expectations frequently caused persons with diabetes to react with feelings of guilt, shame, and lowered self-esteem because they were judged as being irresponsible and

lacking in self-control; feelings of failure and learned helplessness often resulted that were very destructive to self-management motivation (Bissell, May, & Noyce, 2004; Vallis, 2001).

Several researchers have investigated the right use of power in health care professions. Barstow (2002), and Callaghan and Williams (1994), proposed that the voices of patients are historically less powerful than those of helping professionals. Because they are in positions of trust, helping professionals need to be more conscious not only of the power differential between themselves and their patients, but also of how it affects their relationships. Barstow defined this power differential in terms of intent and impact, where intent is the desired effect, and impact is the actual effect one person's behaviour has on another. Mitchell and Lawton (2000) presented Parse's view of the intent of the professional as one of understanding the individual's reality and being there for them. Barstow proposed that while helping professionals have good intent, they are not always mindful of the negative impact they can have on their clients; a conscious awareness of this impact can make caregivers more sensitive, compassionate, and able to sympathize with the humanness of others.

While some research has shown that health care professionals can behave in negative and potentially destructive ways, a balanced perspective is necessary. Other literature sources reveal health care professionals who display more positive and insightful attitudes toward the needs of persons with diabetes.

Physicians were found to be effective in many ways. Havas (1999) proposed not only that patient-centred physicians acknowledge the impact of diabetes on their patient's lives, but also that support from them, and from patients' family and friends is essential for the success of a prescribed course of tight glucose control. Another study found that there is an association between positive patient experiences with the doctor-patient relationship and good metabolic control, in particular, that poor glycemic control may have its foundation in behavioural and emotional difficulties (Viinamaki, Niskanen, Korhonen, & Tahka, 1993). The metabolic goals of treatment must be individualized for each client, and should take into consideration the family as well as other important factors, especially those psychosocial in nature (Meltzer et al., 1998). Helseth et al. (1999) described physicians who are sensitive to the complexity of diabetes management, concede to the personal knowledge of their clients with diabetes, understand their limited role as physicians, and recognize that clients are trying to balance diabetes management with the realities of their lives.

Nurses, as essential members of the diabetes health care team, advocate a holistic approach to the care of persons with diabetes. The impact of this holistic approach in nursing practice has been researched. Holistic assessment, in which the person's perspective is sought and valued, is crucial to the nurse's ability to be therapeutic (Hwu, 1995). The focused education and support that can result from holistic assessment can help persons with diabetes to follow

through with effective self-care (Wikblad, 1991). Patients perceive holistic caring to be more evident in nurses' sensitive physical caring behaviours, and less evident in interpretive and spiritual caring behaviours. Emotional distancing and negative body language are perceived as very non-caring behaviours that negatively affect patients' recovery by decreasing their self-esteem and feelings of control over the situation (Williams, 1997). The stressors of type 1 diabetes can affect all family members, including well siblings; it is essential to care for the whole family by providing anticipatory guidance, counseling, and education to well adults who have a sibling with type 1 diabetes (Smith, 1998).

The need for therapeutic partnerships between all health care professionals and persons with diabetes has been researched, the focus being the experience of living with type 1 diabetes. The following recommendations indicate new understandings. The adherence framework has not been successful because it reflects the health professional's view of diabetes, not the "insiders view." There is a need for partnerships in which health care professionals and persons with diabetes collaborate to achieve good diabetes care (Callaghan & Williams, 1994; Hernandez, 1996; Maclean & Goldman, 2000). Persons with type 1 diabetes must live with the consequences of the personal choices they make every day, choices made more difficult by the complexity and unpredictable nature of this disease; for that reason, it is essential to concentrate on their lived experience of diabetes in order to

individualize their care (Mitchell & Lawton, 2000). The whole health care system should show more sensitivity to holistic practice by understanding that because diabetes requires such major lifestyle changes, every individual with diabetes has a deep need to make sense of their situation (Ternulf Nyhlin, 1990). Of the many psychosocial factors identified as being most crucial in interactions with health care professionals, therapeutic verbal and nonverbal communication has the most significant impact. In order to understand the perspectives, ways of coping, and challenges of persons with diabetes, it is essential to use respect, empathy, support, and caring (Goldman & Maclean, 1998; Mitchell & Lawton, 2000; Nichol, 1999; Polonsky et al., 1995; Robinson, 1993; Toljamo & Hentinen, 2001; Vallis, 2001; Willoughby et al., 2000).

### ***Diabetes Management / Diabetes Education***

Understanding the experience of living with type 1 diabetes, in the areas of diabetes management and education, is becoming more evident in current research studies. While hands-on, daily diabetes management involves numerous skills, the aspect of management that has received the most attention in the research literature is glycemic control. However, diabetes educators, in recognition of the importance of the findings of qualitative research, are now incorporating these findings into many aspects of their diabetes education programs.

Diabetes management studies focus on the effect of uncontrolled blood glucose levels on the lives of persons with diabetes. In one study, participants utilized their knowledge, experience, and consultation with health care professionals to develop strategies to prevent hypoglycemia; they sought balance in their blood glucose levels, not precise control, because the multiple consequences of hypoglycemia adversely affected their lives (Maclean & Goldman, 2000). Poor glycemic control, especially the acute complication of hypoglycemia, had very negative effects on how the participants lived with diabetes. Hypoglycemia was disruptive to daily life and was a source of fear, anxiety, and embarrassment (Drass & Feldman, 1996). Hypoglycemia can have negative consequences, from mild discomfort and embarrassment to acute emergency. It can cause both physical restrictions and cognitive impairment to individuals with diabetes, and major stress to their families (Rubin, 2002). Those close to persons with diabetes, family, friends, and co-workers, must be helped to understand the symptoms of hypoglycemia and know how to help them with decisive action (Merbis, Snoek, Kanc, & Heine, 1996; Rubin). Recent severe personal stressors were significantly associated with poor glycemic control, whereas positive life events could improve it; this improvement is associated with changes in self-care practices (Lloyd et al., 1999). Persons with diabetes and health care professionals should accept that fluctuating blood glucose levels occur with diabetes. In this way, they can avoid the trap of expecting stable

behaviour and adopt the more flexible expectations of minimizing abnormally high or low blood glucose levels (Vallis, 2001).

Diabetes education is essential to understanding and taking responsibility for intensive self-management of the disease (Diabetes Control and Complications Trial Research Group, 1995; Diabetes Control and Complications Trial Group, 1996; Drass & Feldman, 1996; Hernandez et al., 1999; Jones et al., 2001; Nichol, 1999; Rubin, 2002; Strauss, 1996). These studies also found that interactions with diabetes nurse educators, dieticians, and other members of the health care team are part of the education process.

Current research has addressed specific aspects of diabetes education that indicate insight into the experience of living with diabetes. Some of these studies have acknowledged that persons with diabetes have many needs to be met in education programs, over and above the need for knowledge of the disease. Persons with diabetes should not be made to fit into educational frameworks but their individual needs should be met by adapting content and method (de Weerd, Visser, Kok, & van der Veen, 1990; Goldman & Maclean, 1998; Tillotson & Smith, 1996). Education should be continuous, helping to meet the changing needs of persons with diabetes (Reichard, 1996; Sprague, Shultz, Branen, Lambeth, & Hillers, 1999; Wikblad, 1991). Diabetes education should promote diabetes as being compatible with a healthy life (Jacobson, 1996; Lundman et al., 1990; Toljamo & Hentinen, 2001; Wikblad, 1991).

Many researchers have recommended assessment, exploration, and intervention in diabetes education programs, in these following areas: social issues, especially family relations and support; emotional issues such as adaptation to diabetes, stress management, and coping styles; decision-making; attitude and meaning of diabetes; motivation (Beeney et al., 1996; Brennan, 1996; Hendricks & Hendricks, 1998; Jacobson, 1996; Kokkonen, Lautala, & Salmela, 1994; Polonsky et al., 1995; Strauss, 1996; Vallis, 2001; Wikblad, 1991; Willoughby et al., 2000).

In order to meet the psychosocial needs of persons with diabetes, and thereby demonstrate an understanding of the experience of living with the disease, researchers have developed a number of educational tools and interventions. Some of the following have been suggested: provision of psychological services within the diabetes clinic to address coping and stress issues, utilization of the principles of adult learning, motivational interviewing, visual aids, behaviour modification, self-awareness strategies, tutoring, problem-solving training, self-study, *The Stages of Change Model* – a behaviour change intervention, a nurse coaching intervention following diabetes education, individual and group learning, computer-based instruction, mass media education approach, and chronic care clinics (Bonnett et al., 2001; Hernandez et al., 1999; Jones, 1990; Jones et al., 2001; Lloyd et al., 1999; Maldonato et al.,

1995; Reichard, 1996; Stott, Rees, Rollnick, Pill, & Hackett, 1996; Strauss, 1996; Wagner et al., 2001; Whittemore, Chase, Mandle, & Roy, 2001)).

### **Compliance / Adherence**

The terms compliance and adherence have been used repeatedly in the research literature to describe health care professionals' perspectives not only of ideal diabetes management but also of the persons who live with type 1 diabetes (Cameron, 1996; Lo, 1999; Lutfey & Wishner, 1999; Maclean, 1991; McLeod, 1998; Toljamo & Hentinen, 2001; Vallis, 1998; Weiss & Hutchinson, 2000).

Though commonly used, the actual meaning of these terms is ambiguous. It is evident that there is a progression from concrete, one-sided thinking to a more all-inclusive attitude that sees beyond treatment regimen adherence to the varied and complex life patterns and responsibilities of persons with type 1 diabetes. The following section provides an overall discussion of the research literature relating to compliance and adherence. Specific aspects of compliance and adherence are then presented using the subheadings: (a) beyond compliance and adherence, and (b) the patient as expert.

Lutfey and Wishner (1999) carried out a literature review to bring clarity to the terms compliance and adherence. They concluded that compliance suggests a restricted, medical-centered model of behaviour while adherence implies more patient autonomy with the medical treatment regimen. Adherence

is difficult to measure as there are no standard measurement tools and no consensus on a definition (McLeod, 1998). Other researchers have proposed that compliance implies an authoritarian attitude by health care professionals with an insistence on patient conformity to treatment goals, while adherence is intended to be non-judgemental having the patient taking an active and voluntary role in treatment, with health care professionals as partners (Cameron, 1996; Lo, 1999; Weiss & Hutchinson, 2000).

The complexity of type 1 diabetes does not lend itself to these simplistic terms. Researchers have found that compliance and adherence do not convey the psychological, emotional, and social context of diabetes self-management or the ever-changing self-care behavioural demands (Cameron, 1996; Maclean, 1991; Vallis, 1998). Labelling clients as compliant or non-compliant is not productive as it oversimplifies patient behaviour and does not provide opportunities for valuable, creative interventions (Lutfey & Wishner, 1999; McLeod, 1998; Toljamo & Hentinen, 2001).

Other researchers have addressed the deeper meaning of diabetes self-care over the long-term (Hwu, 1995; Mitchell & Lawton, 2000; Polonsky et al., 1995; Ternulf Nhylin, 1990; Toljamo & Hentinen, 2001; Willoughby et al., 2000). Assessment of each individual's ability to cope with lifelong self-care is essential to distinguishing between those who choose compliance and those who have compliance imposed on them. Only in this way can supportive measures be

planned that address both individualized expectations for self-care and personal interpretations of health (Kyngäs & Hentinen, 1995; Maclean, 1991). Diabetes self-management is much more than the application of theory about the disease to daily diabetes care. Self-management is the responsibility of the person with diabetes. It takes a great deal of effort and time, and personal meanings are attached to these behaviours (Aalto et al., 1997; Fitzgerald et al., 1995; Paterson & Sloan, 1994; Vallis, 2001). Uncertainty is inherent in diabetes self-management in that adherence to self-care does not guarantee good metabolic control (Price, 1993; Ryan et al., 2002).

### ***Beyond Compliance and Adherence***

Compliance and adherence are terms that convey health care professionals' paternalistic attitudes in that persons with diabetes are expected not only to do as they are told by complying with every aspect of the treatment regimen but also to refrain from stating any opinions to the contrary. A number of researchers have questioned this attitude to diabetes care and to persons with the disease.

Hernandez (1995) challenged the traditional compliance/adherence paradigm within diabetes education programs for the reason that this approach implied domination of the person with diabetes by insisting on diabetes control. She advocated a movement toward learning from clients and becoming reflective

practitioners. Strauss (1996), and Wikblad (1991) agreed that health care professionals have something to learn from persons with type 1 diabetes. While Strauss asserted that compliance as an approach to treatment was incredibly naive, he believed that the numerous psychological issues affecting treatment adherence could be assessed quite readily with scales and questionnaires. This researcher is using a quantitative approach to a qualitative problem. Wikblad proposed a move away from the compliance/noncompliance focus to a holistic approach that recognizes patients' perspectives and meets their communication, support, and education needs.

A qualitative, grounded theory study identified a construct that moves beyond the compliance and adherence models. Robinson (1993) explored how life can be managed with a chronic condition. At diagnosis patients and families can see only the problems associated with the condition, so they construct and live a story of life as normal. They realign the focus away from the perspective of chronic illness as a negative burden toward the construct of normalization, in which individuals with the disease and their families seek a quality of life. They achieve this by finding equilibrium between recognizing the problems of the disease and interpreting these problems in such a way that difficulties are minimized while abilities are emphasized. The benefit of creating a story of normalization is an improvement in quality of life. The story of normalization supports hope, even when experiencing adversity, and it involves a wellness

orientation that focuses on abilities, not deficiencies. A negative aspect of normalization is that health care professionals consider the persons who use it to be in denial. This attitude of health care professionals is based on their perception of life with a chronic condition as a “problem-saturated” life. Participants felt judged and obstructed by health professionals when they used normalization to help them live with chronic disease.

### ***The Patient As Expert***

Learning to self-manage type 1 diabetes has been described as an evolving learning process with many stages of trial and modification. Persons with diabetes have gained knowledge, experience, and confidence (Maclean, 1991; Maclean & Goldman, 2000; Paterson et al., 1998). They have attained expertise in their own diabetes management. Therefore they do not always judge it as necessary to comply with the prescribed medical regimen. They seek a recognition and respect for their personal knowledge and expertise, and a partnership with health care professionals (Hernandez, 1996; Hernandez et al., 1999; Maclean & Goldman; Paterson & Sloan, 1994; Paterson & Thorne, 2000a, Paterson, Thorne, Crawford, & Tarko, 1999; Price, 1993; Reichard, 1996).

Bissell et al., (2004) investigated the construct of concordance as a replacement for compliance/adherence in health care relationships.

Concordance in relationships is based on negotiation between equals, to achieve

a therapeutic alliance, in which openness and respect for the patient's agenda is paramount. It was proposed that these relationships could result in mutually agreed goals by recognizing and utilizing the expertise of both patients and health care professionals.

Paterson et al. (1999) supported the concept of "the patient as expert" with their investigation of the construct of transformation in living with type 1 diabetes. It evolves through a series of steps by which participants restructure the self and the illness experience. Participants consciously choose to interpret the illness problem as a challenge rather than a threat by believing that the disease can be controlled. In this way, they are able to bring about a new relationship with the disease and with those who provide health care. They are transformed positively by the experience of living with type 1 diabetes and consider themselves to be experts in their diabetes care. This construct challenges the relevance of the medical model of compliance/adherence. Transformation is positive in that as expert patients, participants feel both independent and liberated, but negative in that they feel alone and solely responsible for their diabetes management.

Other researchers have also looked beyond compliance and adherence to the concept of "the patient as expert" in diabetes management. They have concluded that expert patients have similar characteristics. They are astutely knowledgeable about their own diabetes, are able to reflect and learn from

experience, and are adept at recognizing diabetes patterns of response. They are confident and reliable in knowing their own body cues, in taking appropriate self-care actions, and in achieving good glycemic control even though they do not conform totally to the course of treatment set out by health care professionals. They choose a variety of management styles, influenced in part by their individual personalities (Hernandez, 1996; Hernandez et al., 1999; Maclean, 1991; Maclean & Goldman, 2000; Price, 1993; Reichard, 1996).

Researchers have described the rationale supporting “the patient as expert.” Persons with diabetes have to develop expertise in the decision-making aspects of self-care because they have not been taught how to deal with every unique, uncertain, and often complex problem that arises frequently in day-to-day living with the disease (Paterson & Sloan, 1994; Price, 1993). Mitchell and Lawton (2000) used the metaphor of “a living tapestry” to describe the experience of living with and managing diabetes. They found that persons with diabetes weave this tapestry as they live with the complexities, emotional upheavals, and inconsistencies of this disease, all of which profoundly affect the personal choices they make to achieve a balance in their lives.

Paterson et al. (1998) described the conflict that can arise between persons with diabetes and health care professionals when noncompliance is used to describe the expert patient’s quest for balance. What persons with diabetes view as experimenting, developing expertise, and asserting self-control

in order to achieve this balance, health care professionals judge as cheating or noncompliance. This conflict arises because the goals of health care professionals for balance are focused on control of blood glucose levels within the normal range. Physicians and many nurses work within a biomedical, legalistic framework, the “physician’s knowledge”, that focuses on the physiological aspects of diabetes care. Persons with diabetes consider that balance is achieved when the demands of strict physiological control can be counterbalanced with their perceptions of what a normal, meaningful life is, one consistent with their values and goals.

Researchers have cautioned that “the patient as expert” cannot be anticipated from every person with diabetes. Not all patients may desire this degree of autonomy or feel as confident in their diabetes self-care as do the expert patients (Kyngäs & Hentinen, 1995). Though to some researchers the concept of “the patient as expert” is a natural and logical progression, the literature has shown that many health care providers have not considered this concept at all.

Meltzer, et al. (1998) presented the *Canadian Diabetes Association 1998 Clinical Practice Guidelines for the Management of Diabetes in Canada* as the first clinical guidelines that could be called “evidence-based.” Their assumptions and recommendations portray the person with diabetes as a dependent patient who is the recipient of diabetes care. For example, they recommend that

patients need to be reminded to come for metabolic control and complications assessments; that patients should be offered education; that patients should be encouraged to exercise. All these recommendations put the onus on health care providers to look after persons with diabetes. Nowhere in these guidelines is there even a suggestion that there are persons with diabetes who could and should be considered experts in their care. While the guidelines recommend sensitivity and respect for the unique culture and geography of Canadian Aboriginal communities as they relate to diabetes care, nowhere in these guidelines has there been expressed any sensitivity to the concept of “the patient as expert”. It is troubling that these professionals who are at the forefront of diabetes care are still “doing to” rather than “doing with” persons with type 1 diabetes. It is the whole paternalistic tone of these guidelines that is bothersome. It is the assumption that every person with diabetes not only needs to be looked after but also cannot possibly know anything that health care providers do not know about managing diabetes. These guidelines maintain that persons with diabetes and their families are central to the diabetes health care team, but that the experts in diabetes care are the diabetes health care team. They recommend that persons with diabetes increase their commitment and participation, and strive to take responsibility for their personal health. There is a seeming contradiction here in that if the diabetes health care team are the experts how can they expect persons with diabetes to take responsibility for their

health. Any insight and recognition of the concept of “the patient as expert” is missing too in the updated *Canadian Diabetes Association 2003 Clinical Practice Guidelines for the Prevention and Management of Diabetes in Canada*.

Similarly, Clarke et al., (2001) have presented the American National Diabetes Education Program that was initiated in 1997. These authors, all physicians, emphasize that their strategies are science-based, and their aim is to improve patient outcomes and the practice of health care professionals. These physicians call the list of goals and the focus of this education program “outcomes-focused” - to treat the patient with diabetes. No mention is made of making alliances with these patients or recognizing them as experts in diabetes self-care.

### **Summary of the Literature Review**

It is apparent from the review of the literature that the adults' experience of living with type 1 diabetes is unique and personal, and that the meaning evolves over time. There is a long period of adjustment and daily self-care management. Only a small number of qualitative research articles present insights into what adults with diabetes live through, the complexity of the meaning of diabetes in their lives, their active roles in self-management, their expertise in diabetes decision-making, their seeking of autonomy and a quality of life, and their need for collaborative alliances with health care professionals.

The number and diversity of research articles found can be attributed to the complexity of the disease and the varied aspects of the treatment regimen and lifestyle changes associated with it. Some studies focus on psychosocial factors, others on specific aspects of diabetes self-management, and others on relationships with health care professionals – both positive and negative. One constant factor that emerged was the influence of the findings of the DCCT on most of the current research being done regarding type 1 diabetes. The DCCT has also had a marked influence on the practice guidelines for diabetes in Canada.

Conflicting findings were observed in terms of health care professionals' positive and negative attitudes regarding compliance and adherence. Most nursing studies demonstrate similar findings regarding compliance and adherence, but nurses' recommendations are different in that they advocate for holism and the importance of the person's perspective when planning and delivering diabetes care.

There were definite consistencies across studies with regard to the importance of diabetes education to effective diabetes self-management. The number of studies investigating varied approaches to diabetes education and the development of educational tools and interventions testifies to this.

My phenomenological study is intended to contribute to knowledge of the lived experience of type 1 diabetes in adulthood. It is hoped that it will provide a

unique perspective. The fact that I am a nurse and a person who has lived with type 1 diabetes for most of my life lends a very personal perspective that allowed a special kind of trust and empathy to develop with my participants. They knew I could relate to what they were telling me. They were open in saying that they spoke to me with such candour because I was “. . . a *diabetic and a nurse.*”

## **CHAPTER 3**

### **Methodology**

Phenomenology was the method of inquiry used in this study to gain a deeper understanding of the meaning of the experience of living with type 1 diabetes in adulthood. Phenomenology is a methodology that attempts to capture the lived experience of individuals by an in-depth examination, interpretation, and description of the lived quality and significance of their life events. Phenomenology searches for the universal qualities in unique individual experiences (Hartrick, 1998; Maclean & Goldman, 2000; Paterson & Sloan, 1994; van Manen, 1997). van Manen's phenomenological method of inquiry was appropriate for conducting this investigation because its aim is to increase understanding about actual lived experience through the use of language. This chapter describes how van Manen's approach was used in collecting and analysing the experiences of adults who live with type 1 diabetes in adulthood, the procedure for recruitment of participants, a description of the study participants, ethical considerations, and credibility of findings.

### **Phenomenology**

In keeping with van Manen's (1997) methodology, I took a hermeneutical phenomenological approach. This approach is one in which research and writing are inseparable in connecting with and making interpretive sense of the meaning

of lived experience. In hermeneutic phenomenology, an exploratory, reflective, interpretive method of discovery is used to uncover unique human experiences and express them in a language that brings insight and depth to these experiences (van Manen).

van Manen (1997) presents what he describes as six methodological activities which constitute a practical approach useful in discovering the meaning of type 1 diabetes as it is experienced by adults with the disease. This approach includes a reciprocal interaction among the following six research activities: (1) identifying and becoming committed to a phenomenon of great interest to the investigator, (2) exploring experience as it is lived rather than as it is conceptualized, (3) reflecting on the fundamental themes that characterize the phenomenon, (4) describing the phenomenon through the creative activity of writing and re-writing, (5) maintaining an effective and oriented connection to the phenomenon, and (6) balancing the research context by considering parts and the whole. This section of the chapter will describe how these six research activities were used to examine and interpret the lived experience of adults with type 1 diabetes.

### ***First Research Activity***

The first research activity involves identifying and being committed to a phenomenon of great interest so that the meaning of the lived experience can be

better understood and described until it reveals something of its fundamental nature. In this study, I fulfilled a dream of many years, to try to increase my understanding, and to help others to understand, exactly what it is like to live with type 1 diabetes. My own experience of living well with type 1 diabetes for most of my life gave me a deep commitment to this research. An even greater incentive was my many years of nursing experience, as a staff nurse and nurse educator, with adults who have diabetes. I needed to understand why so many adults with type 1 diabetes do not follow the treatment regimen when the consequences of not doing so are severe complications and even death.

van Manen (1997) cautions that previous knowledge about or experience with the phenomenon being studied can prevent investigators from developing understandings that are directed toward the distinctiveness of human experience. Because the meaning of lived experience “. . . *is usually hidden or veiled . . .*” (van Manen, p. 23), there is a danger that the nature of the phenomenon will be interpreted before it is fully explored. While many phenomenologists consider bracketing, or setting aside pre-existing knowledge or beliefs about the phenomenon as a central concept of the science, van Manen questions whether this can be truly accomplished. He proposes that researchers can obtain a pure description of the participants' lived experience by being fully aware of their own knowledge and beliefs during all stages of the investigation.

For this study, I started by reflecting on my personal experiences with type 1 diabetes thereby becoming more aware of my own feelings and biases. I realized that my subjective experiences would not be identical to those of my participants, yet I felt that there could be a common meaning in our expression of the realities of a shared phenomenon (van Manen, 1997).

### ***Second Research Activity***

The second research activity of van Manen (1997) is exploring the experience as it is lived rather than as it is conceptualized. This activity requires that the researcher explore all aspects of the lived experience as it is lived fully by participants. I started by taping my own lived experience of type 1 diabetes, and by reflecting on it I gained insight into what diabetes meant to me. I felt that my increased personal awareness would help me to “really hear” the participants’ perceptions of their own lived experience of type 1 diabetes. In an effort to establish a strong orientation to the purpose of the interview, I developed an interview guide that I could refer to when necessary (see Appendix A). Once I had done this, I conducted unstructured interviews with seven participants. The feedback from my thesis committee members helped me to improve my interviewing skills and to remain focused on the purpose of the study.

To investigate the phenomenon as it is lived, I interviewed persons who have lived with type 1 diabetes for years. It is through language that we can

discover and describe human experiences (van Manen, 1997). I recorded all the interviews on audiotape. With every participant, I began the interview with the same approach, asking the participant to tell me in their own words what it was like to live with type 1 diabetes, and to feel free to share any thoughts, feelings, and ideas that he/she had. I had used this approach when I taped my own personal experience; I spoke about what it was like to live with this disease in my own words, revealing my thoughts and feelings. All but two of the seven participants started with no further prompting whereas, with the two participants who did not know where to begin, I asked them to start by describing a typical day with type 1 diabetes. According to van Manen, it is necessary for the researcher to "...borrow [the] experiences and reflections . . ." (p. 62) of participants. Consequently I occasionally used my interview guide to elicit information about specific aspects of a participant's experience not spontaneously raised by him/her. When participants indicated that they had completed their descriptions, I concluded the interview with my thanks. The interviews lasted between 60 and 90 minutes each.

### ***Third Research Activity***

The third research activity involves reflecting on the fundamental themes that characterize the phenomenon. van Manen (1997) calls phenomenological themes, "... structures of experience . . ." (p. 79) because they try to capture

the meaning of the experiences on which the participants have reflected. He emphasizes that researchers must seek the essential themes of the lived experience being researched, that is, the feelings and the input derived from the senses, and described, as lived, by the participant. Essential themes are those that give this experience its unique meaning (van Manen).

Data collection and analysis occurred concurrently during this research. I treated my own transcribed interview in the exact same way as the other seven. I read the written transcripts several times while listening to the audiotaped interviews in order to bring depth and clarity to the analysis through reflection, mindfulness, and a caring adaptation to the subject (van Manen, 1997). Each of the eight interviews was transcribed verbatim; this ensured that the transcripts were accurate and allowed me to use journaling to reflect on each participant's experience. Journaling during data analysis involved taking notes and writing down impressions. This process directly influenced the nature and direction of the analysis (Sandelowski, 1995). Themes gave structure and order to the abstract process of finding meaning in lived experience. I used a line-by-line approach to discover themes and patterns in all the transcripts. Care was taken to first understand each transcript as a whole to avoid becoming swamped in words that could cloud meaning (Sandelowski). This allowed for a deeper understanding of each participant's experience (van Manen). The identified themes were discussed and refined and agreed to by my thesis supervisor.

Following completion of the themes, participants were contacted by telephone and each person agreed to read my summary of the findings to ensure that it was reflective of his/her lived experience of type 1 diabetes.

#### ***Fourth Research Activity***

The fourth research activity is to describe the phenomenon through the creative activity of writing and rewriting, an activity that is fundamental to hermeneutic phenomenological research. van Manen (1997) believes that there are four basic existentials in every person's lifeworld. He describes them as preverbal and consequently difficult to describe. These four existentials include ". . . temporality (lived time), spatiality (lived space), corporeality (lived body), sociality (lived relationship to others)" (p. 172). I considered each of these four existentials as I wrote and rewrote each theme. In order to develop a narrative that explained the themes while remaining true to the essence of all participants' experiences, it was necessary to rewrite repeatedly to make the meaning as clear as possible. I used quotations from the interview transcripts to support and clarify my thematic interpretation of the data. Guidance from my thesis supervisor was essential in clarifying and refining the emergent themes. In order to produce what van Manen describes as texts that are oriented, strong, rich, and deep, I submitted successive drafts until the text showed a strength and uniqueness that captured the participants' lived experience of type 1 diabetes.

***Fifth Research Activity***

The fifth research activity is to maintain an effective and oriented connection to the phenomenon. I strived to eliminate preconceived notions and remain focused on and oriented to the meaning of the experience. Throughout the study, I remained deeply committed to exploring and describing the valid and vivid lived experience of my participants who had trusted me with their innermost feelings. Through writing, rewriting, reflecting, and consulting with my thesis committee, I was able to elucidate the participants' meaning of living with type 1 diabetes.

***Sixth Research Activity***

The sixth research activity is to balance the research context by considering parts and the whole. van Manen (1997) recommends both openness and a plan for the research. The plan gives structure, whereas the openness gives some flexibility when unforeseen eventualities occur. My research plan, as outlined, guided my research. I used themes as a way to organize the writing of my research findings. Each identified theme illuminated an essential aspect of the lived experience of type 1 diabetes. The eight themes – the parts, together reveal the whole – the meaning of the lived experience of type 1 diabetes to these participants.

### **Procedure for Recruitment of Participants**

Permission was granted by the Program Director, Medicine, of the Health Care Corporation of St. John's to recruit participants through the Diabetes Education Program. Adults who met the inclusion criteria were identified with the assistance of two diabetes nurse educators who acted as intermediaries. They contacted potential participants by telephone, briefly explained the study, and obtained permission for me to contact them. I then contacted these individuals by telephone, explained the study in more depth, and answered any questions. When they agreed to participate in the study, a suitable appointment time was arranged for the initial interview. All of the adults contacted agreed to participate in this study.

### **Participants**

Eight participants took part in this study. I was one of these eight participants. The other seven had been referred to diabetes education classes at the Health Sciences Centre of the Health Care Corporation of St. John's. All eight participants met the following inclusion criteria: (1) they were adults with type 1 diabetes, 19 years of age or older, (2) they were able to read and write English, (3) they were residents of St. John's or the metropolitan area, and (4) they were willing to participate in this study.

As a guideline to the number of participants, Sandelowski (1995) recommends a minimum of six for phenomenological studies in order to “. . . discern the essence of experience . . .” (p. 182). According to Sandelowski, this number allows a discerning, case-oriented examination, and a current and vividly textured understanding of experience. Phenomenological research usually generates a great deal of textual data from a small number of participants, and this was the case with my study.

Participants' personal information revealed that they ranged in age from 24 to 56 years. Four had been diagnosed with type 1 diabetes as children, one as an adolescent, and three as young adults. The number of years these three men and five women had been living with type 1 diabetes ranged from 5 to 38 years. All participants had post-secondary education. All were employed. Six of the participants were married while two were single.

### **Ethical Considerations**

Before this study commenced, permission was obtained from the Human Investigation Committee, Memorial University of Newfoundland (see Appendix B). Initial contact with all potential participants was made by two intermediaries who were diabetes nurse educators at the Health Sciences Centre in St. John's, who knew these persons as clients, and who were not involved in conducting the research. After briefly explaining the study, the intermediaries obtained

permission from potential participants to release their names and telephone numbers to me. During my initial telephone contact with each interested potential participant, I told them the purpose of the study, the plans for data collection, and the anticipated time period for their involvement in the study. I explained that their participation was entirely voluntary and that they were free to withdraw from the study at any time. I explained fully the safeguards that would be taken to ensure confidentiality.

For me, an ethical aspect of my study was to disclose to my participants my position to the phenomenon. I told them I had type 1 diabetes and that I was a nurse. The subject of researcher self-disclosure has been addressed in the feminist research literature, and is thought to initiate “true dialogue” (Reinharz, 1992).

Before the initial interview began, I asked each participant to sign a written, informed consent. I gave each participant my name and telephone number and encouraged them to call me at any time during the study if they had questions or concerns. I also explained to each participant that while they might not benefit directly from participating in the study, the information they shared might be of assistance to health care professionals in developing new interventions and programs to meet the needs of adults with type 1 diabetes, and perhaps indirectly their needs as well. I explained that there were no anticipated risks from participating in this study. However, I stressed that if any sensitive

issues arose about some aspect of their experience of living with type 1 diabetes, they would be given the option to decide what was appropriate – to take a break, to change the topic, or to conclude the interview. van Manen (1997) maintains, “. . . the best way to enter a person’s lifeworld is to participate in it...” (p. 69), so I took time to develop rapport with each participant. I used verbal and nonverbal communication, especially active listening and using silence to allow participants to reflect and to formulate their thoughts. When necessary, I sought clarification, encouraged comparison, and paraphrased. I really listened and tried to understand their reality in a non-judgemental and supportive manner. I made every effort to be sensitive to their reactions. Throughout each interview, although some participants expressed deep feelings about their experience of living with type 1 diabetes, none of them wanted to conclude the interview early, and all spoke freely to me. One participant stated at the conclusion of the interview, *“It’s only because you’re a diabetic and a nurse that I shared this with you”*.

All reasonable precautions were taken to protect the identity of participants and to ensure confidentiality. The interviews were conducted in private, at a time and place agreeable to the participants. The safeguards I used included securing consent forms, code numbers, audiotapes, and transcribed interviews in a locked filing cabinet that was accessible only to me. Transcribed interviews were coded so that participants could not be identified in any way. As

well, participants were asked to read the summary of the findings chapter, verifying that they could not be identified, and assuring them that they would remain anonymous.

### **Credibility of Findings**

In qualitative research credibility refers to a conviction of the truth of the data, a trustworthiness of findings demonstrated when participants recognize their own experiences in the research findings. A qualitative study is credible when “. . . it resonates with [the] sense of lived life . . .” (van Manen, 1997, p. 27).

Participants are able to recognize their own experience in the reported research findings even though each person's lived experience is invariably more intricate and personal than the select descriptions presented in a study.

I ensured the credibility of this study in a number of ways. The study was supervised by a faculty member at Memorial University School of Nursing who is a nurse researcher well versed in phenomenology as a methodology, and as content expert, an endocrinologist who is an expert in the treatment and support of clients with diabetes. They read the transcripts and gave invaluable feedback that contributed to deeper analysis of the data. Each participant was mailed a summary of the findings and asked to review it to confirm that the findings were reflective of their experience of living with type 1 diabetes. In follow up telephone conversations with six participants, they agreed with the findings. Only one

participant could not be contacted despite several telephone calls. Researcher bias was reduced by (1) establishing rapport with the participants, (2) recording personal and interpretive notes following each interview, (3) consulting frequently with my thesis supervisor, and (4) setting aside preconceived ideas concerning the phenomenon.

The fourth action for reducing researcher bias was accomplished by becoming fully aware of all the personal knowledge and beliefs I have about living with type 1 diabetes, and by making a conscious effort to maintain this awareness throughout the entire investigation. It was critical for me to do this as I was a participant in my own research study. I did not find this to be a difficult task. As a researcher, I am a nurse and a professional first and foremost, and even though I have intimate, firsthand knowledge of type 1 diabetes, I approached the interviews and data analysis with as much objectivity as I could. My research committee was invaluable in helping me with this aspect of credibility in that they read the transcripts, questioned and critiqued my findings, and kept me focused on the purpose of my research.

## CHAPTER 4

### Findings

What is the meaning of living with type 1 diabetes? How do adults adjust to, cope with, and live day to day with this complex disease? Eight participants told me their stories about living with type 1 diabetes and through the interplay of our shared language, disclosed deep insights into these questions.

Data analysis has revealed eight interconnected themes that express in language the depth of their lived experience of type 1 diabetes (van Manen, 1997). The themes are: (1) *Constant Vigilance*, (2) *Struggling for Stability*, (3) *Striving for Freedom*, (4) *Surviving Perceived Noncompliance*, (5) *The Lived Experience of Blood Glucose Fluctuations*, (6) *Enduring Sustained Uncertainty*, (7) *Family Support: Sustaining or Smothering*, and (8) *Being Alone with Diabetes*. These phenomenological themes attempt to capture the essence of living with type 1 diabetes in adulthood.

#### ***Constant Vigilance***

Type 1 diabetes is a lifelong, demanding disease. There is no time out; no day off. The realities of living with type 1 diabetes are always being on the alert, ceaseless attention to body signals, planning ahead, and decision-making – on every aspect of daily life. These realities required participants to be constantly vigilant about its presence, its warnings, and the endless ways in

which this disease affected their bodies. They spoke of the persistent energies they had to put into living with their diabetes. It was an unrelenting intrusion into their lives: “. . . *diabetes is always there*”.

Constant vigilance was described as one of the most difficult aspects of living with type 1 diabetes because participants had to shoulder this responsibility “. . . *24 hours a day, 7 days a week . . .*”, thus it was identified as a theme early in the study. Participants related that they had to develop a sense of constant vigilance for several reasons. Type 1 diabetes never relapses, it has to be continually controlled by a complex treatment regimen, and the reaction of each person to the treatment plan is unique.

These women and men described a state of perpetual readiness that enabled them to be prepared to respond with immediate action to sudden changes. They always felt they had to be constantly assessing, analyzing their diabetes data, and making intervention decisions:

*It's something you have to be conscious of over a 24-hour basis, and no other aspect of my life requires that level of concentration.*

The participants spoke of how they always had to be alert to the present as well as prepared for the future – the future often being as close as what could happen next:

*My typical day consists of consciously being aware to always have certain things with me. Always. Even going down the hall at work, I have my purse with me.*

They were required to develop over time and with experience, a special kind of vigilance that was unique to them as individuals. They called this heightened perception of body cues as “. . . *being tuned in*”. They spoke of how they could be better tuned in when they had a good knowledge base about their diabetes. This knowledge helped them to recognize and understand the significance of body cues. Knowledge enhanced the importance of constant vigilance as a valuable tool for diabetes control:

*You take what you've been taught, you narrow it down to the possibilities of what it could be, and you make your decision.*

The participants felt they could be effective in their constant vigilance if they made diabetes an integral part of their daily activities:

*Usually a mental check before I go out the door, “Do I need to take anything else?” So, I'll think ahead and say, “Do I have enough pen needles at work, or do I need to bring another insulin cartridge?”*

Constant vigilance became even more important in avoiding the serious acute complications of hypoglycemia or hyperglycemia. This attention to detail was described as a preventative strategy, a safeguard:

*It's kind of a protective mechanism; if you don't develop something like that, then you could end up in a situation which is, well, life-threatening.*

Constant vigilance requires a high level of critical thinking and problem solving. Participants explained that this vigilance was most beneficial when their decisions were balanced with prior experience and a measure of confidence:

*Even in just your insulin control and your diet control, you sort of gotta to plan ahead and look back to connect what has happened to you over the last few days to what you did at a certain time and what you didn't do. It probably makes you a bit more analytical.*

Because constant vigilance is a monumental task that must become a way of life, it can be very stressful:

*I think that [diabetes] is frustrating. That's probably one of my best descriptive words because [diabetes] is so – everyday. Every minute there's something affecting it. But sometimes, it's the everyday little nit-picky things that drive me crazy.*

### ***Struggling for Stability***

In health, the body's internal environment is in equilibrium, a dynamic state of balance in which internal levels vary, but always within a narrow range of normal. In this context, the healthy body is stable, a state in which any disruptions are quickly balanced (Lutz, 1994; Thompson, 1995). In persons with type 1 diabetes, physiological stability of blood glucose levels is absent because of insulin deficiency, but with treatment, health care providers expect persons with diabetes to achieve normal blood glucose levels; they call it diabetes control. While health care providers think of this aspect of diabetes as control, persons with diabetes think of it as stability. The participants are trying to attain physiological equilibrium of their blood glucose levels, but because of the difficulty involved in attaining this goal, there are also psychological aspects to the struggle for stability. In this context, stability can mean steadiness,

perseverance, and strength – of the persons – the participants, trying to achieve this stable state in controlling their diabetes (Lutz, 1994; Thompson, 1995).

These women and men acknowledged that they do not produce insulin and because of this, the finely tuned and complex mechanisms of metabolism are altered. They recognized that diabetes could play havoc with the stability of their body functions yet, they maintained that diabetes treatment regimens and lifestyle changes were not always effective in stabilizing their disease. They spoke about how difficult it was to create physiological as well as psychological stability and that in working toward this goal, they had to be ready to struggle, to be prepared to exercise sustained effort. Thus, struggling for stability was identified as a theme in this study.

The participants related how they utilized formal diabetes education and experiential knowledge in their struggle for stability. They applied this knowledge through diligent organization, planning ahead, and adhering to routines, approaches that helped them to stabilize their diabetes.

Knowledge helped participants to not only understand the disease and its treatments but also to take up the struggle to balance the many factors affecting their diabetes:

*[Knowledge] makes a lot of difference; you're not quite as fearful then. Now, here's the situation. You don't expect to have it happen to you, but now it's happened, so handle it according to the guides.*

These women and men spoke highly of the diabetes educators who had taught them about type 1 diabetes and the treatment regimen. They appreciated the one-to-one interactions with diabetes educators and their ongoing support. Nevertheless, participants felt that one important element had been missing in their education; they had not been taught how to take all this new knowledge and fit it into their lives. They were left to their own devices in trying to tailor this knowledge to fit them as individuals, making their struggle for stability all the more intense and confusing. At times, they felt overwhelmed by this struggle:

*Does it [diabetes] control you or do you control it? There's days I'm not sure which. I don't want it to control me. I want to be in charge, but there's days I think, "It's got me licked this time".*

Participants explained that it is an ongoing effort to achieve stability because diabetes is always changing. There must be “. . . *management of everything*”. Participants felt they could be effective only if they established and adhered to set routines. All participants were able to describe a typical day, indicating just how routine their lives were:

*A typical day – just very routine – same old breakfast all the time, cause it works and the same old insulin. No matter how much I don't feel like eating, I eat every breakfast and my lunch.*

Detailed planning ahead and diligent organization were essential in order to co-ordinate all aspects of the treatment regimen with the effects of fluctuating blood glucose levels, exercise, stress, and illness. This planning ahead and organization involved tight scheduling of every activity. A participant described

herself as a “. . .*scheduled planner*”. It was a necessity in the everyday struggle for stability.

If deviating from tight scheduling and set routines by having a social evening out, participants needed to consider every eventuality that could possibly occur. This meant not only being organized with insulin, food, and blood testing equipment but also judging the timing of all these interventions.

In the ongoing struggle for stability with their type 1 diabetes, participants' interpretation of diabetes stability and that of most doctors and some nurses often clashed. These health care providers insisted that adhering to the rigid treatment regimen would result in diabetes control, meaning consistently normal blood glucose levels every day and over the long-term. The participants' viewpoint was much different. They felt that achieving consistently normal blood glucose levels would involve an intolerable rigidity of lifestyle, a fixation with blood glucose levels that would exclude any degree of normalcy. Several participants who, during pregnancy were able to achieve normal blood glucose levels, realized that this goal was achievable, but at the cost of living a regular and fulfilling life:

*So, I found out I could have good blood sugars, but it was just tunnel vision for blood sugars, and nothing else mattered at that point; you've got something to work towards. But I wouldn't be able to live like that. You would have to eliminate almost everything else in your life. And you know, that's not living!*

Participants realized that every person reacts individually to the treatment regimen, so they decided to make compromises and to use trial and error in an effort to fit this regimen into their own lives. They referred to compromises as “. . . *tradeoffs* . . .”, and explained them this way:

*I don't try to lock myself away and have perfect blood sugars but have no life, that's not the point. If it takes ten years off my life, well that's a trade-off I'm willing to take, living a reasonable, normal life, and a satisfied life.*

Trial and error meant finding the right balance between intervention and outcome. They called trial and error a process, a “. . . *getting back on track* . . .” that was complex, very time-consuming, and required a great deal of energy and commitment:

*I think diabetes is trial and error because there is no reason why certain things happen. There are days that I can exercise everyday the same time; I can eat the exact same food for two days in a row and I'm [blood sugars] totally different.*

The benefit of “. . . *getting back on track* . . .” outweighed the struggle to achieve it. By using positive action and problem solving, participants were usually able to rectify imbalances.

Two integral parts of the struggle for stability were the pervasiveness of this task, and the persistence that was required to achieve even an acceptable level of diabetes stability. The struggle was so pervasive that it could take quite a toll on the person with type 1 diabetes:

*There's [me] the woman and the wife that just gets shelved. Because by the time I do the 'Mom thing' and then the 'diabetes thing', that usually takes up most of my time.*

The most difficult aspect of persistence was that it was unceasing, sustained, and never-ending; it had to become a way of life:

*I think that if nothing else, people with diabetes should be given a pat on the back for persistence, for going on again. It is hard to do this when they don't know why their blood sugars are all over the place. Just having the courage to carry on with this regimen when it doesn't work all the time, I think that should be recognized.*

There are many negative aspects to the struggle for stability. These women and men needed a positive driving force to help them to keep on with the struggle. This positive force was motivation. Participants related that any motivation must be felt deeply by the person and must come from within. Some chose to focus on a positive aspect of diabetes stability, that they could experience a sense of well being and live a fairly normal life. For other participants, their main motivator was the threat of complications, while for others it was only when complications struck them that they put more time and effort into re-establishing stability:

*When complications are something that somebody else has, or something you read about in a book, they don't hit home. It is when you have your first laser treatment; it is when the first bit of protein shows up in your urine, that's when it starts to hit home.*

The complex, multi-faceted process of struggling for stability was summarized by this participant:

*You can't just let it get to you and sort of give up, throw up your hands and say, "Well, I've got this, that's it, it's over". I think that is the reason that you stick with your control, 'cause it's easy enough to say, "I'm sick of this! The hell with it! I'm giving this up, and what happens, happens!" I thank God, I've never felt that way. At times it gets me down, but I never got to the point where I thought, "This is just not worth the trouble anymore". I've often said, "I've lasted this long, and if I keep at it, I can stay healthy, and that's what I want to do".*

### ***Striving for Freedom***

Freedom can be considered an absence of restraint or repression, an ease of action, power of self-determination, an enjoyment of personal liberty (Lutz, 1994; Thompson, 1995). Freedom as we know it, is compromised or denied when a chronic disease like type 1 diabetes strikes, and the individual is left to decide to either accept or surrender to the loss of freedom, or to reclaim as much freedom as is possible.

Striving for freedom had many meanings for the participants. They knew that freedom could not be liberation from this life-long disease, so it came to mean an easing of the constraints that type 1 diabetes, by its very nature, imposes on the person. Freedom came to mean the personal choice of not allowing this disease to take over their lives. Moving forward and getting on with life was important to them. They strove for freedom by continuing to do their best to fit type 1 diabetes into their lives and to moderate its restrictions. Striving for freedom was a higher ideal of seeking a quality of life, a degree of self-determination in management, and as such, it transcended the struggle for

stability. Striving for freedom became part of everyday life. The participants were prepared to work towards creating a sense of freedom in the face of their insulin dependency, hence the theme: striving for freedom.

When they were diagnosed with type 1 diabetes, the freedom of their usual way of life was changed forever. They described poignantly the magnitude of how quickly they were expected to accept the disease, of how they had to drastically modify their familiar lifestyle while feeling that they were being forced by the diabetes to do so:

*I had started to formulate so many strong habits in my lifestyle, and they were radically changed in a 24-hour period. [This disease] is a non-negotiable type of thing. Your back is to the wall with nowhere else to go.*

These women and men dealt with these intense emotions by thinking in a comparative way. While the diagnosis of type 1 diabetes was not welcome, “. . . *I will always say that it could be worse*”. They described how it helped to compare diabetes to other types of illnesses that they might have developed, ones that could be far more debilitating. To reason in this way helped to lessen the impact of what they had, thereby reducing the implications of their loss of freedom. It helped them to not only accept type 1 diabetes but also to strive for a new kind of freedom, that of adapting to the disease and getting on with life:

*I've often told people that if I had to pick a condition to have [it would be diabetes]; it doesn't stop me from doing anything. If anything, I should be healthier than the average person that's not mindful of their food intake and their activity.*

In the time following diagnosis, participants felt a real dependency on doctors and nurses. There was a sense of resigning their freedom to these professionals:

*The first year it was like, if [my doctor] told me to take six [units of insulin], I took six no matter what I ate.*

Over time, this dependency became stifling, especially when participants were afforded little respect for their hard-won knowledge about their own diabetes. In their search for freedom, many of them chose to adopt forms of resistance. They reacted by staying away from health care providers and trying to manage on their own:

*[When health care providers insist], "It is my way or the highway", at that point I'm out there thumbing.*

In their striving for freedom, these women and men learned various strategies that helped them to cope with the demands of type 1 diabetes. They tried not to dwell on the disease and become distressed by it as it was ". . . *only self-defeating*". They explained that continuous adaptation was a part of striving for freedom: "*Diabetes is a reality; I just learn to live with it step-by-step*".

Participants were torn between adhering to the rigid lifestyle and desiring some degree of spontaneity in their lives:

*If I had a choice it wouldn't be my lifestyle. But you have to incorporate that rigid lifestyle into your routine every day, and if you don't then you pay the consequences later. But it is my life now; I have to do it.*

Other participants were positive about the diabetes lifestyle and treated it as normal and acceptable. This attitude enabled them to use problem-solving to achieve a perceived degree of freedom:

*If I know I am going to be out late, then I will just bring my insulin and glucometer with me. I bring everything in [my knapsack] just in case something comes up; then you know, spontaneously, I can go and do it.*

It was often difficult to maintain the energy and effort that went into finding ways to strive for freedom. The emotional impact of living with type 1 diabetes could overwhelm their coping strategies:

*There are other times I say, "Why in the hell did this happen to me? Why do I have to go through my life like this?" I've done that more than once. If there is anything that could depress the hell out of you, it's got to be diabetes.*

These women and men described type 1 diabetes as ". . . a very personal disease . . .", and asserted that they know ". . . their own diabetes . . ." very well. They experienced a sense of personal freedom when they acknowledged the reality of type 1 diabetes in their lives and made the decision to take ownership, to make voluntary choices about self-management that reflected their experiential learning:

*I'm going to keep my sugars in the single digits; I'm not shooting for a 6.8 or a 7.2 because if I do, I'm going to be hypoglycemic half the time and I'm going to be pricking my finger ten times a day. I'm not willing to do it.*

Participants sought balance and choice in a broad sense, beyond rigid adherence to the diabetes treatment regimen, to a quality of life. They realized

that only with good control were they freer to live the lives they had planned.

They exercised their power of self-determination by learning to co-exist with type 1 diabetes:

*Once I knew I could deal with this diabetes, I felt a real strength within myself that I didn't know I had. And from then on, diabetes became a challenge, and a way for me to prove to myself that I could deal with this, that I could live a normal life, and do the things I wanted to do. You need to have a sense of control that comes from knowledge and discipline.*

These women and men experienced a sense of freedom when they were able to live “. . . a full life . . .”, while still dealing with externally or internally imposed limitations. They were continuing to strive for freedom but it was at a higher, future-oriented level. Even though they know and live with the reality that there are no guarantees of ultimate success, their ultimate goal was to live well, in hope, with type 1 diabetes on their own terms. It was the attitude each person brought to controlling the disease that allowed him/her to feel any sense of freedom:

*Having spirit, a positive attitude, a sense of humour, and diligence are qualities that a [person with diabetes] needs to be able to live a full life. I made up my mind that you can't live your life in fear; you can't waste the good times of today worrying about tomorrow. Sometimes you've got to take life and go with it. I know subconsciously when I look at something that I want to do, somewhere I want to be, the diabetes end always kicks in; I probably don't even realize it.*

### ***Surviving Perceived Noncompliance***

Noncompliance is a term that is found in the research literature, especially regarding patients' lack of conformity to treatment goals set by health care providers. For the outsider looking in, noncompliant behaviour is generally viewed as an act of disobedience or an act of rebellion. For the insider, it can have a very different meaning. What others call noncompliance, they call being assertive and displaying individuality (Cameron, 1996; Lo, 1999; Lutfey & Wishner, 1999; McLeod, 1998; Weiss & Hutchinson, 2000). The participants in this study felt that they were being perceived as behaving in a noncompliant manner, when in fact they were not. When their diabetes was not perfectly controlled, most doctors and some nurses judged them unfairly, accusing them of not complying with the prescribed treatment regimen. Participants were accused of being irresponsible and of being undisciplined. For some participants, deep feelings of shame and defensiveness arose from these judgemental attitudes. They felt frustrated and powerless. They acknowledged that they spent their energies trying to survive these pre-conceived notions, hence the theme: surviving perceived noncompliance.

When the participants were diagnosed with type 1 diabetes there was, of necessity, an interpersonal interaction initiated between them and the doctors involved in their chronic care delivery. Participants had hoped to benefit from the ongoing support and guidance of working with these doctors, but what they

expected and what they experienced were decidedly different. Interactions were devoid of reciprocity. The frequent negative nature of these interactions had a profound impact on how participants lived with their type 1 diabetes.

Many participants related that a power differential existed between them and health care providers. They spoke of the “. . . *us / them mentality* . . .” of many doctors who are in positions of power, and consider that it is the place of persons with type 1 diabetes to listen and comply. Little questioning was permitted during interactions, especially if these questions challenged the doctor’s view on noncompliance. Participants described the attitudes of many doctors as:

*... one of arrogance, and one of: “I’m in charge and you’re not. I’m the doctor and you do what I say, and if you don’t, go ahead and find someone else.”*

These women and men experienced deeply felt frustration, anxiety, and discouragement when faced with these judgemental attitudes of doctors who used a dehumanizing “. . . *cut and dried* . . .” approach. One participant related how belittled she felt when accused of noncompliance by her doctor:

*“No, that is not good enough. Your [blood glucose levels] have to be between 4 and 6 [mmol/L]”. [I felt that] trying to get [my blood sugars] between 4 and 7 was totally insane because there is no way you can do it and have it perfect every day.*

Some participants called doctors the “. . . *textbook profession*. . .” because they expected strict compliance with every aspect of the diabetes treatment

regimen, at all times, in order to achieve the goal of normal blood glucose levels. Participants felt they were being judged by a different standard – the average person was not expected to live an unvarying, rigidly controlled life, but they were. They felt that this expectation was not even achievable. Most doctors did not consider this perspective; they did not treat the person, only the disease. Visits to doctors were stressful because they consisted only of assessments for diabetes complications and critical reviews of blood glucose records:

*I feel that doctors' expectations of perfect blood sugars are just not realistic. And using terms like non-compliant and poor control – this is the health care professional's perspective of what diabetes is. What the books say and how your body reacts are two completely different things. I think that it's the "textbook profession", but this is very much an individual, personal condition.*

Participants felt that many doctors showed little insight into their individual lived experience of type 1 diabetes, and consequently their psychological and emotional responses to diabetes were not being addressed. These doctors did not understand that this disease was one aspect of their complex, active, multi-faceted lives:

*So many [doctors] have the "book smarts" but not the "people smarts." [The medical profession] addresses the situation; doesn't address the audience. It does a cookie cutter, giving everyone the same mould.*

These women and men related how they have learned on their own to take responsibility for controlling their type 1 diabetes as well as they could. Their own sense of what needs to be done to live with this disease often went

against the stringent, soul-destroying regimen prescribed for them. Participants had to deal with the negative consequences of that – of being perceived as noncompliant and experiencing the deeply-felt frustration of being made to feel downright “. . . *bad and irresponsible*”. They had to suffer the condemnation of being judged as “. . . *out of control*”. Doctors had the power and there was a backlash when participants expected to have valued their personal knowledge, experience, and expertise with type 1 diabetes:

*But see, what happens is – you are questioning the authority of a profession. My basic difficulty with the medical profession is that they can spend 15 minutes with me and dictate for the rest of my life; I could only hope to become that proficient!*

Some participants reacted by expressing their dissatisfaction. They felt disparaged. They knowingly became defensive, but never noncompliant. Others reacted by trying to manage on their own and seek out doctors only when they had to, only when they could not find their own solutions:

*If I don't feel I'm an equal partner [with the doctor], I won't go back to see him or her – definitely not!*

There was a sense among the participants that many doctors and some nurses were trying to make them feel guilty by using “. . . *fear tactics* . . .” such as describing terrible complications, to force them to comply with the diabetes regimen. They felt they were being viewed and treated as though they were being noncompliant, and feelings of guilt were often aroused:

*Usually after supper, either one of two things happen, I'll either go for a walk or feel guilty about not going for a walk. I'm a great one for guilt trips. I try and get exercise as much as I can, don't do it as regularly as I should. But I spend a lot of time thinking about it, but it doesn't help matters much.*

Some participants took these accusations of noncompliance to heart, affecting how they viewed themselves and their lives. But to some extent, all participants internalised the guilt:

*At times, I feel frustrated and fed up with the rigidity of my life and the constant pressure to toe the line. I'm not allowed to stop being "good", to stop controlling my diabetes. I'm not allowed to be human – to drink too much, to be the life of the party. I am judged very severely if I lapse. I am a bad, uncaring person if I do that.*

Some participants fought back and refused to take on the guilt that was being externally imposed on them. It was their way of negating any accusation that they were noncompliant:

*And I let [the doctor] know kind of quickly that I was a no-nonsense kind of person. "I don't need your guilt. I am big and ugly enough to take care of myself. You are dealing with an adult. I'm not listening to you talk down to me, or talk over me."*

These women and men survived accusations of noncompliance in several ways. Many used humour. Humour was their defence against frustration and anger. Humour came from barriers breached and troubles survived. It was a positive force that lightened the load of the diabetes regimen, and especially the unfair judgements of noncompliance by appealing to the amusingly absurd and ridiculous side of a serious situation:

*I think more than anything else, having a sense of humour, and being able to look at the funny side of life, has helped me to cope. And when you laugh, it is such a release, and it puts your whole life back into perspective.*

Having the ability to use humour when speaking about the very negative aspects of complications is a tribute to the ability of these participants to not only survive but also to rise above life's unhappiness. Then, even the dire threats about the consequences of noncompliance can appear more tolerable:

*When I get out of bed, one of the first thoughts I have is, "Well, I'm out of bed for another day, that's good!" (Laugh). "Everything seems to be working. I can look out the window and see the road; that's a good start!" (Laugh). I'm getting to be sarcastic here now. But I think that's there at some point, I'm thankful that I got another good day out of it, so I don't take it for granted.*

A downside to the use of humour by participants is that it can be misunderstood. It was sometimes perceived as denial, or noncompliance, resulting in health care providers jumping to the wrong conclusions and judging these participants adversely and unfairly:

*Because you joke or make a funny remark about something as serious as diabetes, they see you as a person who doesn't give a damn, who is not compliant. They are judging you based on their interpretation of the world. But it is often the case that those who persist and do well are strong people who have a sense of humour and can laugh at their situation.*

Other participants survived accusations of noncompliance by attempting to understand the point of view and motivations of health care providers. Despite the participants' feelings of being misunderstood as individuals, they did feel that

health care providers who were judgemental, had good intentions and had their best interests at heart:

*The medical profession is doing things for the right reason – for the right concern. It's the wrong methodology – it definitely is!*

Participants had high praise and a lot of respect for doctors and nurses who were enlightened and intuitive, who treated them as total persons, not just a disease. These health care providers did not stoop to accusations of noncompliance but displayed affirmative attitudes, were sensitive to participants' needs, and developed rapport with them. They were willing to be “. . . a sounding board and give an objective point of view . . .”, and to form with participants “. . . a partnership . . .” for diabetes control by using “. . . a negotiation process . . .” in managing their diabetes:

*The medical profession are becoming more aware of the fact that the person with diabetes should be a very integral, a very important part of the control.*

These women and men try to change ingrained attitudes and narrow views of compliance by being open about what they want and need, and by expecting “. . .recognition and respect . . .” as the basis for interactions with health care providers. They want to be heard. They want to be understood, to experience compassion and empathy in their interactions:

*I want [health care providers] to say, “It must be hard. I admire you for keeping at it. You have every right to be frustrated at times. Let me help by listening. We'll work on this together”. It's the positive feedback that*

*gives you a sense of optimism; a sense of, "Yes, I can meet the challenge"; that helps you to go on.*

Participants want interactions with doctors and nurses to leave them with balanced feelings of support, and independence, and self-reliance. They want these health care providers to expect them to not only maintain high standards of care but also to demonstrate more understanding of how difficult the treatment regimen can be for them:

*If I go see a medical professional, I see them for 15 minutes. And then, for the remainder of that day, for the remainder of my life, I have to deal with [my diabetes]. So you can give me all the experience and all of the knowledge that you want in that time frame. But when I walk out of that office, I'm responsible for it.*

### ***The Lived Experience of Blood Glucose Fluctuations***

The hallmark of diabetes control is normal blood glucose levels. Maintaining these normal levels is the major goal of all diabetes education and treatment regimens. The signs and symptoms of low and high blood glucose levels are well known, outlined in step-by-step progression in an objective, scientific manner. Abnormal blood glucose levels are considered to be a major problem in type 1 diabetes, and the research literature abounds with the cause, effect, treatment, and control of blood glucose levels. Nowhere is there presented the subjective view of these fluctuations, the actual lived experience of low and high blood glucose levels.

The participants offered enlightening insights into this experience – the physical, mental, emotional, and social disruptions caused by fluctuating blood glucose levels. It was a real issue for them, an ongoing, ever-present reality because their blood glucose fluctuations were unexplained, erratic, and unpredictable. Achieving and maintaining consistently perfect blood glucose levels, within the narrow range of normal, became a very difficult, complex, and frustrating task because even with diagnosis and rigid treatment, fluctuations occurred. Participants described how these variations in blood glucose levels made them feel, and how they interrupted their pursuit of a normal life. Thus, an emerging theme in this study was the lived experience of blood glucose fluctuations.

The onset of low blood glucose levels is sudden, and participants had become adept at recognizing subtle symptoms:

*I'm trying to express my thoughts, and they don't come out clearly, or I can't think of a word that just won't come. I know then that my neurons need sugar!*

The experiences of more overt symptoms was explained as the trauma of going into shock:

*Your knees go weak, you start to shake. You go pale and break out in a cold sweat. You have to sit down. Your thought processes are fuzzy. Your heart is pounding. The craving for food, any food, is overwhelming.*

The worse part of the experience was the confusion, trying to marshal thought processes so that appropriate action could be taken:

*You feel everything slipping out of your control and you know you have to do something about it. It won't go away on its own. You have to try to control the fear and remain calm too.*

The symptoms of hypoglycemia were so distressing and so difficult to describe fully and clearly, that the only words one participant could articulate were: *"It's an awful feeling! I'd do anything not to get a low!"*

The thought of low blood glucose levels engendered feelings of dread, *"How long before the next one?"* These women and men spoke of the urgency to be prepared for fluctuations at all times because of the suddenness of onset. The slightest indication of low blood glucose was something they had to be very aware of during everyday activities, and even more during exceptional times:

*In exams, I'm thinking the whole time, "Oh my God! I hope my blood doesn't go low; what will I do?" It is definitely stressful.*

Because low blood glucose levels *"... always seem to come at the busiest time of day . . ."*, they were intrusive. At times they led to frustration and intense irritation because participants felt so unwell:

*I sometimes say, [diabetes] is like having another child in the house, whose needs need to be met. And sometimes when my blood [sugar] goes low, it needs to be now.*

Participants with hypoglycemia unawareness experienced even greater stress because they had no signs and symptoms of hypoglycemia at all. They had to depend on others to recognize the symptoms for them and to initiate treatment.

Compounding the experience of hypoglycemia was the rebound effect of treatment – high blood glucose levels. These elevations put participants into an unstable condition that lasted until their blood glucose finally returned to normal, often hours later. This instability made coping with everyday responsibilities quite difficult:

*So often I have to push through these times, forget about how rotten I feel, and focus my mind on what I have to do.*

In contrast, elevated blood glucose levels could be detected as a rapid onset of “. . . *over-whelming weariness*”. These women and men described “. . . *a heaviness, a dragged-down feeling radiating from the middle of my body*”. They had to put forth an effort to find the positive energy to go on with their daily activities when all they wanted to do was withdraw from others and rest until they felt better.

It is very interesting to note that many participants related that they experienced feelings of physical, mental, and emotional well being when their blood glucose levels were moderately elevated, up to 10 to 13 mmol / L.; they had energy and were productive. Some reasoned they felt this way because they had no symptoms at all of low blood glucose.

Several participants cited elevated early morning blood glucose levels as the hardest to correct and, therefore, the most disheartening to deal with because of all the effort they had to put into trying to normalize them while they

felt so weary and miserable. One participant had followed all the treatment guidelines and she related:

*I can't get control. I've done everything I could, and gosh, "How come it's so high?" It's just perplexing. I have to work doubly hard all day long to get it back in control.*

The psychosocial experience of blood glucose fluctuations was difficult to endure. Participants spoke of feeling a sense of resignation to the fact that fluctuations were an unfortunate part of living with type 1 diabetes:

*Everything I do every day puts a turn on how my blood sugars are going to turn out. Your blood sugars go up and your blood sugars go down. No matter how careful you are, sometimes you don't know what it's going to be. I cannot get two consecutive days with the same blood sugar.*

The unceasing energy and effort that had to go into living with blood glucose fluctuations was very demanding. Even though the readings might not be good, participants still continued to test, to adjust, and to work at trying to achieve the normal range. Compounding the experience of the fluctuating blood glucose readings was the added concern of what these unstable, abnormal blood glucose levels were doing to their bodies:

*Because my blood sugars are erratic sometimes, I think, according to the rules, I should have had problems before this. I have a friend the same age as I am, and the same duration of diabetes, who is having trouble with her legs. It is frightening to me.*

For these women and men, the experience of a day of fluctuating blood glucose levels is an arduous day, one that is hard to imagine for persons who do not have type 1 diabetes:

*I cherish the short hours of well being in my day because I know that I'll soon be feeling miserable again when my blood sugar changes. Then my blood sugar drops and my body is stressed with all the feelings of being in shock. Or my blood sugar goes up and I experience an indescribable weariness. Then I just want to crawl in a hole somewhere and go to sleep.*

### ***Enduring Sustained Uncertainty***

Being able to tolerate some degree of uncertainty is part of daily living but when illness strikes, the magnitude of uncertainty increases markedly. Sick persons experience a bewilderment, a state of suspense, as if they are set adrift without a sense of direction or expectation. With acute illness the uncertainty may be intense but is often short-lived as the acuity of the illness subsides and persons resume a normal life. But with a chronic illness such as type 1 diabetes, uncertainty is sustained and becomes part of a new, unsettling reality – the familiar, normal life will never return. Participants spoke of these aspects of uncertainty, of feeling forced to think ahead to what might be, to what they might have to endure in living with type 1 diabetes – the alterations, limitations and even complications of the disease. From this source, the theme of enduring sustained uncertainty developed.

Participants acknowledged that they live with a sustained sense of uncertainty. Type 1 diabetes is unpredictable both in their daily lives and in the future. So often, there is no reason why their daily diabetes control is unstable. They were acutely aware that there is a fragile side to life in that one time of

letting diabetes control lapse could trigger the disease to do some invisible, irreparable damage that would then bring them closer to complications. These women and men spoke about “. . . *being at risk* . . .” for the complications associated with diabetes and how this term “at risk” contributed to uncertainty about their future:

*I feel disappointed that there have not been really huge advances toward a cure [for diabetes], just add-on solutions, and that worries me, the threat of complications.*

Interwoven with their concerns for themselves being “at risk” are the participants’ worries about their children developing type 1 diabetes: “. . . *the thoughts of my children having diabetes, I can’t deal with that at all*”. This was a significant area of uncertainty that they could do little about. They relate that they are able to cope with type 1 diabetes themselves, but enduring the uncertainty of their children’s health takes greater sustaining efforts:

*By having children, you take that conscious thought that there is a possibility that you could pass [type 1 diabetes] on to them. And if not to them, your grandchildren. So, that thought I wrestled with, very long and very hard.*

Enduring sustained uncertainty is not easy. These women and men must live with this constant sense of uncertainty while not relenting from their diabetes control. Many described how they wished that the worry created by the uncertainty could be taken away. They longed to be free from the distress that comes with the uncertainty of trying to make everyday treatment decisions:

*That's when I wish somebody would say to me, "OK, This is what [insulin dosage] you need to take". If only someone could say exactly what you need, and that's all, just take it and don't worry about it anymore.*

Another effect of enduring sustained uncertainty is that participants become more future-oriented. They acquire the ability to think in the present while being acutely aware of the uncertainty of what the future may bring:

*[It] makes me dwell too much on the future as opposed to the present. When I'm thinking about something that's a bit long-term, whether it be a purchase, or a change of something in my life, I'll think, "Well that's ten years from now; am I going to be walking in ten years? Am I still going to be driving in ten years? Am I going to have both my legs in ten years?"*

These women and men have used a variety of approaches to help them to endure this sustained uncertainty. They have learned a new definition of normal in which uncertainty becomes part of the fabric of living. Acknowledging that there are risks in certain behaviours, and making conscious efforts to avoid these risks and maintain ". . . a balance . . ." is another approach that the participants use to live with sustained uncertainty:

*I lead a healthy lifestyle, so I don't have to indulge and prove anything by downing alcohol, smoking myself to death, or overindulging in chocolates. Because every one of those has a negative reaction for the diabetic's body, which is not functioning the way it ought, then the risks are doubly enhanced. [This attitude] has made me healthy for thirty-five years.*

The participants spoke of the benefits of applying ". . . a sensible approach. . ." in living with type 1 diabetes, but even this approach had positive and negative aspects. On the positive side, it enabled them to gain insight into

their personal strengths, which in turn helped them to deal more effectively with the uncertainty of type 1 diabetes:

*You can fight insulin dependent diabetes all you like, it's not going to go away. And if you are sensible about it and play the game by the rules, then you can have an interesting, and exciting, and a full life.*

The negative aspect of being sensible is the way in which others could perceive them when they are adhering to the treatment regimen, being intelligent, and living a good lifestyle:

*To be told you are sensible, always made me think of this little old lady in oxford shoes, with a grey bun tied at the back of her head with a hairnet over it. And wow, here I was a sensible person!*

Participants spoke of the importance of being fully educated on “. . . risk management . . .” and of “. . . being analytical . . .” as ways to help them live with this sustained uncertainty. They felt that an objective, problem-solving approach contributed favourably to managing the uncertainty:

*I keep [type 1 diabetes] as part of pretty much every major decision, and all the minor decisions I make, [while] not letting it interfere too much with things I really want to do. But that said, I don't just throw caution to the winds. I'm always saying, "What do I have to do to cut the risks as much as possible". This is risk management.*

Applying these approaches at all times can be an exhausting exercise, consequently participants spoke of the importance of strong motivators to help them maintain and improve diabetes control:

*I have no complications. And I'm taking this opportunity now, without complications, to make my move. I'm going to have to get my act together, and I'm really trying.*

Positive motivators are even more powerful than negative ones, and for most of these participants, their children were their positive motivators:

*The fact that I have children and I want to see them grow up, it is a big motivator. It requires that you be there, in full capacity.*

### ***Family Support: Sustaining or Smothering***

The participants in this study spoke of the value of family support. They depended on family to help them cope with their type 1 diabetes, interacting with them and being supportive while accepting the reality of this disease in their lives. However, many of the participants described how family support could at times sustain them, that is it gave them strength, while at other times, the support was more overwhelming and made them feel suffocated and repressed. These contradictions generated a theme of family support: sustaining or smothering.

Sustaining family support was positive, strong, constant, understanding and reassuring. It began at diagnosis, continued to mature in a steadfast manner, and led to the development of a positive attitude to life with type 1 diabetes. Families gave strength and encouragement:

*When I was diagnosed, my father said to me, "This is something that you have to deal with, and you can do it". That's all I needed to hear!*

Participants related, with varying degrees of emotion, how supportive their families were at the time of diagnosis, when everyone had to deal with ". . . the

*shock . . .*” and the “*. . . numbing effect . . .*” of the diagnosis. They “*. . . all went through the nightmare together . . .*”, when their lives were turned upside down and they had to reach out to support each other through the devastation, the grieving:

*When I first came home, Dad would let me practice on him . . . he'd let me put the needle in his arm, so it didn't seem so bad to me to have to do it.*

Sustaining family support spread beyond the nuclear family to extended family members who reached out with their caring. Everyone helped participants to keep their lives in perspective. The whole family learned to live with a new definition of “normal” together. The positive effects on participants of this extended network of support were immeasurable:

*The support I had from day one has made more of a difference to me than anything else, than any doctor or educator ever did. I got [that support] from everybody – my whole family – my sisters, my aunts and uncles, everybody. And I think that's why I'm sitting here now, sitting in one piece, 38 years later.*

Participants whose families supported them without smothering and showing the deep fear and anxiety they felt, accepted type 1 diabetes in their lives, adopted a proactive attitude, and felt empowered to take on their diabetes management themselves. These participants developed confidence, living full and active lives, socializing with peers, and taking on careers:

*When I was diagnosed I felt, “Wow, [my parents] think that I can do this!” And from then on I became more confident and I felt I could live a normal*

*life with diabetes, and I could do the things I wanted to do. That strong and positive attitude was something that I carried with me all my life.*

As participants grew away from parental influence and support, the friends they dated and their choice of partners were influenced by their need for support. For younger participants, there were concerns and challenges about the reaction of friends they dated to the disease and its treatments:

*I have a boyfriend. Any day now, [since my diagnosis], he has got to see me give myself a needle, and he is probably not going to want that, so that is pretty tough.*

Ultimately, these women and men chose spouses who were supportive of them and their diabetes management. Their spouses then became their principal support persons, though many participants still maintained close and supportive ties with their parents and extended family members. What was most crucial to participants was that their spouses would listen and would try to empathize with them as they coped with their diabetes:

*At times, when the stress of diabetes and its control is more than I can deal with, [my husband] will say, "It really must be awful. I'd hate to have to do all that you do, all the time. I really admire the fact that you do it, and you don't make any fuss about it. You just go on with it and do it." Just the fact that he's there for me, and he supports me when I need it, at those critical times, that's what I need to get me through.*

These spouses had to come to an acceptance of type 1 diabetes in their lives. When they accepted the restrictions of the diabetes' lifestyle as "normal", and supported their spouses, life together continued on smoothly. These spouses took on this nurturing role:

*I go on with [type 1 diabetes] as part of my life. [My husband] goes on with it as part of his life, living with someone who has diabetes. And I have the greatest, greatest respect and compassion for people who live with diabetics. We are hard to live with at times, and the disease can be a pain in the neck!*

Even though family support was essential, participants acknowledged that type 1 diabetes was their disease and they had to deal with it themselves.

Participants, who felt strongly about this, felt indebted to their families for instilling this proactive attitude in them. It helped them to find inner strength and to grow in confidence:

*I was made to look out for myself to a good extent, with lots of support, that first, if I don't deal with this, don't expect for someone always to be there to pick up the pieces. Deal with it, live your life; that attitude was instilled in me from as far back as I can remember. And that I think has a lot to do with what I am today.*

Not all participants experienced empowering family support. Some participants' families were smothering, showing constant anxiety and taking over the treatment regimen for them. These families ". . . were worried to death".

Smothering arises out of very positive motives and deep caring, but this smothering can consume the family and extinguish positive, empowering attitudes. Smothering does not inspire confidence. Family members who adopted this approach, caused frustration, resentment and even rebellion, because participants wanted to be independent:

*And I just figured I was fine. I was invincible. And when I got to teenage years, when I was out later or eventually staying out, Mom had no control*

*anymore. I didn't know what I was doing; thought I knew it all, you know. Of course every teenager, in every subject, thinks they know it all.*

Instead of strengthening, smothering family support undermined the confidence of participants causing negative attitudes to develop. It created a constraining dependency, a bleak feeling that type 1 diabetes controlled all of life:

*I moved out temporarily, but ended up moving back home. All of a sudden I just didn't feel right; it just struck me one day, and I just got really, really overwhelmed by it. And I thought to myself, "What a drag! I'm so dependent on people. This is awful!"*

When families responded to living with type 1 diabetes with protracted anxiety, participants internalised these fears. They experienced self-doubt, a learned hopelessness, erratic diabetes control, and a poor quality of life:

*I check [my blood sugar] all the time. I find it really frightening. I've always got food [with me]. I'm not worried, anxious- worried, but it's always there.*

### ***Being Alone with Diabetes***

Being alone with diabetes was described by participants as a personal aloneness, as feeling apart from others, isolated, and separate. This sense of being alone was not alleviated by receiving support from family and others. Participants felt that they were carrying the burden of this chronic illness themselves because they were not able to articulate the depth of this experience

to others who did not have type 1 diabetes. The magnitude of their personal isolation led to the identification of the theme: being alone with diabetes.

Participants had to assume total ownership of their diabetes and because of this they felt they were on their own in making treatment decisions every day and night: *"I feel I'm still, still on my own. I'm really alone with this [diabetes]"*.

Participants described this feeling of being alone as a very personal emotional experience because no one else can carry this burden for them. No one else can truly comprehend it as they are experiencing it. It is impossible to describe in terms that others would understand:

*[Type 1 diabetes] is very much personal. You can't explain it. It's like trying to explain a piece of music. Oh, it's nice; it's soothing; it's relaxing. But it doesn't give the impact of it. It doesn't give you that twitch or twinge that you feel at the end when the trumpets kick in or the drums roll. It's very much personal.*

There are many facets to being alone with diabetes. Other persons tend to look beyond the similarities participants share with other people and instead magnify their differences, creating a new kind of being alone. Participants were labelled as *". . . the diabetic . . ."* being viewed as a disease, not as persons: *"I want to be known as myself – know 'me' first and be 'a diabetic' second"*.

This sense of being alone developed during the months following diagnosis. It was a time of anxious solitude when every experience was new, when constant learning and adjustment had to take place. This time of being alone was most difficult because it was:

*The year of firsts. It's your first week with diabetes; it's your first month with diabetes. It's your first low sugar-alone; it's first high sugar-alone. It's your first squash game without adjusting your insulin-alone. It's the first time you go on a long road trip in your car-alone.*

The participants spoke about the experiences of being alone that were generated when they were treated by the general public as a collective group with a common disorder, instead of individuals with a common disorder. The general public's ignorance of the truth regarding type 1 diabetes was revealed in their stereotypical images of what "a diabetic" looks like, what it means to have diabetes, and how diabetes could not possibly be synonymous with looking well. They believe that type 1 diabetes is such a serious disease that people who have it must be very ill. They do not even understand the diabetes treatment regimen:

*Four needles! Oh dear, dear, dear! [Your diabetes], it's getting worse is it? . . . I try to explain to [them], the four shots a day basically only mean you have more control.*

The general public's perception of what it means to have type 1 diabetes can be extreme. It is usually based on the horror stories they hear of persons with terrible diabetes complications. These perceptions are not helped by diabetes campaigns that emphasize long lists of complications, and never relate the positive aspects of the diabetes lifestyle. The negative reactions and outspoken comments of the general public were hurtful to participants and were usually endured alone:

*I always "like" the ones who know me for years and don't know I have diabetes. They practically fall on the floor when they find out I have diabetes, "You're a diabetic – I can't believe it! You have only one head. You've got both your legs. It's amazing!" That attitude is out there.*

Some participants have experienced employers who do not understand type 1 diabetes and its treatment and therefore do not expect them to be able to function normally. This attitude has affected the careers of some participants. Participants spoke about how they felt alone with their type 1 diabetes when co-workers or friends would question every food they ate, and panic in an emergency situation. These people did not really understand the disease. They understood the individual even less:

*A lot of times people assume that if there is anything wrong, [your blood sugar] is always low, and "Get her sugar; she is diabetic!" They associate diabetes with sugar.*

Because they feel overwhelmed by the enormity of the problem, these participants feel that they must struggle alone against changing these ingrained misconceptions:

*A lot of people will say, "You don't look like you have it". I don't think that people with diabetes look like anything. But they say that you look very healthy. You are very healthy!*

The most poignant reminder of how isolating type 1 diabetes can be is the distress of participants who have already started to develop complications. They experience an ever-present anxiety, a distress that is magnified because it is suffered in solitude:

*How much longer can I stay in reasonable condition and still do the things I have always done? Am I going to be legally blind? Am I going to be going around with one leg? Am I going to be too late when they finally say, "We've got a cure"? It is something that's on my mind every day.*

## **CHAPTER 5**

### **Discussion**

The purpose of this phenomenological study was to gain insight into the meaning of the experience of living with type 1 diabetes in adulthood. Although the data from the participants in my study revealed the uniqueness of each person's experience, detailed analysis of this data helped me to understand that the qualities of this experience are universal. While some of the findings of my study are supported by previous research, the depth of the ongoing impact of type 1 diabetes on participants' lives was not found in any previous research studies. The purpose of this chapter is to examine the findings from my research, how these findings relate to the theoretical and research literature, and how new insights from this research can contribute to our knowledge and understanding of the lived experience of type 1 diabetes in adulthood.

#### **Living With Type 1 Diabetes**

The findings of my study reveal important insights into the perspective of these participants, the negative and positive aspects of their lived experience of type 1 diabetes. The findings reveal the deeply felt emotions, the fears, the isolation, and the discouragement that these women and men endure everyday. The findings also give insight into how difficult and complex diabetes management can be, the toll that this disease takes on persons with it, and how

most health care professionals and others fail to recognize more than the physiological consequences of the disease. In addition, my findings highlight the resolve and courage of these women and men, and how they aspire to live fulfilling and productive lives while meeting the challenges of type 1 diabetes.

### **Relationship to Current Theory**

The findings of my study challenge the current theoretical thinking on diabetes management. A strong sentiment among my participants was that they wanted to be recognized for the significant personal knowledge of type 1 diabetes that they bring to encounters with health care providers. They challenged the concepts of compliance and adherence as being realistic orientations for guiding health care practices. Their experiences demonstrate how difficult it is to fit their lives into these narrow perspectives.

The compliance/adherence framework has been the most prevalent theoretical framework regarding diabetes management to date. However, no true consensus has been reached regarding the definitions of compliance and adherence, and the applications of this framework. Most researchers relate that adherence is preferable to compliance because adherence implies a more autonomous role for the patient in self-care delivery (Cameron, 1996; Lo, 1999; Lutfey & Wishner, 1999; McLeod, 1998; Weiss & Hutchinson, 2000). Other researchers have found that this framework not only implies domination of the

person with diabetes but also is too simplistic, as there is no recognition of the complex emotional and social factors that influence diabetes self-management (Aalto et al., 1997; Cameron, 1996; Fitzgerald et al., 1995; Hwu, 1995; Lutfey & Wishner, 1999; Maclean, 1991; McLeod, 1998; Mitchell & Lawton, 2000; Paterson & Sloan, 1994; Polonsky et al., 1995; Ternulf Nhylin, 1990; Toljamo & Hentinen, 2001; Vallis, 2001; Willoughby et al., 2000).

The experiences of my participants, especially those presented in the themes *struggling for stability*, *striving for freedom*, and *surviving perceived noncompliance* contribute to an argument against the use of a compliance/adherence framework. This framework does not take into consideration the effect of other aspects of type 1 diabetes on these persons' lives.

A number of nursing researchers have challenged the compliance/adherence theoretical framework, and advocated replacing it with more holistic approaches that recognize the value of learning from and reflecting on the perspectives of persons with diabetes (Hernandez, 1995; Wikblad, 1991). New insights have been gained from phenomenological studies done by Hartrick (1998), and by Paterson and Sloan (1994). New theories and models have been developed from the findings of grounded theory research; Hernandez (1996) developed the Theory of Integration, while Price (1993) developed the Diabetes Self-Management Model. New constructs have been developed by nurses and

other health care providers who were not physicians. Robinson (1993) proposed the construct of normalization through which persons seek a quality of life in living with a chronic condition. Normalization involves a wellness orientation and supports hope by focusing on abilities, not deficiencies. Bissell et al. (2004) proposed the construct of concordance that involves respect for the patient, negotiation to achieve goals, and a therapeutic alliance in which the expertise of both patient and health care professional are utilized. Paterson et al. (1999) proposed the construct of transformation in living with type 1 diabetes in which persons restructure the self and the illness experience in a positive direction, accept the illness as a challenge, and themselves as experts in diabetes care. Maclean (1991), Maclean and Goldman (2000), and Price (1993) support the concept of "patient as expert" in diabetes management. Many physicians do not usually agree with this concept. They label persons who do not adhere strictly to the treatment plan as being noncompliant, when in fact these persons are seeking a balance between diabetes management and their own values and goals. Finfgeld (2000) has studied courage in young adults with chronic disease; one of the diseases was type 1 diabetes. This researcher displays a distinct view in that she values and appreciates these persons, who are learning and maintaining courage, as they employ strategies that help them to transcend their health problems. Finfgeld presents them as persons to be respected for their ingenuity, their mature and responsible approach, and their perseverance. She

does not see them as cheating, or being defiant, or purposefully aggravating health care providers.

One common thread of these holistic approaches, just described, is respect for the person with diabetes. It is a respect that is derived from a more all-encompassing view of life with chronic illness. These approaches indicate compassion, a willingness to ease the constraints of control, and openness to hearing the voices of persons who live every moment of their lives with diabetes. Although these researchers accept the concept of “the patient as expert” as a natural and logical progression, research results indicate that many physicians have not considered this concept at all. Although phenomenological research is not theory-building research, there is a sense of authenticity to these more holistic approaches that is reflected in the findings of my study.

### **Relationship to Current Research**

Living with type 1 diabetes has a profound effect on how individuals with this disease experience their lifeworld and the four basic existentials in this lifeworld, i.e., lived time, lived space, lived body, and lived relationships to others (van Manen, 1997). Some of the themes identified in my study are primarily related to one of these existentials, while others cut across a number of them due to the close interrelationships among the themes. These four basic existentials will be used as an organizing framework to discuss how my findings

are congruent with those of other researchers who have studied the impact of type 1 diabetes on the lives of adults with this disease.

The existential of lived time is revealed in most themes. It is subjective time in which past, present and future are interrelated (van Manen, 1997). In the theme *constant vigilance*, participants described lived time as a state of perpetual readiness. They had to be alert to the present as well as prepared for the future because of the persistent presence of type 1 diabetes in their lives. They needed to be continually engaged in diabetes assessment and decision-making in every aspect of daily living. These findings are in keeping with the work of researchers who report the multiple decisions to be made every day, the great deal of effort and time involved, and how the personal responsibility for this self-care can affect persons with diabetes personally, emotionally, and socially (Aalto et al., 1997; Fitzgerald et al., 1995; Maclean, 1991; Paterson & Sloan, 1994; Rubin, 2002; Tillotson & Smith, 1996; Vallis, 2001).

For my participants constant vigilance was one of the most difficult aspects of living with type 1 diabetes. Similarly, studies on managing type 1 diabetes found that the problems and stress of engaging in this type of vigilance could be overwhelming (Price, 1993; Robinson, 1993), and that these difficulties were compounded because psychological and emotional responses were not being addressed (Beeney et al., 1996; Maclean & Goldman, 2000). Conversely, there are gaps in the research literature concerning the reality of this all-

pervasive *constant vigilance*. The reason for this exclusion may be that persons who live through it, not those who are objectively observing it, can comprehend this subjective aspect of the existential of lived time. Those on the outside looking in can see the tasks to be done, and the actions to be taken by persons with type 1 diabetes, but they cannot discern the depth of vigilance required before, during, and after these actions are taken.

The existential of lived time is revealed in several aspects of the theme, *struggling for stability*. It is captured in the participants' involvement with an oppressive management plan consisting of precise timing, tight organization, and planning ahead. Similarly, researchers found that the frustrations of diabetes and its rigid treatment were overwhelming at times, leading to emotional distress and a lower quality of life (Aalto et al.; Goldman & Maclean, 1998; Polonsky et al., 1995). My study offers additional insights into the *struggle for stability* not previously revealed in the research literature. My participants related that they had been taught about type 1 diabetes and its treatment by health care providers, but had not been taught how to take all this information and fit it into their lives.

The existential of lived time, at a higher future-oriented level, is revealed in the theme, *striving for freedom*. It is manifested in the participants' pursuit of a quality of life by not allowing this disease to control them. They did so by reinterpreting who they were as persons, and by reshaping their future through

learning to continuously adapt to type 1 diabetes. Their freedom was in their personal choice to take ownership and responsibility for self-management, now and into the future. They were able to live a full life by applying a positive attitude to living with type 1 diabetes, and thereby developing a new relation to the disease. Paterson et al. (1999) supported these findings in their description of the personal transformation that persons with type 1 diabetes could undergo to experience an enhanced meaning in their lives. Other researchers found that refining one's identity to incorporate a chronic illness, and to maintain the sense of self, was an important challenge of diabetes management (Finfgeld, 2000; Goldman & Maclean, 1998; Newbern, 1990).

The existential of lived relationships to others is also revealed in *striving for freedom*. Lived relationships are maintained with others that allow persons to rise above the self and search for purpose and meaningfulness in life (van Manen, 1997). The lived relationship with most doctors was not a positive one for my participants. There was a clash between their interpretation of diabetes control and the interpretation of doctors, who insisted on rigid adherence to the treatment regimen, believing it resulted in consistently good glycemic control. Participants found not only that rigid adherence did not always result in good glycemic control but also that this rigidity was intolerable and excluded any degree of normalcy in life. Similar to my findings, many researchers investigated autonomy in an attempt to understand how individuals balanced the excessive

self-care demands of the diabetes lifestyle with their need for self-direction in their lives (Goldman & Maclean, 1998; Hartrick, 1998; Maclean, 1991; Mitchell & Lawton, 2000; Paterson & Sloan, 1994; Reichard, 1996; Vallis, 2001; Wikblad, 1991).

Other researchers found not only that the goals for diabetes control, imposed on their participants by health professionals, were not attainable at all times but also that health professionals were not responsive to their perspectives of what diabetes control should be; their participants wanted health professionals to appreciate their need to find their own balance between rigid diabetes control, and a meaningful, manageable lifestyle (Goldman & Maclean, 1998; Mitchell & Lawton, 2000; Paterson et al., 1998). Like my participants, other persons with diabetes sought a recognition and respect for their personal knowledge, experience and expertise, and a partnership with health care professionals (Hartrick, 1998; Hernandez, 1996; Hernandez et al., 1999; Kyngäs & Hentinen, 1995; Maclean, 1991; Maclean & Goldman, 2000; Paterson & Sloan, 1994; Paterson & Thorne, 2000a; Paterson et al., 1999; Price, 1993; Reichard, 1996).

In *striving for freedom*, my participants wanted doctors to understand their perspective, that they were intensely involved with their diabetes, and that they were doing their best to live a quality life by fitting diabetes in with every other aspect of living. By seeking understanding, my participants may have been seeking harmony. Most persons do not want to have negative interactions,

especially with those to whom they must turn for help. Neither do they want to be falsely accused and misunderstood. Participants in my study appeared to be experiencing an internal conflict that was difficult to resolve.

The existential of lived relationships to others is disclosed in the theme *surviving perceived noncompliance*. This theme illustrates the powerful influence of intent and impact. The intent of all health care providers is to promote good diabetes control so as to prevent complications. However, the impact of many doctors and some nurses on my participants was very negative when they unjustly accused them of noncompliance with the diabetes treatment regimen. Their negative attitude, and the inappropriate language they used to describe my participants, caused feelings of shame, defensiveness, and powerlessness to develop. To some degree, all of my participants internalised this guilt. This theme also reveals how my participants survived unfair accusations of noncompliance in an effort to retain their sense of self in the face of intolerance and misunderstanding.

My participants' accounts of domineering doctors' who accused them of noncompliance revealed a moralizing attitude, an observation supported by a number of researchers. Benner et al. (1994) stated that this attitude of the moral responsibility of patients to comply sets up a high likelihood for blaming persons with chronic disease. Other researchers felt that labelling patients oversimplifies their behaviours and does not increase understanding of their viewpoint (Lutfey

& Wishner, 1999; McLeod, 1998; Toljamo & Hentinen, 2001). Similarly, it was found that blaming patients and wanting to control them can adversely affect them by causing feelings of shame, failure, isolation, and learned helplessness; it can even lead to long-term hopelessness, depression, rage, and decreased self-confidence (Bissell et al., 2004; Herman, 1997; Maclean & Goldman, 2000; Vallis, 2001). Other researchers related that helping professionals are not always aware of the power differential between themselves and their patients and how it affects their relationships; they proposed that conscious awareness of impact and intent can make caregivers more sensitive and compassionate (Barstow, 2002; Callaghan & Williams, 1994; Mitchell & Lawton, 2000).

There is another aspect to the existential of lived relationships, especially with doctors. Most of my participants found these relationships with doctors to be disappointing and frustrating. There was not a sense of working together to achieve diabetes control, but a distinct division of the doctor as the expert and authority in diabetes care, and the patient as the disease to be controlled. Comparable results were found by other researchers who recounted situations in which health care professionals did not understand or listen to persons with diabetes about their body's distinctive responses; they did not understand that type 1 diabetes can affect persons' quality of life by causing higher levels of emotional distress due to the frustrations of the disease, the treatment regimen, and the threat of acute and long-term complications (Aalto et al., 1997;

DeCoster, 2003; Hendricks & Hendricks, 1998; Lundman & Norberg, 1993; Lundman et al., 1990; Paterson & Sloan, 1994; Polonsky et al., 1995).

Many participants in my study survived these accusations of noncompliance by using humour. Researchers have found that humour has a normalizing effect and is a valuable coping mechanism, if it is used appropriately. It can increase optimism, encourage adaptability, and put life in perspective (Finfgeld, 2000; Hunt, 1993; Lieber, 1986; Pasquali, 1990; Rubin, 2002; Schaeff, 1998).

My participants and their doctors had the same goal, good blood glucose control and prevention of complications, but there was difficulty in reaching that goal because of antagonistic relationships. The reason for this may be due to the way in which doctors are educated and socialized. This, in turn, may influence their expectations and approach to persons with type 1 diabetes. Schaeff (1998) found that many health care providers, and especially physicians, are educated in the scientific method in which objectivity, observation, and analysis are learned and practised. It can be a distorted, limiting method in that it separates people from life as it is lived. Tanzola and Houlden (2000) found that the amount of instruction in diabetes over the three to four years of undergraduate medical education in Canada varied from 7 to 42 hours, with experiences for clinical clerks being an area of weakness. Vandagriff, Stern, Orr, and Golden (1993) hypothesized that it was during medical school training that

students' attitudes and beliefs were formed which could influence their treatment decisions later as practitioners.

In order to increase our understanding of the lived relationship between doctors and persons with diabetes, it is necessary to understand the definite influence of a major study on type 1 diabetes, the Diabetes Control and Complications Trial (DCCT). The significant results of this trial demonstrated a reduction in the development and progression of the long-term complications of diabetes, if normal glycemia was achieved through intensive therapy. This involved complete adherence to a very long list of procedures (Diabetes Control and Complications Trial Research Group, 1995; Jones et al., 2001). In this trial, there is no reference made to a holistic view that includes the psychosocial effects of intensive therapy on persons with type 1 diabetes, the very persons who are the focus of this research.

The women and men in my study emphasized that doctors who use the textbook approach have good intentions and have their best interests at heart, but they use the wrong methodology to try to achieve results. A number of researchers verify this. Doctors are seeking the most efficient methods of translating the conclusive results of the DCCT into practice. Consequently, most physicians have adhered to these recommendations with a focus on strict compliance with the treatment regimen, their goal being good glucose control

and prevention of complications (Beeney et al., 1996; Havas, 1999; Helseth et al., 1999; Hernandez, 1996; Hunt et al., 1998; Jones et al., 2001; Nichol, 1999).

There are two troubling implications to the findings from the DCCT. One is that doctors now have even higher expectations for persons with diabetes to achieve lower blood glucose targets through strict compliance. The second is articulated well by House and Keen (1998). They proposed that guidelines for optimal diabetes care will not automatically translate into optimal care because even simple recommended changes permeate the medical profession slowly; the focus now is on salvage care, not preventative care of persons with diabetes, with huge amounts of money and resources being put into treating diabetes complications. If these projections are even close to being correct, it will not only take years for current diabetes practice guidelines to be instituted but also the hopes of persons with diabetes for recognition and respect will be dashed. It will take even longer before persons with diabetes are acknowledged as valuable, contributing members of the diabetes health care team with much to offer and teach health care providers about type 1 diabetes.

As important members of the diabetes health care team, nurses and their impact has been studied, in particular the effect of a holistic approach in nursing practice, and the ways in which nurses can be most therapeutic in their delivery of diabetes care (Hartrick, 1998; Hwu, 1995; Wikblad, 1991; Williams, 1997). Ternulf Nyhlin (1990) recommended that the whole health care system show

more sensitivity to holistic practice; she felt that this could be achieved by understanding that because diabetes requires such major lifestyle changes, every person with this disease has a deep need to make sense of their situation.

Other researchers have supported the findings of my study with their research focus on the lived experience of type 1 diabetes. They recognized the need for therapeutic partnerships between health care providers and persons with diabetes that break down hierarchical relationships (Callaghan & Williams, 1994; Hernandez, 1996; Maclean & Goldman, 2000; Reichard, 1996). These viewpoints present a more insightful approach to lived relationships in diabetes management.

The women and men in my study revealed another aspect of lived relationships in their belief in the importance of the formal education and support provided by diabetes educators. My participants also valued the knowledge they learned from interactions with other persons who have type 1 diabetes, from support groups, from interested and caring physicians, from their own reading, research, internet searches, and their own experiential learning. This finding is supported by the literature. Since the release of the DCCT, diabetes education is considered to be an even more important element to understanding and taking responsibility for intensive diabetes self-management (Meltzer et al., 1998). Finfgeld (2000) found that present and future courageous management of chronic illness was dependent on knowledge and understanding of the problem

and its treatment. Interactions with diabetes nurse educators, dieticians, and other members of the health care team are part of the education process (Diabetes Control and Complications Trial Research Group, 1995; The Diabetes Control and Complications Trial Research Group, 1996; Drass & Feldman, 1996; Hernandez et al., 1999; Jones et al., 2001; Nichol, 1999; Reichard, 1996; Rubin, 2002; Strauss, 1996).

New insights were revealed in the theme *surviving perceived non-compliance*, especially regarding my participants' reactions to the negative judgements of doctors. Some became defensive, openly expressing their dissatisfaction, while others engaged in more potentially harmful behaviour. They tried to manage on their own and seek out doctors only when they couldn't find their own solutions. Participants appeared to be making a conscious choice based on their own moral and ethical values. It seemed preferable to them to fight back or go it alone rather than suffer the trauma of false accusations that were deeply offensive to them.

My study also reveals other ways in which participants survived accusations of noncompliance by being assertive concerning their wants and needs, and by trying to understand what motivates doctors to act in negative ways. No studies have been found that reveal these insights into how persons with diabetes cope with false accusations, possibly because the focus of my

study was the persons with diabetes themselves, their emotions and responses as revealed by them, and not as suppositions of outsiders looking in.

The most important insight derived from the theme *surviving perceived noncompliance*, is that the women and men in my study want all health care providers not only to expect them to maintain high standards of diabetes care, but also to demonstrate more understanding of how difficult the treatment regimen can be, and to stop judging them. My participants want to live healthy, productive lives. They are not seeking an easy way out of the hard work and discipline of diabetes control, and neither are they being noncompliant. My participants appear to be seeking recognition as adults who can rise to the challenge, and adults who expect to be treated in a just way.

The basic existentials in the theme *the lived experience of blood glucose fluctuations* are lived time and lived space. In this theme, the subjective view of high and low blood glucose levels is revealed as a disruption that effected every aspect of my participants' lives. Participants related that health care providers did not appreciate how unpleasant these symptoms were, or the energy and effort that went into trying to control blood glucose fluctuations.

Lived space refers to the world in which persons find themselves at home and experience everyday affairs (van Manen, 1997). During these abnormal fluctuations, lived space is experienced as a threatening, negative space full of

anxiety, fatigue, urgency, and apprehension. My participants did all they could to bring their blood glucose levels back to normal as quickly as possible.

Lived time is experienced during low blood glucose fluctuations as time in the present, a time of rapid, overwhelming symptoms bringing the person down into confusion, trembling, fear, and shock, coupled with an urgent need to treat it. There is time in the future, hours spent trying to bring the rebound hyperglycemia back to normal, and time spent dreading the onset of the next low fluctuation in blood glucose levels. Similarly, present and future lived time are experienced during high blood glucose fluctuations, a time that dragged because of debilitating weariness that lasted for hours while participants worked to normalize these blood glucose levels. Since high levels were the most difficult to correct, it was so disheartening that participants felt like giving up. Lived time is also experienced during moderate elevations of blood glucose as a time in which many of my participants felt very productive and energetic. They described this as a time of wellbeing and happiness, and a time when creativity and all mental processes were most acute, whereas health care providers consider these blood glucose levels to be harmful.

These experiences are not reflected in any of the research literature. Several researchers attempted to recommend approaches to facilitate blood glucose management, but these views are objective views, reflecting the observations, interpretations, and recommendations of persons who have never

lived through this experience (Lloyd et al., 1999, Vallis, 2001). My study reveals the subjective view, the lived experience, and a possible explanation for the gap in the research literature that could confirm these experiences. These vivid descriptions of blood glucose fluctuations also give insight into why many of my participants tried to keep their blood glucose levels slightly elevated. The symptoms of hypoglycemia and hyperglycemia were so distressing and debilitating that they tried to avoid them, and kept their blood glucose at a moderate level, one at which they felt well and were most productive.

Lived time is the basic existential in the theme *enduring sustained uncertainty*, especially the temporal dimensions of present time and future time (van Manen, 1997). Sustained uncertainty was always present in that my participants had to live every moment of their lives with the anxiety caused by the uncertainties of type 1 diabetes. My participants saw their future only too clearly because unstable diabetes control leaves them vulnerable to the risk of developing diabetes complications. My participants related that diabetes control is so uncertain because there is no reason why instability occurs, and they wished that the worry created by uncertainty could be taken away. This finding is supported by Vallis (2001). Several researchers found that uncertainty was inherent in the process of self-managing diabetes because adherence to self-care does not guarantee good metabolic control (Price, 1993; Ryan et al., 2002), while other researchers discovered that the threat of acute and long-term

complications can affect subjective health and quality of life; fear has an impact not only on the stress experienced but also on the coping abilities of persons with diabetes (DeCoster, 2003; Hendricks & Hendricks, 1998; Lundman & Norberg, 1993; Lundman et al., 1990; Rubin, 2002).

New insights were disclosed in the theme *enduring sustained uncertainty*. Participants related that part of being “at risk” were their worries about their children developing type 1 diabetes. They could do little about this significant area of uncertainty, but it frequently strained their coping abilities. No studies were found that addressed this uncertainty. My participants revealed a variety of approaches to help them manage this sustained uncertainty that included being sensible, being analytical by using a problem-solving approach, and keeping motivated. These approaches were all objective, cognitive strategies that when combined with a positive outlook, helped them to cope.

The theme of *family support: sustaining or smothering* encompasses three existentials: lived space, lived relationships, and lived time. For the participants in my study who experienced sustaining family support, lived space and lived relationships were warm, welcoming, and understanding. They felt supported as they learned to develop a positive attitude to life with type 1 diabetes. For participants who experienced smothering family support, lived space and lived relationships became confining and frustrating because their independence was threatened.

The existential of lived time was seen as occurring in the past and the present. The type of family support experienced in the past, whether sustaining or smothering, was carried forward to present time and continued to affect relationships within the family. These findings were supported by the literature. Schaef (1998) indicated that as part of a larger whole, we exist in the context of a family system. Finfgeld (2000) discovered that courage in chronic illness is maintained by the support and encouragement of significant others, especially positive family role models. A few researchers have alleged that support from relevant family and friends can improve diabetes self-care when they and the person with diabetes are part of a patient/health care professional partnership (Havas, 1999; Meltzer et al., 1998; Paterson & Sloan, 1994; Tillotson & Smith, 1996). Assessment of social issues, especially family relations and support, was recommended in diabetes education programs (Beeney et al., 1996; Brennan, 1996; Gerstle, Varenne, & Contento, 2001; Hendricks & Hendricks, 1998; Kokkonen et al., 1994; Polonsky et al., 1995; Strauss, 1996; Vallis, 2001; Wikblad, 1991; Willoughby et al., 2000).

The adults in my study who were smothered by family were eventually affected negatively; their confidence was undermined, and they experienced a sense of learned hopelessness. They internalised their families' fears. Similarly, Schaef (1998) found that trying to take over another person's life by "helping" can be as detrimental to the person they are trying to help as it can be to them,

whereas Finfgeld (2000) found that negative family role models do not inspire courageous behaviour in persons with chronic health problems. Other researchers discovered that spousal help can have an impact on the autonomy of persons with diabetes in that they have a need to counter the demands of diabetes care, and the concerns of their spouses, with their own needs for autonomy and self-esteem (Bailey & Kahn, 1993).

Despite the importance of family support, my participants acknowledged that diabetes was their disease and they had to deal with it themselves. But it was the positive support of their families that had given them inner strength to grow in confidence. Schaef (1998) discovered that while others can be supportive, persons have to be responsible for their actions and the consequences of their actions; if persons saw themselves as victims, they gave away their personal power, and indulged in a mode of negative thinking that could cause a downward spiral, constricting the possibilities of their lives.

My study revealed several new aspects of family support. A new finding was the importance of the extended family in helping participants live with their diabetes. This large and far-reaching circle of support had immeasurable positive benefits in that it supported both the persons with diabetes and their nuclear families. Another finding was that each participant's choice of partner was influenced by his or her need for support in maintaining his or her diabetes lifestyle. These partners came to accept the restrictions of the diabetes lifestyle

as “normal”, and took on the nurturing role. It appeared that these partners reflected the positive attitudes of most participant’s families, attitudes that participants knew from experience were very valuable. Another finding was how negative smothering families could be. They were found to undermine the confidence of some of my participants, making them feel dependent and hopeless.

Lived time and lived relationships to others are the principal existentials in the theme *being alone with diabetes*. Lived time is revealed in how my participants came to reinterpret who they are now in the present as persons with diabetes, based on the persons they were in the past before illness struck them. As they learned to live with type 1 diabetes, the past changed under the pressures of the present that compelled them to conform to life with diabetes. Time in the present changed too in that my participants had to live with a new perspective on life to come, being alone with diabetes. Participants who already have complications of diabetes expressed how alone they felt with the physical and emotional distress of not only present suffering but also of a future of worse things to come.

All my participants described that they feel personally alone, apart from others, and separate as they live with type 1 diabetes. Because these participants have to assume total ownership of their diabetes, they feel they are

on their own in making treatment decisions. Contentious relationships with health care providers only reinforce their feelings of being alone.

Lived relationships to others are revealed in this theme in several ways. The sense of being alone is not alleviated by support from family and others; they are labelled as "diabetics", as being different, when the focus is their disease, not them as persons; and they feel most alone when faced with the enormous problem of the ignorance of the general public, and stereotyping and prejudice in the workplace regarding their abilities as persons with diabetes.

The adults in my study emphasized that their own personal attitude was very important in helping them to cope with feelings of being alone with diabetes. They stated that a negative attitude of feeling different, and feeling singled out because they have type 1 diabetes, can lead to defeat, self-pity, and being overwhelmed and unable to take on the very demanding task of managing this complex disease. In contrast, a positive attitude of feeling strong, able to manage, and able to access help and support when needed, disperses feelings of being alone, and empowers them to live a quality of life, not just an existence.

These findings were supported to some degree by the work of Paterson et al. (1999), who discovered that persons, who have been transformed by type 1 diabetes, could feel alone and solely responsible for their diabetes management. Hartrick (1998) found that persons with diabetes do not meet the North American cultural value of being healthy; they are considered to be different.

Most of the women and men in my study dealt with this aloneness by transforming the sadness and loss that never went away, into the quiet strength of accepting what could not be changed, and making it a part of life. They pulled pieces of happiness from each day and celebrated it, choosing not to dwell on the sadness and the negative aspects of the present and the future. Finfgeld (2000) postulated that courage in long-term illness could be promoted and maintained by reassuring persons of their worth and their ability to make a valuable contribution, in spite of their differences.

There is very little in the research literature supporting the theme *being alone with diabetes*. This is a very personal emotional experience not usually perceived by others. My study revealed that this sense of being alone developed during the months following diagnosis when every experience with diabetes was new and anxiety provoking. Another finding is the ignorance of the general public about type 1 diabetes and persons who have it. This ignorance has negative implications for persons with diabetes in that it has affected interpersonal relations with others, and for some, even their careers. My participants felt that it can be an overwhelmingly enormous problem in that they must struggle alone to change these ingrained misconceptions. They stated that much emphasis is currently placed on the negative and frightening aspects of diabetes, and this incomplete information is affecting the lives of persons who already live with type 1 diabetes.

## Summary

My phenomenological study yielded rich data and deep insights into how incredibly pervasive type 1 diabetes is in the lives of the eight women and men who took part in it. Type 1 diabetes is not simply inconvenient, or frustrating, or life is not merely lacking in spontaneity, as has been brought forward by other studies. The value of the findings of my study lies in the fact that these are the perspectives of persons who have type 1 diabetes, related by a nurse researcher who was one of the participants in this study, and has had type 1 diabetes for thirty-eight years. This gave me a unique perspective and assisted in the development of these insights.

The findings from my study challenge the current theoretical framework of compliance/adherence. They support the work of other nurse researchers who have recommended a more holistic approach that shows respect for the person with diabetes, and recognizes that they have a great deal to teach all health care providers about living with this disease.

The use of the four basic existentials of the human lifeworld (van Manen, 1997) as an organizing structure in this chapter was valuable. It gave even more insight into how type 1 diabetes has drastically changed, and continues to change, the lives of my participants. My research study has revealed the actual experience of unrelenting vigilance, and the lived experience of blood glucose

fluctuations. It has revealed how persons feel deeply alone with this disease while they continue to seek a fulfilling life. It has revealed the trauma of the shame, blame, and guilt they experience because of the power differential that exists between them and many doctors and some nurses. My study has also revealed their courage, strength, and discipline, their ability to rise above the negativity and their own vulnerability, to carve out a good life by making type 1 diabetes a part of it.

Insights gained from researching lived experience should help the reader to consider a new reality, one that was expressed to me by a diabetes nurse educator who spent several days with me. She said, *"I never realized before that this is what we expect from our patients; that this is what it is really like to live with type 1 diabetes!"*

## **CHAPTER 6**

### **Nursing Implications**

This study on the lived experience of eight adults with type 1 diabetes has a number of implications for the nursing profession. This chapter presents how the findings could be used to inform nursing practice, education, research and policy.

### **Nursing Practice**

The findings of my study have implications for nurses working with adults with type 1 diabetes. The findings of my study illustrate the ongoing psychosocial impact of type 1 diabetes on these women and men. The distress of fluctuating blood glucose levels, the emotional aloneness, the sustained uncertainty, and the accusations of noncompliance are deeply felt and traumatizing emotions. Nurses need to be aware of these important psychosocial issues in order to help persons with type 1 diabetes.

They can begin to meet these needs by using a positive approach, and by treating these adults as self-directed, responsible, and problem-solving individuals. Nurses need to reflect on their own practice with adults with type 1 diabetes, and improve on their interpersonal skills. Through open communication that projects sensitivity to their needs, and a respectful approach, nurses can plan and implement competent, individualized care.

Nursing theories are valuable in guiding practice because these theories consider more than the physiological aspects of type 1 diabetes. The application of nursing's grand theories and/or middle range theories can help nurses to become more thoughtfully aware of the realities of the diabetes lifestyle, to get beyond the more readily observable behaviours, to the complex meanings and needs of these persons. The application of theory to practice can assist nurses in taking the competent, caring actions that are the corner stones of good health care practice. The practical aspects of living with the diabetes lifestyle can be approached in more creative ways that actively involve persons with diabetes and enhance their creative thinking abilities.

My study has shown, and is supported by other research studies, that persons with diabetes who have a partnership with nurses and whose input is valued, live a better quality of life by integrating diabetes into their lifestyles. The task of providing care to persons with type 1 diabetes can be made easier, and is less frustrating for nurses, when they have clients who are responsible, accountable for diabetes control, and happier with their quality of life. It is beneficial for nurses to recognize that adapting to and fitting type 1 diabetes into each individual's lifestyle is a process that takes time and effort. Nurses can therefore experience less pressure, a decreased need to blame and judge persons who are not progressing well, and an increased security in knowing that

adaptation can be worked through at each individual's pace, with support and encouragement.

Psychosocial needs could be met with support groups, including a peer support telephone group (Payne, 1995), and a 24-hour hotline used to answer questions, give advice on insulin adjustment, and give support to clients and families. A nurse coaching intervention could be valuable as well (Whittemore et al., 2001). More research is needed to evaluate the efficacy of these approaches in lessening both the emotional aloneness and the sustained uncertainty of type 1 diabetes.

Clinical nurse educators can play an important role by providing research-based seminars and interactive workshops to staff nurses. Open discussion of these research findings can be invaluable in discovering staff nurses' perspectives, challenges, and successes in caring for adults with type 1 diabetes. Such valuable discussion, with respect shown for staff nurses' problem-solving abilities and past experiences, can motivate them to learn more about integrating new research findings into their clinical practice.

Most important of all is changing attitudes, from negativity, domination, and apportioning blame to a positive perspective based on admiration, respect, and an openness to what persons with diabetes have to teach all health care providers. Nurses can act as advocate by establishing a standard of caring for persons with type 1 diabetes in which disrespectful, demeaning behaviour is not

acceptable. When nurses act as advocates for persons with type 1 diabetes, it helps these persons to achieve their goals in life while maximizing their diabetes control.

Nurses can be instrumental in making appropriate referrals to other health care providers to meet individual needs of persons with type 1 diabetes. Home care referral nurses, social workers, and community health nurses can be very supportive of persons with type 1 diabetes. In rural areas, the role of the community health nurse is essential for follow-through, teaching, and support of these persons and their families. In areas where this support is minimal, various types of media can be used as educational tools, such as audiovisual and computer programs.

My study has highlighted the significance of knowledge, experience, and education in living with type 1 diabetes. Diabetes nurse educators play a very valuable role in education. There is a need to evaluate current teaching programs for their efficacy in meeting the needs of persons with type 1 diabetes. Diabetes education programs need a psychosocial component that is considered to be as important as the theory and management skills components are now. Persons with type 1 diabetes should be taught about process in adapting to this disease. An educational program that is positive, interactive, and strength-building, not negative and fear-producing, that teaches practical skills and coping skills, and that can be accessed when needed, can serve to empower persons to

live well with type 1 diabetes. This type of program is based on the importance of process, and has the potential to help diabetes nurse educators to use their valuable time and limited resources most effectively.

My participants emphasized the importance of positive motivators to help them continue with the struggle to stabilize their type 1 diabetes. If diabetes nurse educators recognize the importance of personal motivators for their clients, they can assess and support them as part of overall psychosocial assessment, planning, and intervention.

Knowles' humanistic approach to adult learning (Feuer & Gerber, 1988) can be applied to diabetes education. Knowles postulated that the best approaches to working with adult learners were using teachable moments, participatory learning, learning in groups, and the teacher as a facilitator rather than a lecturer.

Based on the findings of my study, the following areas need to be addressed. Instead of teaching persons with type 1 diabetes everything they need to know in several consecutive classes, staged learning can be sensitive to a person's readiness to learn, and can help to meet individual learning needs. Zemke and Zemke (1995) believe that adults seek out learning experiences to cope with life-changing events, and this increases their readiness to learn. Teaching persons essential skills, such as how to tune in to their bodies, can be very valuable. They can be taught the significance of distinctive signs and

symptoms, and how to take specific, positive action. Role-playing can help adults deal with the “what if’s. . .”, and the “what do I do when . . .”, that are such a stress-producing part of living with type 1 diabetes. Based on how alone my participants felt when they were newly diagnosed, and during the first traumatic year of living with type 1 diabetes, there is a need for closer follow-through and support during that time. My participants found that family support was vitally important to them. It is necessary to enhance that support by education programs that emphasize the family’s significant role in sustaining long-term diabetes management. Finally, there is a need for public education on the positive aspects of the type 1 diabetes treatment plan that support a normal, healthy lifestyle and an ability to work and contribute to society. The Diabetes Educator Section of the Canadian Diabetes Association can play a very important role in disseminating this information, and thereby helping to break down harmful stereotypes that negatively affect persons with type 1 diabetes every day.

### **Nursing Education**

The findings of my study have implications for nursing education. Nursing education programs at the undergraduate and graduate level, need to include in their curriculum, content that prepares nurses to be sensitive to psychosocial issues when caring for people with type 1 diabetes, their families, and other support persons. Nursing curriculum needs to emphasize the importance of

therapeutic communication – of really hearing people with diabetes, of being understanding, respectful, and open to their perspective and experiential knowledge of their own diabetes. Nursing curriculum can emphasize the supportive, informational, and facilitative roles nurses can fulfill in their interactions with persons with type 1 diabetes. In students' clinical experiences, role modeling by clinical instructors and staff nurses, plus clinical conferences to discuss positive and negative communication experiences, can serve to equip students with therapeutic communication strategies, and make them more sensitive to the impact of type 1 diabetes on their clients. Too often, nurses fall into the medical model of cause and effect, and objectivity, and become as judgmental as many physicians.

In nursing students' communication learning labs, diabetes research findings can be introduced as case studies. Students can be taught how to integrate psychosocial issues through group work and role playing, and be encouraged to discuss their own ideas about how to implement effective strategies in their own nursing practice.

### **Nursing Research**

Nursing implications for research arise from the findings of my study. More research needs to be carried out on specific psychosocial aspects, including the right use of power, especially intent and impact, when caring for

persons with type 1 diabetes. Further research using intervention-related studies needs to be done. The findings of these studies could assist persons to deal with the emotional impact of type 1 diabetes, especially persons who are not as proactive, well-educated, and articulate as the women and men in my study. Research on their need for stress-reducing interventions such as exercise, counseling, and support groups could be valuable. The women and men in my study live in urban areas where resources are available. Research exploring the experience of adults in rural areas could be valuable, especially interventions to meet their learning and support needs. Some participants in my study related that a multidisciplinary team enhanced their diabetes education. Outcomes-based research could be done to evaluate this approach.

### **Nursing Policy**

Advanced practice nurses can play a pivotal role in the development of workable nursing policy. Advanced practice nurses can help to fill in the gaps and inequities in our health care system (Ackerman, Norsen, Martin, Wiedrich, & Kitzman, 1996). Policies supporting programs that promote prevention, education, and adaptation for the population of adults with diabetes are needed. With the help of diabetes educators and other nurses, advanced practice nurses can lobby politicians to set up special interest groups for diabetes, lobby the national and local branches of the Canadian Diabetes Association to set up task

forces and working groups, and the general public as well to lend their political strength to this process of improving preventative diabetes care. Advanced practice nurses can advocate for greater equity in sharing health care resources so that funding is available to support preventative therapy, especially intensive insulin therapy, and teaching and support programs throughout Newfoundland and Labrador. This can be accomplished by providing more diabetes nurse educators to work in both rural and urban settings. House and Keen (1998) found that the majority of persons with diabetes will die of arterial damage. How much better would it be for our health care system, but especially for the quality of life of persons with diabetes, if funding was directed toward preventing these terrible complications. Research has found that psychosocial needs must be met before persons with diabetes can start to take on the complex management of type 1 diabetes and be successful with it.

Advanced practice nurses can fill a leadership and advocacy role with government by acting as Nursing Consultants for diabetes at the Department of Health level. They can develop policies that reflect a wellness orientation, with prevention of complications as a major focus, for positive client outcomes. They can be resource persons, serving to bridge the gap when governments change, so that there is continuity in programs and policies. The presence of such persons can help to eliminate bureaucratic red tape and improve interdepartmental communications (Anderson, Bruner, & Satterfield, 1995).

Other roles that advanced practice nurses can fill would be valuable in other areas where nurses practice. As practitioners, advanced practice nurses can assess and intervene in planning and providing holistic care for people with type 1 diabetes, and their families. As educators, they can promote a learning environment for clients, families, students, nurses, and other health care providers. Advanced practice nurses can collaborate with diabetes educators in program planning, as resource persons. As consultants, they can improve care for people with type 1 diabetes by sharing specialized knowledge, and an objective perspective, with other members of the health care team. As researchers, advanced practice nurses can facilitate diabetes-related clinical research by front-line nurses, especially qualitative research with a psychosocial focus. They can assist not only with having these results published in nursing journals, but also with applying these research findings to the development of vibrant, effective, innovative programs that have positive client outcomes. As leaders, they can promote quality programs and services, and develop standards of care (Association of Registered Nurses of Newfoundland and Labrador, 1997; Ackerman et al., 1996; Fitzgerald & Wood, 1997; Knaus, Felten, Burton, Fobes & Davis, 1997).

## Conclusion

Advances in medical technology, coupled with convincing research evidence for tight blood glucose control, has changed the face of diabetes management, placing more stress on the person with the disease to achieve the goals set by health care providers. But research has not kept pace with the psychosocial aspects of these changed expectations on the persons with type 1 diabetes, who have to carry out all the new procedures, record-keeping, and critical decision making. Few researchers have considered the viewpoint of these persons, especially regarding the lived experience of type 1 diabetes. The emotions and frustrations experienced, the accusations endured, and the constant hard work and diligence of persons with type 1 diabetes have received little attention.

My phenomenological study was undertaken to explore the lived experience of adults with type 1 diabetes. van Manen's (1997) method of inquiry was used to conduct my study. In-depth interviews were conducted with five women and three men. From the interview data, eight themes were identified: (1) *Constant Vigilance*, (2) *Struggling for Stability*, (3) *Striving for Freedom*, (4) *Surviving Perceived Noncompliance*, (5) *The Lived Experience of Blood Glucose Fluctuations*, (6) *Enduring Sustained Uncertainty*, (7) *Family Support: Sustaining or Smothering*, and (8) *Being Alone with Diabetes*.

Findings from my study have provided support for findings in previous research studies. My study has also provided new insights into the actual lived experience of type 1 diabetes that go beyond previous research. These findings have implications for nursing practice, education, research, and policy especially regarding the psychosocial aspects of living with type 1 diabetes.

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**APPENDICES**

**APPENDIX A: INTERVIEW GUIDE**

## **Appendix A: Interview Guide**

I am very interested in what it is like for you to have diabetes for which you need to take insulin injections. You are free to share any thoughts, feelings, and ideas you have. I would like you to tell me what it is like to live with diabetes in your own words.

### **Examples of Questions to Facilitate the Interview:**

1. How did you feel when you were diagnosed with diabetes?
2. What is it like to know that you are dependent upon insulin injections?
3. How do you live with this condition? Describe a typical day.
4. How have you learned to live with diabetes?
5. What has been the impact of diabetes on your life?

**APPENDIX B: LETTER OF APPROVAL FROM THE HUMAN INVESTIGATION  
COMMITTEE, FACULTY OF MEDICINE, MEMORIAL UNIVERSITY OF  
NEWFOUNDLAND**







