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The Lived and Learning Experiences of Individuals withType 2 Diabetes

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Nadia Najjar

A thesis submitted to the Faculty of Graduate Studies and Research in partial fulfillment of the requirements for the degree of Master of Education.

IN

Adult and Higher Education

Department of Adult Career and Technology

Edmonton, Alberta

Fall 1994

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The undersigned certify that they have read, and recommend to the Faculty of Graduate Studies and Research for acceptance, a thesis entitled **The Lived and Learning Experiences of Individuals with Type 2 Diabetes** submitted by **Nadia Najjar** in partial fulfillment of the requirements for the degree of **Master of Education** in **Adult and Higher Education**.

Dr. Sue Scott

Dr. John Osborne

Dr. Marion Allen

June 7, 1994

Abstract

This descriptive phenomenological study explored the actual experiences of three individuals with Type 2 diabetes. Specific emphasis was placed on these individual's learning experiences. Participants were selected purposively. Attempts were made to include as diverse group of participants as possible based on age, gender, and socioeconomic status. The purpose of this study was to explore patients' perspectives of their disease and of their learning processes as a means to facilitating the development of diabetes patient education programs suited to individuals' learning needs.

Serial unstructured interviews were used to collect the data. Each participant was interviewed three times. Each interview focused on actual lived aspects of the individual's experiences. All interviews were recorded then later transcribed for analysis. Hierarchial thematic clustering similar to that described by Colaizzi (1978), Giorgi (1976), and Osborne (1990), was the primary data analysis technique. 'Within persons' analyses were conducted; these were followed by 'across persons' analyses. Twenty two themes were found and are reported in Table 7. These themes formed the essential structures of the participants' Type 2 diabetes experiences. A sequential learning model was developed from these themes. Implications for diabetes educators and patient education programs are discussed.

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There are many to whom I owe acknowledgement and thanks:

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My family who supported me and loved me through it all;

My classmates and colleagues whose lives enriched my own;

My professors and instructors whose rich experiences and genuine willingness to share them broadened my perspective;

My team: Jackie, Jacqueline, Laura, Michelle, Julianne, and Lee who encouraged, supported and loved me so magnificently, and Lee whose 'big picture' attitude helped me to see more of the 'forest' and less of the 'trees'.

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CHAPTER I

Introduction

Rationale

Diabetes education has been an integral component of diabetes care for at least fifty years (Dunn 1990). Over the years, the process and content of the education has changed dramatically as health professionals have learned more about the disease and its effect on people's lives. To date, diabetes remains a major health impediment and diabetes education remains a primary way to minimize that impediment because it is through education that individuals learn to manage their disease and live well with it. Health professionals, then, have had the primary responsibility in educating patients about the most salient and relevant disease management strategies.

In 1983 Hoover criticized health professionals for not looking beyond metabolic control measures and other physical indices as disease management strategies to the individual's specific learning needs, attitudes, and general well being. In addition, researchers and practitioners have recognized that strict emphasis on adherence to disease management strategies has been insufficient to eliminate the incidence of diabetic complications. To date, diabetes affects 5 - 6% of our population (Davidson 1991). In people over sixty-five years of age, the prevalence is closer to 20% (Davidson 1991). In terms of complications, diabetes is the leading cause of new blindness; one of every three people on dialysis has end stage renal disease secondary to diabetes; and 50 - 75% of lower extremity amputations take place in people with this disease (Davidson 1991). Finally, if deaths due to vascular disease in people with diabetes are ascribed to it, it becomes the third to fifth leading cause of death (Davidson 1991).

As a result two major types of research have dominated the diabetes care/education literature. The first has consisted of technological advances that mimic as much as possible the non-diabetic state. The underlying belief, now reality in light of the D.C.C.T. (Diabetes Control and Complications Trial)study results done with individuals with Type 1 diabetes (Canadian Diabetes Association, 1993), has been that the closer to normal blood glucose levels, the less the risk of diabetic complications. The second area of intense interest has consisted of research into the educational processes that serve to facilitate patients and their families towards optimal diabetes self-management.

Much of this educationally-oriented research has been directed at the measurement of patients' attitudes, levels of personal responsibility and, underlying health beliefs towards diabetes. For example, psychometric scales such as the Diabetes Attitude Scale have been widely tested with the diabetic population. Practically speaking, diabetes education programs by and large, continue to use information transfer techniques and strategies as the primary method of instruction such as lectures supported with handouts rather than instructional methods that involve critical reflection which foster attitudinal change. In other words, the practical application of the findings from these scales remains absent from a good majority of diabetes education programs.

There are several theories of adult learning that can be found in the adult education literature such as Mezirow's (1991) theory of transformational learning. This theory describes a fundamental worldview shift, or perspective transformation that occurs as a result of a learning endeavour that involves critical reflection and rational discourse. This theory which has at its center a cognitive process, has been further developed by others such as Brookfield (1991) into an instructional process to be used in the instruction of adults. Certainly, the diagnosis of diabetes as will be seen throughout this work, can be considered a major life disorienting event that requires significant attitudinal and behavioural changes which ultimately can bring about a worldview shift. What function diabetes educators have in facilitating this process remains unclear. However, they evidently bear some responsibility for this transformational process in light of their other educational responsibilities. What, for example, are educators' responsibilities in educating patients' families and the larger community? Questions of advocacy, community development and outreach plague diabetes educators who have up to this point focused on educating patients about their disease management strategies.

In addition, there remains a paucity of research into diabetes *as experienced* by the individual and their family. In fact, relatively little interest has been shown by the scientific community into understanding the contextual meaning of life for individuals with diabetes. The insider's perspective which is phenomenologically based has as its roots human science research. The value of this approach in terms of the educationally-oriented diabetes research has to do with practitioners gaining a clearer understanding of their patients' learning needs, barriers, and support systems. This in turn would foster the development of educational programs that are more suited to the individual learners.

It is undoubtedly true that many diabetes educators are well aware of the significance of diabetes in their patients' lives. Furthermore, these practitioners have most likely developed their own understanding of the meaning of their patients' diabetes and have adapted aspects of their educational programs to accommodate these insights. However, this understanding is individualistic in nature and fragmented across the profession. As a result, there has not yet been any decisive collective action taken towards the modification of diabetes education practices to a more learner-based mode of learning.

To date, phenomenological diabetes studies have been conducted predominantly with individuals with Type 1 diabetes. However, in terms of prevalence in North America, 90% of patients have the non-insulin dependent type of diabetes, also known as Type 2 diabetes (Reaven 1989). Reaven (1989) speculated that at least some of the reasons for the research focus on Type 1 diabetes have included the fact that Type 2 diabetes tends to occur in overweight middle-aged individuals whereas Type 1 diabetes often occurs in pre-teen youngsters and despite many advances, Type 1 diabetes continues to drastically reduce life expectancy. In addition, Type 1 diabetes management tends to be more clinically based and as such the prospects of technological advances and technical manipulations tend to be far more effective than is the case with Type 2 diabetes management which tends to be more lifestyle and behavioural in nature. Finally, people with Type 1 diabetes are usually symptomatic at the onset and throughout the course of their disease. As a result, they tend to be treated more seriously by health professionals, in contrast to individuals with Type 2 diabetes who are often asymptomatic at onset and often even throughout the course of their disease. It follows then that Type 2 diabetes is vastly different from Type 1 diabetes in incidence, management, and possibly even in patients' experiences. As such the perspectives of individuals with Type 2 diabetes merit exploration and study.

Research Questions

The fundamental research questions guiding this study were: What are people's life experiences of Type 2 diabetes? What were their significant learning experiences? And finally, to what extent did these individuals experience a transformation in their perspectives regarding their life with the diabetes?

This study approaches these questions from a qualitative perspective; an attempt to understand the lived-world experience, in search of the "what is this like for you" rather than "why is this so." Since phenomenology is the basis for all research, it seems appropriate to initiate exploration in this manner, considering there is still much ground breaking involved in this area of interest. A good description and understanding of the experience will lay the foundation for future research that may look at some of the "Why" and "How" questions.

Statement of Significance

The significance of this study was fourfold: Firstly, research into patients' perspectives about their disease has been remarkably meager. Berger and Luckman (1967) have outlined that this kind of research about people's perspectives may provide patterns of information about their behaviour that is relevant to health professionals' understanding, and subsequently, to the delivery of patient care/education. This is particularly true in light of the social construction of reality and our co-constitution with our world.

Secondly, patients are health care's primary resource; they are the central reason for the existence of diabetes education programs, and diabetes education as a profession. As such the potential of the development of a program that is relevant to patients and that may be helpful in ameliorating the primary dysfunctions of the disease, namely the diabetic complications, is of tremendous importance.

Thirdly, since 1980 there has been a growing body of literature on diabetes patient education and counseling. Researchers and practitioners are interested in discovering how best to help people with diabetes manage this complex lifelong disease. In the reality of daily practice, educators have tended to lag behind researchers in their development and/or implementation of diabetes patient education programs that foster optimal diabetes adjustment . The present study attempted to highlight information about patients' lives that educators may need to consider in the development of educational programs. This in turn may help to foster optimal diabetes adjustment in patients.

Finally, patients' descriptions of their diabetes and of their learning experiences may provide some illuminating information about the characteristics of effective diabetes educators. To date, there is little data about the human skills that are characteristic of effective diabetes educators. Much of the research has focused on the technical and content expertise that diabetes educators must possess as prerequisites to their professional practice.

The next chapter will review the pertinent literature. This includes a historical review of diabetes education, a review of the research available on patients' perspectives of their disease, a close examination of the theory of transformational learning and finally the philosophical foundations of the chosen research method.

Chapter III discusses the method used along with procedural aspects pertaining to the study.

Chapter IV presents the data that was collected and thematically abstracted.

Chapter V will conclude the study with a discussion of the findings, implications and limitations of this study as revealed by the investigation.

Definition of Terms

Type 2 diabetes: also known as non-insulin dependent diabetes mellitus (NIDDM). A progressive endocrine disease that typically occurs in middle adulthood. Its hallmark characteristic is elevated blood glucose levels both pre-prandially and post-priandially. This type of diabetes does not necessitate the use of insulin unless other behavioural therapies such as diet, exercise, and oral hypoglycemic agents have failed to ameliorate the high blood glucose levels.

Type 1 diabetes: also known as insulin dependent diabetes (IDDM). A progressive disease that typically occurs in individuals under the age of forty. Its hallmark characteristic is absolute insulin deficiency and excessively high blood glucose levels. Lifelong administration of insulin is necessary for an individual with this disease to survive.

Existential-phenomenological psychology: A discipline that "seeks to explicate the essence, structure, or form of both human experience and human behaviour as revealed through essentially descriptive techniques including disciplined reflection" (Valle & King, 1987, p. 7).

Co-constitutionality: This notion refers to "being-in-the-world" (Valle & King, 1978, p. 8) which essentially means that an individual gives meaning to his/her own world. That is to say that any individual's experiences are contextualized to his/her own world.

Hemoglobin A1C: A laboratory test result that depicts the average blood glucose levels of an individual over the three months preceding the test.

CHAPTER II

Review of the Literature

Introduction

The purpose of this literature review is to outline some of the findings that pertain to diabetes education. This includes a report of diabetes and diabetes education studies that have used the interpretive paradigm specifically to explore patients' perspectives of their disease. In addition, the review addresses the evolving role of diabetes education as a disease management strategy, and explores the value of the phenomenological approach as a method for this study.

Historical sketch of diabetes education

Diabetes patient education has been an integral component of diabetes care for at least fifty years (Dunn 1990). The purpose of the education process has been to enhance patients' understanding of the disease and its treatment strategies in order to facilitate self-management, and thereby reduce the incidence of diabetic complications (Reaven 1989). This process, it has been believed, enhances patients' adherence to treatment strategies as taught (Rubin, Peyrot and Saudek, 1989; Davidson, 1991). Traditionally, physicians have had the primary responsibility for their patients' education. Typically, this education has consisted of information that physicians are inherently well qualified to provide; namely, information based on the diagnosis and treatment of diabetes and its complications (Reaven, 1989; Davidson, 1991).

Since the early 1970s, nurses and other health professionals have joined physicians in their patient education responsibilities. In 1983 the United States National Advisory Board [on diabetes mellitus] developed national standards for diabetes patient education programs (Brown, 1990). In 1986 Canadian standards for national diabetes education programs were developed by the Diabetes Educator Section of the Canadian Diabetes Association through a consensus process in collaboration with physicians, education and nutrition consultants and other health professionals involved in diabetes clinical practice, education and research (Diabetes Educator Section Canadian Diabetes Association [DES of CDA], 1989). The primary functions of these standards are to "facilitate self-care by patients with diabetes and to reduce the socio-economic impact of diabetes to society" (DES of CDA, 1989, p. 19) by ensuring that appropriate education programs are available and accessible throughout the country. These standards delineate needs assessment, administrative, program, and quality assurance requirements. However, there are no measures in place to ensure their enforcement. Furthermore most of the standards are subject to interpretation by the individual health practitioner--for example, identification of barriers to learning under the needs assessment standards could potentially mean social barriers, or they could also be interpreted as individual barriers to learning such as reading or writing difficulties.

Lack of enforcement of standards, and/or their misinterpretation due to their lack of clarity may in part explain the inconsistency of diabetes patient education programs in effectively enhancing patient self-care behaviours and psychological adaptation (Surwit, Scovern and Feinglos, 1982; Brown, 1990; Beeney and Dunn, 1990). Without doubt, patient education programs have succeeded in increasing patient knowledge and their self-care without eradicating the life difficulties and challenges including the complications that often accompany diabetes.

One only has to look at the current incidence rates of diabetic complications to gain some understanding of the seriousness of this situation. Currently, diabetes affects 5-6% of our population (Davidson, 1991). In people over sixty-five years of age, the prevalence is closer to 20% (Davidson, 1991). In terms of complications, diabetes is the leading cause of new blindness; one of every three people on dialysis has end stage renal disease secondary to diabetes; and 50-75% of lower extremity amputations take place in people with this disease (Davidson, 1991). Finally, if deaths due to vascular disease in people with diabetes are ascribed to this disease, it becomes the third to fifth leading cause of death (Davidson, 1991).

In addition to the rapid technological advances aimed at improving and simplifying treatment of the disease, critics of patient education programs have called for increased attention aimed at meeting patients' learning needs within the educational process (Dunn, 1990; De Weerdt, Visser, Kok, Van Der Veen, 1990). To facilitate this, researchers (Dunn, 1990; Funnell et al., 1991) have called for the development of alternate patient education models that are based on educational and psychological theories of learning. Dunn identified that the traditional medical model, upon which most education programs are currently based "is inappropriate for a chronic illness like diabetes where the major emphasis is on behavioral and lifestyle change" (p. 284). Funnell et al. (1991) identified that successful diabetes self-care "necessitates that patients be able to make informed choices and decisions. . . [and that] knowledge and experience are required to make informed choices, as is the ability to take responsibility for one own's care" (p. 38).

Transformational learning

As an adult educator Mezirow (1991) proposed a learning theory in which the individual adult learner undergoes a perspective transformation following a process that he entitled reflective action. During this process, which is precipitated by a disorienting event, the learner can proceed to examine and to reflect upon three essential components of a learning problem; the first is the actual specifics of the problem or the content. The second is the mechanics of the problem or the process and the third is the underlying assumption(s) about the problem or the premise. In his words, Mezirow (1991) postulated that "our continued learning [is] dependent upon a reflective review of what we have learned, how we learned it and whether our presuppositions are warranted" (p.109). Reflection, according to Mezirow (1991) is understood as an "apperceptive assessment of the justification for our beliefs, ideas or feelings" (p. 8). Critical reflection, on the other hand, is understood as the process by which we engage in premise reflection.

He placed considerable emphasis on premise reflection as the crucial component of perspective transformation because "premise reflection leads to more fully developed meaning perspectives, that is, meaning perspectives that are more inclusive, discriminating, permeable and integrative of experience" (p.111). According to his theory, if premise reflection is absent then the learning experience becomes confirmative rather than transformative because the underlying assumptions about the experience remain unaltered.

Mezirow (1991) argued that his theory of transformational learning is primarily a theory of rationality because, according to him the transformation components including meaning perspectives and meaning schemes exist primarily in the cognitive mind. According to him intuition, feelings and dreams are the principal links which allow us to be influenced in our rational thought. Wilber (1986), on the other hand, acknowledged that transformation necessarily involves a regression or descent during which the individual disidentifies with formerly held beliefs in favour of developing new ones. This process, according to Wilber (1986) is anything but rational because it involves the whole self. Whether rational or not, transformative learning is truly a cardinal objective of adult education.

When examined from this perspective, diabetes education may be considered a transformative form of learning because of the attitudinal as well as behavioural changes that are required for a successful life with diabetes. These attitudes are clustered around a sense of personal responsibility for self-care. The purpose of diabetes patient education now becomes a means to improve patients' quality of life by enabling them to take charge of their own health-- a concept not unlike "learning to live well" with the disease.

To emphasize wellness of the whole person, diabetes educators must recognize that patients are experts on their own lives and that educators are experts and resources on diabetes. This shift from a knower non-knower relationship to a co-learner relationship demands that educators be able to understand patients' contextual learning needs as well as how to create learning environments conducive for transformational learning to take place. For this reason a phenomenological exploration of patients' learning experiences may help to shed light on patient's personal and contextual learning needs and whether transformational learning has occurred and what were the circumstances conducive for this type of learning. A summary of patients' experiences of diabetes follows.

Patients' perspectives

One of the earliest studies that investigated patients' perspectives of their disease and of their education was reported by Quint in 1969. She interviewed families of children with diabetes who were at different chronological points in the transition from pre-adolescence to adulthood in order to gain some understanding about what it meant to have diabetes. In addition, Quint investigated the effects of the disease and the recommended treatment strategies on the enactment of social roles. Quint (1969) concluded that diabetes interfered with the social order of the family in two ways; firstly, when the diabetes and its treatment regimen interfered with already established roles and activities, and secondly, when this interference became a source of tension in the patterning of the social relationships of the family members.

Of particular relevance to diabetes educators was her finding that parents of children who developed diabetes most often felt overwhelmed by the amount of information they had to absorb and by the tremendous sense of responsibility they felt towards caring for their children. Quint's study was done with families of children who had insulin dependent diabetes mellitus and extrapolation of her data to the adult population with non-insulin dependent diabetes mellitus can only be done cautiously. However, there may be value in considering the volume of information patients must absorb, and the disruption caused to the individual's life brought on by the rigorous demands of the disease's treatment strategies as a potential barrier to treatment success.

Indeed Nyhlin (1990) reported that patients in her study expressed a need and a longing for "wider concern of the health care system to include their situations in the family, at work, and in society" (p. 802). Moreover Nyhlin concluded that "the message delivered to diabetic patients by the health care system and by the literature is that adhering to the regimen means that one can achieve a state of well-being which is comparable to the average member of society" (p. 798). Therein lies the difficulty. To achieve a state of well-being, an individual with diabetes must comply with the treatment regimen almost to the exclusion of the demands of one's family, one's work, and one's societal roles.

In 1983 Hoover reported that people with diabetes can suffer from burnout largely due to the unrelieved stress of daily decisions that must be made. These include "resisting the temptations of sweets, alcohol, too much food as well as coping with the awkward social situations such actions create" (p. 41). She even accused diabetes education programs of delivering the message of perfectionism as the behavioural goal for all people with diabetes. "The compliant patient is a perfectionist and perfectionists burnout" (p. 41). The message then is that diabetes education must be first and foremost about living with diabetes. As educators, we will only be able to accomplish this fully if we understand what it is like for our patients to have this disease in their homes, families, jobs, and in all other aspects of their lives.

Luft (in Nyhlin 1990) said that diabetes care in the future must "bridge the distance between diabetes as defined from a strict medical viewpoint as a metabolic disturbance, and the patient's experience of his disease as a medical . . . social and psychological problem" (p. 798). Wikblad's findings (1991) confirmed this conclusion. Participants in her study reported that their contacts with the diabetes care system were often superficial and related only to metabolic control. "Those who had acceptable metabolic control experienced positive feedback from the care team, while those who had unacceptable metabolic control did not receive positive responses or support to the same degree" (p. 837). It is impossible to conclude with any certainty if understanding of patients' life context by any members of the care team would have altered those findings. Wikblad (1991) concluded that in order to expedite self-care, patients required some basic knowledge about diabetes as it applied to daily life. As well, patients' relatives needed to be included in the educational process, and educational followups were necessary for sustained knowledge. Furthermore, she concluded that diabetes education "was a complex process [that included] behavioural reinforcement and emotional peer support directed both towards the patient and towards those closest to him" (p. 842).

In an effort to understand why some patients comply with medical regimens while others seemingly do not, Roberson (1992) investigated the meaning of compliance from patients' perspectives. She interviewed 23 adult African Americans, five of whom had diabetes, and found that patients "define compliance in terms of apparent good health and seek treatment approaches which are manageable, livable, and in their views, effective" (p. 7). In essence, her study participants developed systems of self-management which suited their lifestyles, belief patterns and personal priorities. Modification of treatment plans was in fact a way to exert autonomy over the regimen especially when the individual was dissatisfied with the treatment plan. Wikblad (1991) reported a similar finding in that participants in her study wanted to be responsible for their disease and expressed frustration at the apparent lack of support from the diabetes care team to do this.

Among her participants Roberson (1992) discovered that there were several variables which affected self-management. These included practical realities such as money, social concerns such as the ability to eat and drink as others, the fear of being dependent on a treatment regimen, and a belief that God would guide and look after one's wellbeing. Perhaps her most interesting finding was though many of her participants would be labeled non-compliant by health professionals, the participants saw themselves as "doing a pretty good job" (p. 7). She concluded that there appeared to be great need to enhance patients' efforts to live well with a chronic disease rather than focus on identifying compliance rates and subsequent ways to alter them. To accomplish this "health professionals must learn more about clients' perspectives of their health problems and their treatment and then respond to these perspectives appropriately" (p. 24).

In an interesting study reported by Wikblad, Wibell and Montin (1991) participants' views of their health were compared to the metabolic control variable: hemoglobin A1c. No relationship could be discerned between patients' perceptions of good health and the blood test variable. Furthermore, 25% of the participants reported that they had abandoned important life goals against their will because of the presence of diabetes. These participants rated their own mental balance lower than any of the other study participants. In addition, these people exhibited the lowest attitudinal scores towards diabetes. Wikblad et al. (1991) concluded that "when members of a diabetes care team observe "lack of meaningfulness" or "adaptation problems" in patients, they are tempted to respond with technical solutions--a new mode of insulin administration. . . The metabolic control may improve, or remain good or bad, but unhealth is likely to persist if the real problems have not been identified" (p. 76). In other words, the concept of health is determined by the individual with the disease and is not estimated by a laboratory test. Wikblad et al. (1991) further concluded that research needs to be conducted to determine if these attitudinal difficulties towards diabetes could be ameliorated if diabetes care teams had a better understanding of patients' life needs.

Lundman, Asplund, and Norberg (1988) also investigated the relationship between emotions, attitudes in individuals with insulin dependent diabetes, and metabolic control (hemoglobin A1c). They also were not able to determine a conclusive relationship between these variables. However a number of participants with good metabolic control expressed negative feelings towards diabetes more often than those with poor metabolic control. Though these findings were not statistically significant, it is apparent that attitudes and emotions are perceived as key components of good health by patients It is therefore not possible for a laboratory test to assess these components of one's health. Far too many health professionals compare patients' health to metabolic control, and far too many diabetes education programs focus on the achievement of good metabolic control as the substantive measure of good health.

It is of interest to note that none of the participants in the patients' perspectives studies reported above had non-insulin dependent diabetes. All participants had insulin dependent diabetes. In terms of prevalence, 90% of patients with diabetes have the non-insulin dependent type of diabetes, also known as Type 2 (Reaven 1989). Possible reasons for the lack of studies delineating the experiences of individuals with Type 2 diabetes were postulated by Reaven (1989) as follows: Insulin dependent diabetes or Type 1 typically occurs in a far younger population, and despite advancements in medical management, it drastically reduces life expectancy. Secondly, people with Type 1 diabetes are usually symptomatic at the onset, and throughout the course of their disease. As a result they tend to be treated more seriously by health professionals in contrast to individuals with Type 2 diabetes who are often older and asymptomatic at onset. In addition, people with Type 2 diabetes sometimes remain asymptomatic throughout the course of their disease. It follows then, that Type 2 diabetes is vastly different from Type 1 diabetes in incidence, management, treatment, and possibly even in patients' experiences. As such the perspectives of individuals with Type 2 diabetes merit exploration and study.

CHAPTER III

Methods

Introduction

This chapter begins with an explanation for the choice of method and a discussion of personal biases and presuppositions concerning the phenomenon. This is followed by a description of the procedure adopted, the criteria for selection of the participants, and the data collection and interpretation format.

Rationale

The purpose of this study was to describe the experience of having Type 2 diabetes and to explore ways in which that description may best be used to enhance the diabetes education process. There was no interest in determining a cause and effect rather the focus was on gaining an insider's perspective of the experience. For this reason, the phenomenological approach was appropriate.

The experimental method seeks to answer "why" questions concerning a phenomenon, whereas, the phenomenological method is concerned with discovering "what" the phenomenon is (Valle & King, 1978). This study was unique because there was a dearth of literature that discusses the patients' perspective of Type 2 diabetes. Even though many "why" type questions arose, the "what" must be established before the "why" (Valle & King, 1978). Identification of the phenomenon has to be the first step (Colaizzi, 1978). In attempting to understand the Type 2 diabetes phenomenon, the phenomenological approach may well clarify its essential structures and their inter relatedness.

Philosophical foundations of method

Phenomenology is the study of one's conscious experiences (Osborne, 1990). This approach is holistic and qualitative in nature. It is an approach that is deeply rooted in human science which posits that as individuals we are *of* the world rather than in it. In other words, our experiences and realities make up our world and are not separate or distinct from us. In this manner, we co-constitute with our world (Osborne, 1990). In this way, the basis of phenomenological research involves understanding or grasping the phenomenon by focusing on the lived-experience (Colaizzi, 1978; Giorgi, 1970).

This approach seeks out the essence, structure and form of an experience through a reflective and descriptive process (Valle & King, 1978). In comparison to the natural science paradigm, phenomenological research does not search for quantitative relationships or even the determinants of a phenomenon; rather it follows Husserl's (1962) precept of "returning to the things themselves" in understanding the experience (Colaizzi, 1978). Osborne (1990) explained the aim of phenomenological research:

> . .to understand a phenomenon by allowing the data to speak for themselves, by attempting to put aside one's preconception as best as one can. The method provides us with descriptions of experience which are then interpreted by the researcher from a particular theoretical perspective...if there is a structure to the phenomenon it will transcend particular interpretations. Hypotheses may be generated from such a descriptive method and be subsequently tested by the methods of explanatory science. (pp. 10 - 11)

Giorgi (1975) maintained that even though the phenomenological method can be flexible in its orientation the approach can be practiced with rigor and discipline. The traditional scientific approach often refers to objectivity, validity, reliability and generalizability as evaluative criteria for true research. These criteria are also fundamental to the phenomenological approach.

Objectivity

Phenomenology has been criticized for being too subjective and introspective (Giorgi, 1984). According to the natural science approach, objectivity involves knowing the world independent of humankind as a subject: denying the presence of the scientist in science (Giorgi, 1970). Colaizzi (1978), however, maintained that denying experience is not being objective. True objectivity requires us to recognize and affirm that which we experience and the experience of others; experience exists for us all. The experience is not inside us, rather, it is exemplified in the manner in which we act toward the world. In response to the question of whether research can be objective when human experience is accepted as psychological content, Colaizzi offered:

> ... experience is (a) objectively real for myself and others, (b) not an internal state but a mode of presence that is existentially significant, and (c) as existentially significant, it is a legitimate and necessary content for understanding human psychology. (p. 52)

Validity

The concern with validity in the natural science approach involves using a measuring instrument that actually measures the hypothesized variable. In phenomenological research the concern with validity is determined by the ability of the method to investigate the phenomenon. The aim of the researcher is to present a description congruent with the participant's lived-experience of the phenomenon (Wertz, 1984), untainted, as much as possible, from researcher bias.

Osborne (1984) discussed four major ways of checking for validity in phenomenological research. First, the researcher addresses his/her own predispositions and biases through rigorous self-reflection. This process (bracketing) enables the reader to evaluate the interpretations of the data in conjunction with the researcher's frame of reference. Second, the researcher refers back to the participant during the interpretation and collection of data to check for interpretive accuracy. Third, the presentation of a coherent and convincing argument may present an accurate understanding of the phenomenon although rhetoric skills may well influence such perceptions. Finally, there is the consideration of generalizing the interpretations. The question is asked: do other people who have experienced this phenomenon identify with the interpreted structure?

Reliability

In the natural science approach, reliability refers to replicability, consistency, and stability of measurement (Osborne, 1990). Wertz (1986) pointed out that "qualitative reliability is not achieved merely by the repeated reenactment of the same perspective, nor a holding constant of context" (p. 202). He explained that qualitative reliability:

> ... requires an intelligent variation and interrelation of different subjective perspectives and factual contexts, which alone discloses the invariant core of what something is and means. The criterion of qualitative reliability is therefore persistence of meaning through the factual variations. (p. 200)

Osborne (1990) explained that "different interviewers of different co-researchers produce situations which are never repeatable but which provide multiple perspectives which can lead to a unified description of a phenomenon ... stable meaning can transcend variable facts" (p. 26). It is difficult to separate reliability from validity in the qualitative approach because both look to the "what" is being studied in deriving meaning (Wertz, 1986). Wertz added: "standardization becomes arbitrary the moment it loses sight of the larger series of the different possible approaches which alone can bestow any true privilege upon it from particular viewpoint" (p. 200).

The major risk to both validity and reliability lies in the interpretive process (Osborne, 1990), and in the participant's ability to recall the phenomenon (Mason, 1990). Using appropriate reliable questions and returning to the participant for verification will provide the researcher additional confidence in the data (Mason, 1990). The final test for accurate interpretation is left to the reader who can compare the conclusions with the data (Osborne, 1990).

Generalizability

The phenomenological approach strives for empathic rather than statistical generalizability. Empathic generalizability implies that the description of the experience resonates with another who shared in the experience. The purpose is to attain an understanding of an experiential concept and to avail intersubjective agreement with others who experience the phenomenon (Polkinghorne, 1980; Angus, 1988). For this reason, rather than being concerned with random sampling, participants are chosen on the basis of being able to "provide rich descriptions of their experiences of the concept and who are able to engage in their own imaginative development of events and variations" (Polkinghorne, 1980, p. 19).

If then as diabetes educators we desire to understand our patients' lived experiences and particularly their learning needs, we must understand our patients contextually, that is, as they appear within their worlds. Diagnosing patient learning needs based on our understanding of the disease, or worse yet, based on our experiences is no longer acceptable. The value of phenomenology lies in its attempt to uncover the whole meaning(s) of a phenomenon from the participant's viewpoint. In so doing, diabetes educators would gain valuable insight into their patients' perspectives.

Approaching the Phenomenon: Bracketing

The presence of the researcher is unavoidable in this type of study. It is difficult, if not impossible, to prevent personal presuppositions and biases from influencing the formulation of the research questions, data collection and interpretation. For this reason, it is important that the researcher "attempts to articulate predispositions and biases through a process of rigorous self-reflection so that those who read reports of the research will be able to take the frame of reference of the researcher into account" (Osborne, p. 11, 1990).

The following is an explanation of my interest in this study and my understanding of the Type 2 diabetes phenomenon. I have been a diabetes educator for approximately five years. Over the course of the five years, I have found myself thinking about how best to help people learn about their diabetes and how best to create a supportive learning environment. I have often wondered about my educational responsibilities beyond the mechanics of teaching patients and their families how to live well with the diabetes. I have asked these questions of my colleagues and have not received a satisfactory response. I believed that patients could identify their learning needs and could inform educators of how they would best learn but I was unsure of how to access that information or how to use it creatively in the development of education programs.

In terms of my own understanding of the Type 2 diabetes phenomenon, the following is a list of my presuppositions:

- the tedium of the disease's management strategies.
- the rigidity of the treatment strategies relative to the individual's life demands/responsibilities.
- the frustration with the complexity of the treatment strategies.
- the stress brought on by failure to adhere to treatment strategies as taught.
- the frustration with the fragmented nature of the health care system.
- the ongoing need for support and encouragement.
- the inadequate support systems both in the home and in the community.
- the financial strain brought on by the treatment strategies including blood testing supplies, medications and specialty foods.
- the ignorance of significant relatives and the general public of treatment demands.
- the fear experienced as a result of passing on the risk of having diabetes to one's children.
- the frustration over job discrimination or even harassment directly attributed to having the disease or to its management.

- the recognition of one's own responsibility for self-care.
- the enhanced awareness of one's own mortality.

The implication of these biases is that they may influence me to show data that is in agreement with my views or experiences. For this reason, I have attempted to not be persuasive, rather, to permit the participants to freely express themselves. The interpretation of the data may consist of preformulated themes that have been brought into the study by the researcher unless the data is allowed to speak for itself. For myself, this is not easily done because I feel convinced that some of the items I have mentioned above are thematic to the Type 2 diabetes phenomenon. The objectives of this study are best met if the influences of such biases are understood and diminished.

Participants

In the phenomenological approach, it is the researcher's discretion as to how many participants are needed to satisfy the research objective. Anywhere from one to ten people should be sufficient (Becker, 1986), although "more than one is advisable for such reasons as attrition or that some participants may not illuminate the phenomenon" (Osborne, p. 13, 1990). It is important, Osborne adds, to find people who have experienced the phenomenon and can provide a rich illumination of it.

Six individuals with Type 2 diabetes were selected from a diabetes day center hospital registry. Three of the six people had been diagnosed with the diabetes within six months prior to enrolling in this study. These individuals, two women and one man, had participated in the same diabetes education classes during the summer of 1993. The other three participants had had the diabetes for several years ranging from two to ten years. These participants had taken the diabetes education classes several years prior to their enrollment in this study. One of these last three people, a woman, had the beginnings of diabetic complications including nephropathy and peripheral neuropathy.

Although, I interviewed all six individuals, I decided to exclude the last three participants from the study and focus instead on the experiences of the individuals who had been recently diagnosed and had attended the same diabetes education classes. I suspected that their experiences would be somewhat similar and would be primarily concerned with the processes of learning to adapt to life with the diabetes, whereas, with the other three individuals, I thought their experiences would be more concerned with the day-to-day mundane demands of diabetes including learning to live with the possibility/reality of the long term complications of diabetes. On reflection, I realized that the educational needs of these two groups of people differed vastly and I felt unable to cope with the huge quantity of data generated by these two very distinct groups of participants.

Data Collection

The dialogical interview is the most common method of gathering data (Osborne, 1990) and very effective toward understanding the phenomenon (Becker, 1989; Colaizzi, 1978). Kvale (1983) describes the interview as:

1) centered on the interviewee's life-world; 2) seeks to understand the meaning of the phenomena in his life-world; it is 3) qualitative, 4) descriptive, and 5) specific; it is 6) presuppositionless; 7) focused on certain themes; is open for 8) ambiguities, and 9) changes; depends upon the 10) sensitivity of the interviewer; takes place in 11) an interpersonal interaction, and may be 12) a positive experience (p. 174).

Of the various interview formats that Becker (1986) discusses, Osborne (1990) suggests one in particular that involves the following three phases:

> The first phase interview is used to establish rapport and inform the [participant] of the nature of the research. The second phase interview is used for data gathering...should not be an interrogation aimed at substantiating the hunches of the researcher. Open-ended, minimally structured interviews are more likely to produce data which might otherwise be missed. ...[Participants] can be asked to reflect further upon the phenomenon ... successive data gathering interviews create a respiralling effect and enable a more complete illumination of the phenomenon. (p. 19)

The interview format used in this study consisted of three in depth one hour interviews with each participant. The interview format was semi-structured. I had prepared a list of questions to probe and prompt the participants if they wandered off topic or became stuck. All the interviews were conducted in the participants' own homes. The study's protocol and ethics were reviewed with each participant during the initial interview. It was at that time that each participant signed a consent form indicating his/her willingness to participate in the study. Data collected in the first interview was verified and probed for further description during the second interview. I shared my interpretations of the participants' descriptions with them during the final interview. I also shared with the participants a written/oral summary of their experience and asked them to fill in any omissions and to correct any misinterpretations.

Data analysis

Data analysis methods vary according to the researcher's preference and objectives (Colaizzi, 1978; Osborne, 1990). Each method, however, seeks to illuminate the phenomenon by discovering its essential structures through hierarchical thematic analysis of the data. This method adapted from Giorgi (1975) and Colaizzi (1978) and reiterated by Osborne (1990) consists of the following steps:

1. Each interview, after transcription, is read several times in order to get a feel for the data. Interview tapes are listened to several times to help with understanding the tone inflexions.
2. Phrases or sentences that pertain phenomenon under study are extracted and numbered.
3. Each extracted significant statement is formulated into meanings. The objective here is to go "beyond what [was] given in the original data and at the same time stay with it " (Colaizzi, p. 59, 1978).
4. The meanings are aggregated into clusters of themes.
5. These clusters of themes are synthesized into higher order clusters.

6. The above process is repeated for each protocol. The final structure for each protocol is presented as a written synthesis.
7. At this point, a validity check with the participants concerning the researcher's interpretations can be conducted.
8. The final step involves a between-participant thematic analysis that reveals a shared structure of experience. This is presented in the form of a written synthesis.

Data analysis in this study consisted of initially reading the interview transcripts several times to help get a feel for the data. Listening to the interview tapes also helped with this initial data analysis procedure because of the tone inflexions and pauses that contributed to the meaning. I made short interpretive notes on the interview transcripts as a result of this process.

The next step consisted of extracting and numbering phrases/sentences that pertained to the Type 2 diabetes phenomenon. All the data provided by each participant was included during this step; in other words, no attempt was made to exclude repetitive data at this point. Each extracted significant statement was then formulated into a meaning unit. These meaning units formed the first level of thematic abstraction and were labeled as paraphrases.

The paraphrases were further thematically abstracted then clustered to form the second order meaning units which were labeled as themes. A further clustering of these themes into adaptational stages was then conducted. These stages were then written descriptively in tables 2, 4, and 6. This process was repeated for each protocol. The final structure for each protocol was presented as a written synthesis. The written synthesis and analyses were then shared with the participants for their validation and/or correction.

The final step consisted of finding themes that were common to all participants. These served as the essential structures of the Type 2 diabetes phenomenon and it was these common themes that were used to develop the transformational model outlined in the discussion chapter.

Procedure

The first step involved finding participants who could best illuminate the phenomenon. After obtaining the necessary official approval from the hospital administration, I approached the staff members of a diabetes day center for a list of their recent program participants. I contacted six people from this list by telephone and invited their participation after carefully outlining the extent of their involvement. A signed consent form was obtained from each participant signifying their agreement to participate in the study.

I began with a one hour interview with each of the three final participants. The approach was semi-structured: I had prepared a list of questions to turn to if the participant became unresponsive or wandered off-topic. I conducted three interviews with each participant; each of these was one hour long. These interviews were conducted in the participants' own homes during the fall of 1993.

After the interviews were over, I transcribed the tapes verbatim and formulated a within-participant analysis (two-level thematic abstraction) of the data provided. Once all the protocols were analyzed then a composite analysis for each participant was devised. This consisted of eliminating redundant or repetitive data. After the within-persons analyses were completed, themes common to all participants were noted. In all there were twelve themes that were common to all participants out of the total twenty two themes.

During the final interview, I shared with the participants my analyses of their descriptions and asked for their validation/correction of my interpretations. I modified the analyses according to their responses. With this phase completed, I proceeded with between-participant data analysis leading to a discovered structure of the phenomenon that I discussed at the end of this manuscript.

CHAPTER IV

Results

Introduction

This chapter presents a description of each participant's experience of Type 2 diabetes. These descriptions are provided in tabular form, revealing the major themes that emerged from each protocol. Two tables are presented for each participant. The first table shows the excerpts from the interview (column 1) followed by a paraphrase of the meaning of that excerpt (column 2) followed by an allocation of a theme to that meaning (column 3). The second table clusters the themes together from the first table, revealing which excerpts demonstrate the theme, accompanied by a general description of the clustered themes. Each participant's experience is then presented as a written synthesis. Finally, a general written synthesis is provided that presents the shared experience of all participants. The names are fictitious.

Individual Descriptions

Mark

Personal Information. Mark is 40 years old, married and has two teenage children. He works as a pastor and also as a mental health worker at a care facility for the elderly. His wife works as an instructor at a local community college. Both he and his wife home-school their children. As a result, he has an extremely busy lifestyle. Prior to the diabetes diagnosis, he and his wife shared meal preparation responsibilities including the shopping and the cooking.

Mark's exposure to diabetes prior to his own diagnosis was limited to his family. Both his mother, father and paternal uncle had diabetes. All had developed Type 2 diabetes late in life. According to him, his mother had taken good care of her diabetes and for the last five years of her life, she had required insulin therapy. His father on the other hand, had taken minimal care of his diabetes and lived a long productive, uneventful life. His uncle, however, had had major diabetic complications including a leg amputation. This uncle eventually died from these complications. The effect of these people's experiences of diabetes on him was remarkable. He repeatedly referred to his uncle and how he hoped he would never suffer with diabetes as he had.

Mark and his family led a sedentary lifestyle. They used a lot of convenience foods such as pizza and enjoyed traditional Ukrainian foods on a regular basis. All four members of the family were overweight and had been for a long period in time although Mark specifically referred to the time following the death of his brother as being the time when he started to gain a substantial amount of weight. This was approximately five years prior to his diabetes diagnosis. During that time, Mark chose to not attend his physician for annual medical checkups for fear of what the physician might say about his excess weight gain. He admitted that he had been aware of his risk of developing diabetes during that time but felt unable to cope with such a reality.

Table 1

Thematic Abstraction of Mark's Diabetes Experience

Excerpts from Transcribed Interviews	Two levels of Abstraction	
	1. Paraphrases	2. Themes
1. I thought I didn't want to go [to the doctor] because I'd been having trouble with my eyes and I don't want to get glasses. Maybe it's just vanity or growing older.	Symptoms of diabetes cause distress about his vision which he attributed to aging.	Diabetes induced grief.
2. Physically I was really tired...I'd been having a lot of headaches. It was a...listless feeling not something I could put my finger onto but...I didn't feel well. However, I'd been going through a lot of stress at that time with my employer.	Description of ill feeling prior to diagnosis of diabetes which he attributed to stress experienced at work.	Diabetes induced grief.
3. He'd [employer] laid 2 or 3 people off because they could not make the deadline to get their class 4 license...There were threats of letters coming around and if you don't do it by such and such a date, you're not going to be working...so I had the stress...I thought that [the symptoms] was all part of it, you know.	Description of stressful work situation which occurred at same time as diabetes symptoms. He attributed diabetes symptoms to this stress.	Diabetes induced grief. Frustration with unsympathetic work boss.
4. When I did go to my doctor...he relayed that my blood pressure is good and my pulse is good and strong...and there didn't seem to be anything else there even the weight gain...I had gained a lot in the past 5 or 6 years when I was told that my brother died. I did put on a lot of weight. It was careless I guess.	Initial medical report favourable despite his anxiety about his weight gain.	Diabetes induced grief

Excerpts from Transcribed Interviews	Two levels of Abstraction	
	1. Paraphrases	2. Themes
5. I was just finishing off last minute details at the counter and literally turned to walk out the door. Another...nurse...called me back in and said there's too much sugar in the urine and we would like to do this again to see what's going on...I don't remember if they made any changes...I know I went to the fasting sugar the next day and he re-booked an appointment for the next week...I think they gave me a diet sheet on that day...and they wanted me to stick close to that diet guidelines.	Description of the time when initial diabetes diagnosis was made. These included the surprise about the diagnosis and the prescription of a strict diet.	Diabetes induced grief
6. I think in the back of my mind it [diabetes] would have happened anyway. It's like I'm doomed. Everybody in the family has got it anyways. I probably will get it.	Expressed resignation about inevitability of his diabetes diagnosis because it is widespread among his family members.	Diabetes induced grief
7. It [diagnosis] was shocking. I think my wife too it more than I did. It was very difficult for her but, you know, because I know it would require a lot of change. Maybe it's time for a life change. I don't know.	Description of his and his wife's emotional reaction to the diabetes diagnosis. He knew that their reaction was related to the lifestyle changes that accompany such a diagnosis.	Diabetes induced grief
8. He [doctor] told me at that time that I would have to go to the adult daycare centre which didn't thrill me. I didn't know exactly what it was but it didn't sound very nice.	Physician directed his care by referring him to diabetic daycare clinic. Mark was angry and uncertain about function of clinic in his care.	Diabetes induced grief
9. It [referral to diabetic clinic] was ...well you mean I can't take care of myself. There wasn't an explanation of what the adult day centre was. It was only you gotta go there...I thought I had to go and see a psychiatrist...you know something in psychiatric daycare where they sit around and smoke all day...What am I supposed to do here?	Explanation of his emotional reaction to the doctor's referral to the diabetic clinic. This reaction was filled with apprehension and confusion as he thought the daycare centre was a psychiatric clinic. The relevance of the diabetic clinic was not made clear to him.	Diabetes induced grief

Excerpts from Transcribed Interviews	Two levels of Abstraction	
	1. Paraphrases	2. Themes
10. The hospital never called and never called and you know you've got to go to the hospital and you know it was bad, you know we gotta get some help here and all I had was this one paper.	Description of his anxiety during the waiting period between the time of diagnosis and attending of the diabetic clinic.	Education crucial to treatment plan success
11. The doctor told me he was going to make the appointment which you know you trust your physician to go ahead and do that but then there was never any follow up. Why hasn't the hospital called? What's going on here? What am I supposed to be doing in the mean time? then it was very confusing [and] frustrating.	He trusted his physician to make arrangements for him to attend the clinic and when that took a long time he became frustrated and confused about his course of action and even if he should trust his physician at all.	Education crucial to treatment plan success
12. I know this sheet [diet sheet] I had received...wouldn't do me. I have to know what I can and cannot do. I can't always, I guess I can be disciplined enough to live by that if that was the only thing that I could do but I know there's other things I could do. I didn't know what I could do.	His anxiety was related to his need to learn about his diabetes management and specifically what alternatives existed to the diet sheet that he had originally been given.	Education crucial to treatment plan success
13. It was kind of shocking because you gotta get in there, you gotta get this taken care of quick because it's bad.	Anxiety and shock expressed about delay in attending education classes and an awareness of seriousness of situation.	Education crucial to treatment plan success
14. Yeah [to needing reassurance] you know you can live with this. You're not going to lose both legs tomorrow and that I could be disciplined enough to control this. you know you can have control over this. It doesn't have to have control over you.	Expressed his need for reassurance about his ability to take care of the diabetes and reassurance about the incidence of complications.	Education crucial to treatment plan success
15. I had constantly been seeing my doctor...and he was very pleased...but I didn't understand exactly what's happening but knowing if he's pleased...it must mean that I'm doing something right...a lot of trust right there.	Mark saw his physician repeatedly following his diagnosis and relied on him to direct treatment and to reassure him about his progress because he himself had limited knowledge about the diabetes.	Diabetes induced grief

Excerpts from Transcribed Interviews	Two levels of Abstraction	
	1. Paraphrases	2. Themes
16. It seemed like there was an awful lot given [information at the education classes] although they have a nice approach the repetition. It's not straight lecture. There's a lot of other things involved but there's still lots...but it was tough...everybody had their questions so I didn't get to ask my questions at times but I just listened to what others were inquiring ...because I had similar experiences.	Recognition that repetition and a variety of teaching techniques were key components to diabetes education classes. At the same time, he felt at times he could not ask his questions because of the other class participants. He found that experience frustrating even though some people had similar experiences to his own.	Overwhelm with quantity of information. Optimal learning conditions included intellectual, experiential and emotional components Identification with classmates as reference and support
17. Both my kids, they're teenagers, they got to attend a few sessions so that was really good because they could remind me of some things that I forgot...but it's still overwhelming.	Children's role in diabetes education was to remind him of information. This was particularly helpful because of the large quantity of information.	Support integral to wellbeing
18. It [education] was a lot to know. There's still a lot of things and I still have questions and I guess there are no answers...There's a big unknown that's sort of in the future. Who knows?	Admission that he still has questions about diabetes that are at this point unanswerable.	Worry about potential outcomes of diabetes.
19. I still have a hard time with the diet...the menu. When they brought out the rubber food (laughs) I looked at that stuff and it didn't mean anything to me because we don't eat [like that].	Expressed difficulty with the food part of the management plan. Foods shown to him not the same as his typical foods.	Personal relevance of education/treatment plan
20. There's a real element of uncertainty about other adjustments that have to be made. I still have questions now...Why do I feel this way? Is this diabetes or is this I'm just tired?	Uncertainty about current symptoms and specifically which are attributed to diabetes and which are not.	Worry about potential outcomes of diabetes.
21. Practically we're not gonna give up pizza in our life. That I've got to know can I have one, two, three or four pieces? What is the thing for pizza? and how do I figure that? I don't understand.	Inability to understand how to calculate pizza into his healthy diet guidelines.	Personal relevance of education/treatment plan

Excerpts from Transcribed Interviews	Two levels of Abstraction 1. Paraphrases	 2. Themes
22. It's still hard for me to understand exactly 30g of cheese...what's 30g of cheese? especially when you've got to grate it. How do you measure that? I don't understand that.	Difficulty in understanding and applying diet guidelines.	Personal relevance of education/treatment plan
23. The other thing is I wish they would have gone a little bit more into...I have allergies and there are certain things that I cannot buy now as a diabetic.	Desire for more information that was personally relevant.	Personal relevance of education/treatment plan
24. I think it's [family support] really a key thing. My family's fairly supportive. However they still don't sympathize in some ways and I realize they can have what they want too...this is what's hard you know.	His family's support of his diabetes treatment plan is important to him. Their support to him means their abstinence from foods that he can't eat and this is difficult for his family to do.	Support integral to well-being.
25. I think they've adjusted very well. They're living with a diabetic where I am the diabetic so that's the difference. They make adjustments for me but they're not me. They're very sympathetic but they don't understand.	Recognition that even though family members are supportive, the diabetes treatment plan is his and his alone.	Support integral to wellbeing
26. They'll [family] make popcorn, they like butter, they just smear it all over there...but I think why are they doing this? They don't need that.	Family members make unhealthy food choices which doesn't make sense to him given his new understanding of healthy food choices.	Concern for other's wellbeing.
27. My Mom has diabetes. She controls hers...My father also had it...He never did control his, took time or anything...My mother's brother had diabetes...and had both legs amputated eventually...you know those things play on my mind.	Several family members had diabetes and each had a variety of experiences with self-care, the consequences of which concern him especially as regards to outcomes of his own diabetes.	Worry about potential outcomes of diabetes.
28. Before it was, you go. I'm not going...now all 4 of us are out there walking so that's a change...we need to remember to do it and ...that this is our life. It'll probably help us all.	Description of family's change in attitude towards exercise and recognition of the permanence of change in lifestyle.	Permanent change in lifestyle requires attitude change and commitment. Support integral to well-being.

Excerpts from Transcribed Interviews	Two levels of Abstraction 1. Paraphrases	 2. Themes
29. I'm satisfied with what's happening right now. I guess perhaps I should go back in and chat more with the dietitian and find out exactly...how many calories am I getting?...I know having weight loss going on and it is ongoing and I'm pleased.	Satisfaction with current status of diabetes and his management of it. There was a general sense of well-being and a lack of urgency about his need to know.	Satisfaction with meal plan. Mastery of treatment plan.
30. My closet has small, medium and large in it and I'm making it into the medium bunch...so it [the weight] is moving so that is satisfying to me.	Steady weight loss satisfying to him and is a sign of accomplishment.	Mastery of treatment plan.
31. I was having low sugar reactions and I have a monitor that I'm taking and I know something's happening and Oh it's a 3-something and I don't know who to call.	Lack of clarity about who to contact when documented low blood sugar reactions occur.	Education crucial to treatment plan success
32. I realize you take sweet...There's something wrong that's causing to go so low. I realize that from the lectures...I contacted the hospital...[and] I contacted my doctor...he's taken me completely off the medication...I guess that was the answer but I...need to be told that and I guess experience is maybe the best teacher. I had to go through it to understand.	Course of action to treat low blood glucose levels understood on an intellectual level but experience necessary for him to apply that information.	Experiential learning paramount and demanding of time and effort.
33. The administrator [at his work site is unsympathetic]. When I asked for time off...he ...said no, you're not sick...I said I have to go to the hospital...He says but you're not sick and I said but I have diabetes...I said I'll have this all my life...he called the hospital and found out that the name of the class was diabetic education so he denied me sick time because it's education.	Description of unsympathetic and unsupportive work boss particularly pertaining to Mark's need for diabetes education.	Frustration with unsympathetic work boss.

Excerpts from Transcribed Interviews	Two levels of Abstraction	
	1. Paraphrases	2. Themes
34. I had to file a grievance and I guess it'll be heading towards arbitration...In the meantime, I'm out $500 which is...you're supposed to have less stress so it's tough...Summer is out lax time of income and not having half my salary for the month is really...a big hunk out.	Frustration and stress with reduced income resulting from his attendance of diabetes education classes.	Frustration with unsympathetic work boss.
35. I think the famous personalities [like] Mary Tyler Moore...she's been the butt of a lot of jokes. Here she is, she's 40, she has diabetes and she's divorced twice...Everybody laughs and well this is really not funny...I mean there's nothing to laugh at. She probably has it under control.	Experiences of famous personalities who have diabetes demonstrate ignorance and unfairness of general public about diabetes.	Frustration with the ignorance and lack of others' discernment
36. It's [diabetes] is very stressful...No wonder there's family problems. You know it's really is quite stressful.	Recognition that stress of diabetes can adversely affect family relationships.	Frustration with the ignorance and lack of others' discernment
37. I feel like I do have a...trusting relationship with...my doctor. However, sometimes I wish there was more of a...free-er exchange of information...I think he's quite knowledgeable...and it's the thing of blame...maybe he should have monitored me better knowing all my history.	Eloquent description of his attempt to reconcile himself with the fact that his doctor did the best he could with regards to his medical care. There was an element of doubt the his physician did not do all he could to prevent incidence of diabetes.	Diabetes induced grief
38. Maybe I'm just looking for other areas to say I didn't have to do this...it's probably still some anger and acceptance of going through.	Admission of anger for having lifestyle change foisted upon him resulting from diagnosis of diabetes.	Diabetes induced grief Permanent lifestyle changes require attitude change and commitment
39. I try to keep a record of what is happening...I have a little bit more scientific ideas and background and I would like to see how you do this. How do you graph this out when you're finished other than here they [blood sugars] are.	Explanation of his learning needs which include more scientific explanations than those he received.	Optimal learning conditions included intellectual, experiential and emotional components

Excerpts from Transcribed Interviews	Two levels of Abstraction	
	1. Paraphrases	2. Themes
40. I try and space my times [for blood testing]...you know just to understand some other things that are happening but I think the understanding is still [lacking]. I think you have to do it to understand it, to really know what's going on and that's difficult.	Description of his need to understand reasons for blood glucose fluctuations. He recognized that experience is a better teacher than intellectual understanding and this was difficult for him to accept.	Experiential learning paramount and demanding of time and effort.
41. I guess it [understanding] all comes with time, knowing where to hit [blood testing] and how to hit and it's still frustrating to me to put [blood] on the tab and have the machine say nothing happened. You got to do it again. That's frustrating.	Frustration with lack of mastery of blood glucose testing technique and a recognition that experience will facilitate mastery.	Experiential learning paramount and demanding of time and effort
42. That's a buck you're throwing in the garbage...It's too much money to throw it away. You gotta do it right the first time and I find that a little annoying but it's knowing how to do it...is to experience it.	Frustration with costly mistakes with blood testing method. He had the expectation that he would be able to do blood glucose testing accurately the first time. He also recognized that experience will facilitate mastery.	Experiential learning paramount and demanding of time and effort.
43. I find people in sympathy but not understanding. I have been given sugarless candy with sorbitol, this sort of thing.	Experience of people's sympathy with his condition unhelpful because of their lack of discernment about diabetes.	Frustration with the ignorance and lack of other's discernment.
44. She [his wife] says well my mother cooks with this [fructose]...so people are very helpful and they're not helpful. I can't have this. This is one of the -ose family. We have a bag of fructose that is sitting there waiting to be used up...perhaps some education would be helpful.	Recognition that people's lack of discernment is related to their lack of knowledge about diabetes and his treatment plan.	Frustration with the ignorance and lack of other's discernment.
45. The fellow that I was travelling with is a diabetic also so it made it really easy to kind of spar off on each other.. it worked out really well and I could see someone else in action that has lived with it.	Seeing and experiencing another diabetic and his management of it helped to reinforce his own treatment plan and reassure him of his ability to live with his diabetes.	Mastery of treatment plan. Support integral to wellbeing.

Excerpts from Transcribed Interviews	Two levels of Abstraction 1. Paraphrases	 2. Themes
46. That [malibu chicken in restaurant] was a good lesson for me...I won't eat the malibu chicken anymore...so how to avoid that? I don't know. I guess to ask for the chicken without the sauce...so that was quite an experience for me.	Eating out experience was a test of his ability to make healthful food choices.	Mastery of treatment plan.
47. I had some things on my leg. I don't know where it came from...Oh no they told me I'd have feet trouble...it was just a terrible thing and I thought good grief...am I gonna lose my leg? and I see what they mean you do have to take care of it.	Discussion of foot care in classes became personally relevant after his own experiences with scratches on his leg. This led him to worry about the potential loss of his leg.	Personal relevance of education/treatment plan. Worry about potential outcomes of diabetes.
48. I'm not monitoring my blood like I was because it seems to be level...When I get that...anxious feeling I think...it's time to eat...Go in...and see what you can eat without destroying anything and that you can handle at this time and you know it seems to subside.	Description of his current handling of low blood glucose reactions in which he casually consumes some food and does not rely on blood glucose testing.	Mastery of treatment plan.
49. I got my walk in on Monday which I was really pleased and then on Tuesday...we walked through there [huge store] you know up and down the aisles, so I actually got my exercise in on Tuesday too so I was really pleased.	Satisfaction expressed with maintaining exercise regimen while away from home and usual routine.	Mastery of treatment plan.
50. My family was also doing exercise [in his absence]...so it was really good and so we;re still in the groove and we're trying to turn that future outlook for us like this is gonna be our life.	Satisfaction expressed with family's maintenance of exercise even in his absence. He also recognized the gradual and permanent change in attitude towards exercise.	Permanent lifestyle change required attitude change and commitment.
51. I think there is a more calming thing right now...the crisis is not, It doesn't seem to be a crisis situation. It can be handled.	Expressed comfort with current situation which is no longer in crisis.	Mastery of treatment plan.

Excerpts from Transcribed Interviews	Two levels of Abstraction	
	1. Paraphrases	2. Themes
52. [When I have a low blood glucose reaction] I have a headache...it feels like I'm exploding so I compare it like a migraine. It just feels like it's popping on the top of my head and on my temples especially...I go like this [rubs temples] and try and get relief. It just feels like a fight going on behind the eyeballs...I've almost experienced like a chill. I thought I was trembling but I didn't see a tremble. I can hold out my hand and see a twitch but I can't see a tremble. My hands...felt kind of prickly numb...around my mouth it was like prickles around my lips...but the biggest indicator that I need to eat. I just feel this urgency that I've got to eat something.	Description of low blood glucose reactions which are unpleasant and involve a throbbing headache, numb sensations in his hands and around his mouth and an urgency to eat.	Experiential learning paramount and demanding of time and effort
53. I have a friend that was diagnosed with diabetes almost to the date a year earlier...and he went through a program...however he's not in control at all...so I said you've got to see a doctor...he's got to be in control...and he's a nice man...like why is he doing this?	Description of his friend's experience with diabetes which showed that his friend is not in control of his treatment plan. Mark was unable to understand this as he himself is very aware of the risks associated with diabetes management.	Concern about others' wellbeing.
54. I think I have other strong motivations. It's nice to have the accountability there just t give me the feedback that I need...However nobody is holding my hand through the meal plan and the exercise...so I have those things fairly well in my control.	Recognition of motivational value of repeated visits to his doctor and a recognition of other motivational factors that help him to maintain the eating and exercise plans.	Extrinsic and intrinsic motivation necessary
55. It [motivation] wasn't necessarily the knowledge that I gained from the classes but the knowledge of what's happened before you know with my uncle's dying...the knowledge that this is serious and don't mess with it.	His motivation to adhere to his treatment plan was derived from the knowledge of his uncle's negative experiences with the diabetes and the fear that he may also have those experiences in the future.	Extrinsic and intrinsic motivation necessary.

Excerpts from Transcribed Interviews	Two levels of Abstraction 1. Paraphrases	 2. Themes
56. I think I can be strong and say this is my time and I must do this...or I must stop now without having that particular dessert...I think I'm strong enough to do that but there are those pressure times that do come and I don't know if I could [remain strong]. I think I could do that.	Recognition of strength he will have to have to maintain healthy lifestyle choices. He was concerned about losing that strength in stressful situations.	Extrinsic and intrinsic motivation necessary
57. The future is difficult to forecast and I'm sure I'll have the grace to go through a heart attack or a stroke or kidney loss or whatever might happen but it's still [frightening]. If I can avoid those things, I'd like to avoid them and [a healthy lifestyle is] a good motivating thing for me.	Anxiety about the future alleviated somewhat by his recognition of the spiritual strength that he has. He also recognized that the motivation to follow healthy lifestyle guidelines is derived in part by his desire to avoid long term complications of diabetes.	Personal responsibility for self-care Extrinsic and intrinsic motivation necessary
58. Through the years I've just tried to eat good old food..We do have some artificial sweeteners...but we've never used the stuff...because it's artificial food. It's not real food, you know so why are we eating this stuff?	Questioned the value of consuming artificial foods that seem to be recommended by diabetic clinic staff. These foods are radically different from those he has tried to consume over the years.	Personal relevance of education/treatment plan
59. The explanation about the production of insulin and why it is important in the process of food so I didn't understand [this before]. I know people had these insulin shots but why is that important for them to go ahead...so I think that was the most important...information that I gained.	Comprehension of function of insulin action the metabolism of food was the most helpful information gathered from the education classes.	Personal relevance of education/treatment plan.
60. I may have had the knowledge because I knew they had heart attacks. I knew they had amputations but I didn't know why...OK so now I understand so it was very important for me. Others in the session may not have picked up on that but I did.	Comprehension of physiology of diabetes and its relationship to development of diabetes complications enhanced personal relevance of treatment plan.	Personal relevance of education/treatment plan.

Excerpts from Transcribed Interviews	Two levels of Abstraction	
	1. Paraphrases	2. Themes
61. I have my log I've been keeping my blood monitoring in so I've also included a column on there and I keep track of my weight and I've also been taking my blood pressure every night so I have other information on hand that I can look at and see [whether] things are settling down or not.	Explanation of his method of keeping track of his treatment plan. This method includes blood monitoring, weight checks and blood pressure checks.	Personal responsibility for self-care.
62. I experience things I think all of us learn as we take it into our minds through our heads and through our experience, so it requires bodily doing through the activity. The health educator could talk all day long but until we experience it, we won't be able to do it.	Explanation of experiential learning for real learning to take place.	Experiential learning paramount and demanding of time and effort.
63. It's not just the lecture. I don't think that would have done it either and of course the emotions were involved because it's my life and I have to do this and in my mind I knew I had to do this and I was anxious to learn it so that's a little motivating to get this down. You know, you'd better understand this.	Involvement of emotions was crucial for him to learn the materials taught. Experiential and intellectual learning and emotional involvement all necessary for optimal learning.	Optimal learning conditions include emotional, intellectual and experiential components.
64. The way she's [CDA representative] it was a gearing towards education of the public and maybe that's what we really do need...but right now my focus at this particular minute is what I'm doing and what is the diabetic association doing for me? It's not like a support group of AA...where you go in and say Oh this week I had such a hard time I took a candy bar...so I have questions on how that functions.	CDA representative implied need for education of public about diabetes and implied that class members had the responsibility in assisting in this function. This was not relevant to him at the time because of his own need to concentrate on his own learning and mastery of treatment plan. This led him to question the value of membership in the CDA association.	Personal relevance of education/treatment plan.

Excerpts from Transcribed Interviews	Two levels of Abstraction	
	1. Paraphrases	2. Themes
65. I don't feel like I can give a lot of time to educate the public right now...I just don't feel like I can fund raise...I don't need a support group...to hold my hand through this so I don't think I would seek them out for that area. I think the area I would want is the information...because they do have a publication.	Statement of what he wants from the CDA which consists of information about diabetes and its management and not public education or fund raising or a support group.	Personal relevance of education/treatment plan
66. There were a few names mentioned [at the clinic] and perhaps these individuals have given their permission...that their names are going to be mentioned...I found that a little shocking and I thought am I going to be the next topic of conversation? I don't walk the streets...with a big D on my chest so why would that information be given to anybody else?	Expressed shock at lack of confidentiality of clinic staff about their various patients. He also expressed a worry that his name would be similarly mentioned indiscriminately.	Support integral to wellbeing.

Table 2

Thematic Clusters of Mark's Diabetes Experience and Generalized Description of Clusters.

Thematic Cluster	Generalized Description
<u>The psychological reaction to diabetes</u>: includes themes: Diabetes induced grief 1, 2, 3, 4, 5, 6, 7, 8, 9.	Prior to the diagnosis of diabetes, Mark was feeling physically unwell. Despite the strong family history of diabetes and his fear of developing diabetes, he attributed his symptoms to aging and to the stress he was experiencing at work. This was his attempt to deny the diabetes. Upon diagnosis, Mark and his wife experienced shock and anger. He directed his anger at himself and he began to feel guilty about his weight gain which he believed precipitated the diabetes. His anger was most obvious when his physician referred him to the diabetic clinic. At that time, he questioned the relevance of the clinic to his personal situation. In addition, he had little information given to him about the clinic and its purpose or function in his diabetes management.

Thematic Cluster	Generalized Description
Learning to cope with diabetes depends on his education and significant others around him: includes themes, Education crucial to treatment plan success, overwhelmed with quantity of information, personal relevance of treatment plan, optimal learning conditions include intellectual, experiential and emotional components, experiential learning paramount and demanding of effort and time, frustration with unsympathetic work boss, frustration with ignorance and lack of others' discernment, significance of educated support. 10, 11, 12, 13, 14, 15, 16, 17, 19, 21, 22, 23, 31, 32, 33, 34, 35, 39, 40, 41, 42, 43, 44, 45, 47, 58, 59, 60, 62, 63, 64, 65.	Once Mark became aware of the need for his education about the diabetes and its management, he became anxious to receive that education and was frustrated with the time wasted waiting for that education to take place. During that time, Mark relied on his physician to direct his treatment and felt helpless because he himself did not know or understand much about the diabetes. He believed the situation to be urgent most likely because of his extended family's experiences with diabetes. He experienced a very unsympathetic even antagonistic boss who made it more difficult for Mark to attend the diabetic clinic because he denied him sick pay. Mark identified his boss' lack of knowledge about diabetes as the cause of his frustration. His friends and family were similarly uneducated about it. These people however were very sympathetic and attempted to be helpful but in actual fact this caused him additional stress because of his attempts to placate them. He identified his family as needing education about the diabetes and its management as well as himself. He identified his learning needs. He wanted the information to be personally relevant and he assessed the usefulness of any information given to him on the basis of its relevance to his life circumstances. He identified experiential learning as the most significant teacher and this was the most difficult to master because it required practice. He also identified that he required rational explanations for courses of action that were recommended to him. He described his need for emotional commitment and involvement in the experiential and rational learning endeavours.

Thematic Cluster	Generalized Description
Adaptation to life with diabetes ;includes themes, support integral to well being, concern for others' well being, permanent lifestyle change requires attitude change and commitment, satisfaction with treatment plan, mastery of treatment plan, worry about potential outcomes of diabetes, extrinsic and intrinsic motivation necessary, personal responsibility for self-care. 18, 20, 24, 25, 26, 27, 28, 29, 30, 36, 37, 38, 45, 46, 47, 48, 49, 50, 51, 52, 53, 54, 55, 56, 57, 61, 66.	Mark's course of adaptation to life with diabetes was marked by his need for his family's support which to him included the whole family's involvement in the exercise and eating plans. He described that initially he wanted to blame his physician for the incidence of his diabetes and he expressed an eloquent desire for life without the diabetes. As his knowledge about the diabetes increased, he exhibited a greater concern for other people's well being especially those with diabetes or those who seemed to engage in behaviours that placed them at higher risk for developing diabetes most notably his children. He repeatedly described his worry about the potential of diabetes complications as an outcome of his diabetes management. In fact it was this worry that motivated him by and large to stick to his strict treatment plan. He acknowledged that his greater knowledge about the diabetes also helped to motivate him to stay with the treatment plan. Mark expressed satisfaction with his treatment plan and his mastery of it even though low blood glucose reactions were markedly unpleasant. He demonstrated that even though he appreciated the support offered to him by his family, he was personally responsible for the success of his treatment plan. He recognized that he had the spiritual strength to endure the suffering caused by any complications. He expressed a deep need for confidentiality and a concern that the particulars of his medical condition may be indiscriminately discussed in the community.

Synthesis of Mark's Diabetes Experience

The diagnosis of diabetes occurred after a period of physical illness and a significant weight gain. Shock was experienced by both spouses. In addition, the individual experienced guilt and frustration related to his carelessness in caring for his health which he believed played a role in precipitating the diabetes. This frustration was augmented by a lengthy delay before he was able to receive any diabetes education from the diabetic clinic. That delay time was fraught with tension and worry when the individual reflected upon the possible negative outcomes of his diabetes, particularly those similar to what members of his extended family had experienced.

During the waiting period, the individual expressed a helplessness about his self-care which was directly related to his lack of knowledge about the diabetes management. He relied upon and was forced to trust his physician to direct his treatment. Coping with diabetes depended upon the education of a number of people beginning with himself and his family and extending out to his friends, colleagues, and those in his work environment. Some of these individuals were very sympathetic and supportive such as his family members while others were unsympathetic and unsupportive such as his work boss.

The value of educated support became clearer to this individual as a result of these experiences because it was through the efforts of others who were similarly educated about his diabetes management that this individual believed he was able to maintain the necessary positive outlook and motivation towards the restrictive lifestyles measures.

The individual was able to clearly identify his learning needs which included intellectual and experiential components. Of these two components, the individual believed that the experiential dimension was far more relevant. In addition, the individual identified the need for his emotional commitment towards the knowledge about the diabetes management. This commitment was paramount in following through with the prescribed lifestyle changes. In addition, the individual expressed a need for reassurance and support and a deep desire for confidentiality.

Adaptation to life with diabetes was marked by periods in time when he expressed a desire for a life without the diabetes and a desire to blame his physician for the incidence of the diabetes. These periods gave way to a gradual adjustment of the whole family towards the new lifestyle and his sense of mastery and satisfaction with the treatment plan.

During the adaptation period, the individual began to express concern and worry about significant people in his life who, because of their lifestyle choices, may be at a greater risk for developing diabetes or its complications. These people included his children, and friends; one of whom was also a diabetic. His worry about potential adverse long term complications was the greatest motivator for him to remain committed to his treatment plan. The period of adaptation concluded when this individual realized that even though the support of his family and health professionals was imperative, he was personally responsible for his treatment plan.

Margaret

Personal Information. Margaret is 59 years old, married, and lives with her retired 71 year old husband. This is her second marriage. She has three grown children and several grandchildren. Both she and her husband spend six months of the year in Arizona where she teaches ceramics and her husband golfs. They live in a small condominium with a full basement. The basement contains her ceramics workshop where she often spends time alone.

Margaret described herself as the primary person concerned with meal preparation activities including the shopping and the cooking. She also has the major homemaking responsibilities. Prior to her diabetes diagnosis, her major life stressor was her husband's ill health. He suffered from several serious bouts of heart disease, a stroke and a case of pancreatitis which almost killed him. Generally, Margaret stated that they had no financial difficulties and they enjoyed a relaxed lifestyle with lots of restaurant eating and socializing.

The diabetes was a total shock to Margaret because there was no previous family history of the disease. She had no experience with the disease except for a close family riend who had Type 1 diabetes for about 30 years. Once she was diagnosed with iabetes, this friend became a source of significant support and guidance for her. She ften questioned him about food and long term complications. He had been quite uccessful in his diabetes management and was free of long term complications. This rovided Margaret with hope for her own complications-free future.

Margaret was slightly overweight as was her husband. With the exception of the ccasional walks with an aging dog, they led a predominantly sedentary lifestyle and with ie exception of the stress related to her husband's ill health, Margaret described their festyle as comfortable and relaxed.

Generally, Margaret found her children to be unsympathetic with regards to her iabetes and its treatment demands. They often expected her to prepare foods for them id their offspring that were unsuitable for her consumption. She found this quite ressful. In addition, she chose to shield her husband from the full implications of the iabetes because of his ill health. As a result, she had little to no family support.

Table 3
Thematic Abstraction of Margaret's Diabetes Experience

Excerpts from Transcribed Interviews	Two levels of Abstraction	
	1. Paraphrases	2. Themes.
1. I was sick all winter...I had achy joints, my mind would go. I couldn't think straight. I was irritable with people...I was sick to my stomach and I couldn't keep anything down. I lost 22 lbs and that was just nerves or something...I thought I had a brain tumor...I was just wiped right out.	Description of her prolonged suffering leading up to the diabetes diagnosis. This included weight loss, sick stomach, dizziness, inability to concentrate, irritability and fatigue. She attributed these symptoms to poor nerves or a brain tumor.	Diabetes induced grief
2. I went to the doctor...he ran the blood tests and...not two days later he says, you'd better get in here, you got diabetes...so I went...thinking that this brain tumor had showed up and he said you got diabetes. He said that's no problem, we'll get it straightened out.	Description of her diagnosis during which time she believed that the brain tumor had become a reality.	Diabetes induced grief
3. We used to eat out a lot...now when we're going downtown, I think well where would we go?...I'd rather come home and eat something I know I can have and I can feel comfortable and enjoy what I'm eating rather than worry well what they've put into it.	Recognition of the difference in her lifestyle as a result of the diabetes specifically with regards to eating out. Her concern about the suitability of restaurant food has led her to choose to eat more of her meals at home.	Permanent lifestyle change required attitude change and commitment
4. I wanna stay home. There's security here. It's stupid when you think about it cause you're taking your two pills and you can go downtown...but I feel better at home. I don't look any different. People don't know you've got diabetes...I don't know what it is. I just don't have the confidence is what it is. Maybe that something could happen...I don't even wanna go south this year.	Recognition that her sense of security and self-confidence has been shaken as result of the diabetes.	Diabetes induced grief

Excerpts from Transcribed Interviews	Two levels of Abstraction	
	1. Paraphrases	2. Themes.
5. At first I was taking it [blood testing] 4 or 5 times a day cause I wanted to find out when I was high and when I was low and what I was doing wrong and finding out if exercise was helping or did it matter what I eat...then if I'm running high for quite a while, I start testing 3 times a day.	Description of her process of discovery of how food and exercise have affected her blood glucose levels. She described a curiosity about how well the blood glucose levels were being managed and what she could do to keep track of them if they weren't in a reasonable range.	Personal responsibility for self-care. Mastery of treatment plan.
6. I can get feeling better or I can get feeling not so good. In these classes we took, it's up to the individual and each person's different...and I feel it's up to me if I want to get feeling better.	By attending the diabetes education classes, she realized that it was up to her to manage her diabetes.	Personal responsibility for self-care.
7. We maybe go out once a week...[like] roast beef at the Bay...I know that leave the gravies off and I'm OK. I can have that and I enjoy it.	Awareness of her ability to select appropriate foods in restaurants while still following diet guidelines.	Mastery of treatment plan.
8. I was even told that with strict diet, I could possibly come off the pills...within a year or so if I really work hard at it and that gave me something to work for. This time I can't see myself living without the pill cause...I'm not leveling out that easily. It's up and down but she said if you work really hard, it's possible to come off that pill or lessen it...I don't look forward to ever taking insulin and so that alone will keep me on the straight and narrow.	Educators informed her that through strict following of the diet, a reduction or elimination of her medication might take place. She viewed this hopefully despite the improbability of this because of the fluctuating blood glucose levels.	Hope for positive future. Extrinsic and intrinsic motivation necessary
9. At night...I just like my cereal and I know that's what's driving it up in the morning...when I go to bed at night it's low, now what do I do?...I have to have something because it's quite low before I go to bed and then I take a pill as well so I gotta get together. It's been better this week cause I've been working on it trying to find out if I can have one cracker...or ...four.	Recognition that food choices have affected blood glucose levels and dilemma about what to eat at bed time to avoid high blood glucose levels the next morning.	Personal responsibility for self-care. Mastery of treatment plan.

Excerpts from Transcribed Interviews	Two levels of Abstraction	
	1. Paraphrases	2. Themes.
10. It gets depressing because you think you're doing everything right, you go for your walk and you come back and test and you're a 16.5 and you just wanna cry cause you've done everything right. It gets depressing. I find myself very depressed.	Frustration and depression result when blood glucose levels don't normalize despite her adherence to the treatment plan.	Diabetes induced grief Experiential learning paramount and demanding of time and effort
11. He's [her friend Bill] lived with it...for some 30 years...and it helps to see him and I know if I've got 30 odd years left, great because I'm pushing 60...there's hope that I'm not gonna die in the next 2 or 3 years because of this.	Bill's longevity and positive experiences with diabetes have provided her hope for a similar outcome of her diabetes.	Hope for positive future.
12. They[her family] don't realize...how very serious it is [diabetes] or it can be and some people....don't have vision impairment . They don't have sore legs and sore joints like I get if I run too high or too low...so it's not serious, you're only a two.	Family support for her diabetes absent because of their ignorance about the consequences of diabetes. The appear to have made light of her suffering.	Support integral to wellbeing Diabetes induced grief
13. My husband realizes. He's pretty good. He helps me a lot. He knows when I'm down...He knew something was terribly wrong.	Description of husband's supportive role.	Support integral to wellbeing
14. He came to one [class], the one I wanted him to come to...and he was fighting a battle for himself. Every year, around September the first, his birthday, he ends up in the hospital, and I knew he was under stress. He had his heart attack 2 years ago. Last year he had pancreatitis. I nearly lost him again and I didn't want to stress him out...He's pretty supportive with me. He'll do the dishes and yeah, he's a good man.	Description of her anxiety about her husband's health and how she has shielded him from most of the education classes for fear of worrying him excessively.	Support integral to wellbeing. Significance of educated support

Excerpts from Transcribed Interviews	Two levels of Abstraction 1. Paraphrases	 2. Themes.
15. [The purpose of the classes] is to understand yourself and what you got and the way you have it. Like there's people there who took insulin that would go out there and have a sundae and go back and take a shot of insulin and that is you;re killing yourself as far as I'm concerned, who are you fooling?	She described the purpose of the education classes as a way for her to understand her diabetes and how to best manage it. She expressed disgust with people who took their self-care lightly by administering extra insulin to cover diet indiscretions.	Personal relevance of education/treatment plan. Personal responsibility for self-care.
16. I knew nothing about diabetes. The doctor don't tell you anything...He just says take these classes...Here's the pill...I mean he's not...into it like they are [educators] they had so many stories to tell of people...that died or lost limbs...and things that were almost unbelievable...[I thought] she's making this up but they showed pictures of things that can happen...and I think everything she said registered to me.	Recognition of the difference in information dissemination between her physician and the diabetes educators. The physician directed her towards the clinic and prescribed the medication while the educators personalized the treatment plan for her and made her aware of potential adverse complications.	Personal relevance of education/treatment plan. Worry about potential outcomes of diabetes. Significance of educated support.
17. You think about it [the diabetes] but then again when you start worrying about it, you know, it's in my hands. I've gotta do something about it. It's up to me to stay on this diet and to exercise and eat proper foods and if I do everything in my power then it's gonna work for me and I gotta think that way.	Margaret worried about potential adverse outcomes of diabetes and comforted herself with the knowledge that she has control over the incidence of those outcomes by following the treatment plan very closely.	Worry about potential outcomes of diabetes. Extrinsic and intrinsic motivation necessary
18. I wanna live and I wanna live without taking insulin as long as I can. Also I think a big thing was the classes...Those voices are in my head and they echo. It's up to you. If you went on this strict diet, you could come down and take less pills. You could cure yourself more or less I say cure.	She expressed reasons for her motivation which included staving off the need for insulin as long as possible. This message was reinforced in the classes.	Extrinsic and intrinsic motivation necessary. Personal responsibility for self-care. Hope for positive future. Significance of educated support

Excerpts from Transcribed Interviews	Two levels of Abstraction	
	1. Paraphrases	2. Themes.
19. There's no diabetes in the family whatsoever...I don't know if I'll hand this down to my kids..yet I've got this so maybe it's the way I've lived. It's stressful. It just happened to me.	Eloquent attempt at understanding why the diabetes happened to her when there was no history of it in the family. She suspected that it was due to her lifestyle.	Diabetes induced grief
20. I don't like it, it gets frustrating. I'll tell you what gets frustrating is to diet and to work hard and do without and do without and for a walk and Oh I've only been 20 minutes, I'd better make it an hour today and keep walking and come home and get a reading of 18.5 I could sit down and cry cause...I think why have I gone through all this and I'm still an 18.5	Frustration with high blood glucose levels that don't respond to prescribed lifestyle behaviours such as following the diet and exercise plans.	Experiential learning paramount and demanding of time and effort Personal responsibility for self-care.
21. They say a number 2 is not that serious, well, God I don't know how a number 1 feels if they have mood swings like mine and they feel as lousy as I feel sometimes, they must feel terrible cause I just don't feel that great most of my time...so a 2 is serious.	Frustration with nonchalant attitude expressed towards individuals with Type 2 diabetes.	Frustration with the ignorance and lack of others' discernment.
22. I'd sure like a refresher every year. I think it'd be great. A two hour lecture from [the educator], man I think that was just great, bring all the crew back and see how they're all doing.	She expressed that a refresher class with her former classmates would help to motivate her.	Extrinsic and intrinsic motivation necessary. Concern for others'classmates.
23. It's just up to me to work with what knowledge I have. If I was ever stuck I would certainly phone up there. I would make no qualms at all..and I know she'd [educator] would say you come on up and let's have a look at it. I know that. They're there...They're terrific people...They're on the ballgame of what's what and they know what you can do and what you can't.	Recognition of her personal responsibility about her self-care behaviours and a realization that the diabetes educators would support there if she had problems. She expressed her faith in them.	Significance of educated support Personal responsibility for self-care

Excerpts from Transcribed Interviews	Two levels of Abstraction 1. Paraphrases	 2. Themes.
24. [The diabetes] helps the people you're cooking for because they're not taking the sugar in like they would be normally...My kids I've also told them, cut back on the sugar and my daughter has a baby who's 18 months and she doesn't get any sugar other than natural stuff. Now's the time to watch it. Why push it?	She now has an enhanced awareness and concern for her family's wellbeing. She educated them about the diabetes and how to avoid its incidence.	Concern for others' wellbeing.
25. He'd [husband] gone to the doctor's...and I had worried about it so extremely. The day he went into the doctor's, I walked the floor here not thinking I was really worried but then on the meter reading a 22 and then I run high for about 3 days. I was trying to figure that's what it was, once they explained that this is what can happen.	Explanation of the connection she made between the stress she experienced as a result of her husband's ill health and her high blood glucose levels.	Experiential learning paramount and demanding of time and effort
26. They [other people] seem more concerned cause they don't know about it so they ask questions, they'll say well how are you feeling today or...you don't look good today. You're pale or your eyes look tired or something. They seem more concerned than my own family.	Friends have been more sympathetic towards her than her family and they have expressed more concern for her well being.	Support integral to wellbeing

Excerpts from Transcribed Interviews	Two levels of Abstraction	
	1. Paraphrases	2. Themes.
27. Two years ago my husband had a heart attack and I started feeling funny then then the stress was very heavy and I thought I was gonna lose him...and I got feeling bad then. Well then a year later he came down with a bout of something else...so I nearly lost him again and they said they didn't think he was going to make it and I'm wondering would all that stress could that have brought this on? that's when I started feeling disorientated...I'm wondering if all that stress and not eating and not being able to figure things out...I'm wondering if that could have brought this on cause there's no diabetes in my family and that could have been the breaking point of it whatever goes on in the system and from then on, I was never normal again.	Reflection on events that may have precipitated her diabetes. These events included major stresses with her husband's repeated sever and life-threatening illnesses.	Diabetes induced grief
28. It [the diet] gets annoying after a while especially if it's something you like and you're hungry, see I don't eat breakfast. I eat a slice of toast which I don't even want but I eat it anyway and then...I have a light lunch. sometimes I could do without lunch but that's not good for me either...but I do like my evening snack which is very bad for me. I guess that's why in the morning...I'm high.	The rigidity of the diet is hard at times for her. Since her diabetes was diagnosed her eating pattern has altered such that now eats 3 meals and an evening snack which she suspects is to blame for her high blood glucose levels in the morning.	Frustration with complexity and rigidity of diet. Personal responsibility for self-care.
29. I had no idea at all how dangerous it really is and you tell somebody that you have diabetes and they say well are you on the needle, well no, I take pills. Oh well that's nothing and nobody understands.	Frustration with lack of understanding shown by public for her with her particular brand of diabetes.	Frustration with the ignorance and lack of others' discernment.

Excerpts from Transcribed Interviews	Two levels of Abstraction 1. Paraphrases	 2. Themes.
30. They [new diabetics] should go through that 4 week course...I mean there's no getting around it because...what will happen is you're gonna run into people like I was talking about at the BBQ. If they went to that course, there's no way they'd be doing that. There's just no way. They don't realize the damage. You just shorten up your life.	Recognition of value of education classes in enhancing each individual's personal responsibility for self-care and in raising awareness about the consequences of poor diabetes management.	Worry about potential outcomes of diabetes. Personal responsibility for self-care.
31. When I'm running high I get hyper...and I'm tired and at the same time...I keep going yet I'm tired. It's the craziest thing and I start hurting: my bones, my back, arms they hurt and I don't feel good and my head starts to kind of throb and I know I'm high.	Description of how she physically feels when blood glucose levels are too high. These symptoms are unpleasant and painful.	Diabetes induced grief
32. When I get low I get little speckles and weak and really tired. I know in the afternoon I gotta make me some supper when I get shaky like that...so I grab a chunk of celery while I'm making supper where before I would have grabbed a butter tart...I'm making my supper hoping I can get it into me before I go lower because it doesn't feel good. You get to a point where you don't wanna eat. You just wanna go and lay down that's it. You don't wanna eat and that's the worst thing you could do, you gotta get something in there and it happens as soon as you eat, it's just like a new person.	Description of low blood glucose reactions and how she has managed them. These reactions were unpleasant and involved weakness, tiredness and shakiness. Left untreated, she would lose interest in eating at all. Margaret has managed these reactions by attempting to eat foods that were part of her food plan. This was difficult to do. Once she has eaten, generally she has felt revived and refreshed.	Experiential learning paramount and demanding of time and effort Personal responsibility for self-care.
33. The dieting part [was the most important thing to learn] and how much [to eat] is one of the key things...I find it frustrating like they're saying half a cup, well half a cup this...because I don't like that stuff...in my mind I'm saying well why can't I have a cup of that cause I don't like this and it doesn't work that way.	Margaret expressed that learning about her food plan was the most important component of her treatment plan because as she described it, it was very frustrating to have only certain quantities of certain foods and unlimited quantities of other foods. She found it difficult and frustrating to comprehend this system of food breakdown.	Education crucial to treatment plan success. Frustration with complexity and rigidity of diet.

Excerpts from Transcribed Interviews	Two levels of Abstraction	
	1. Paraphrases	2. Themes.
34. At the hospital, they'll give you a food plan if you want one, but I was doing OK and once I got the charts saying what's what and how much sugar's in it and how much you can have per meal, that's all you need to have.	She expressed her satisfaction with her food plan and with her understanding of the foods that were recommended for her consumption.	Satisfaction with meal plan. Mastery of treatment plan.
35. The exercise part [was an important part of the classes] and how your body works...and about the eyes, the blood vessels breaking behind the eyes if the build up gets too great you can lose your eyesight and there's been so many documented cases...Feet, I knew nothing about that and that's very important and you know things like that I just don't connect with diabetes just give up sugar and you'll be OK well it doesn't work that way.	Margaret described what she learned and found valuable in the education classes. These items included information about exercise, blood vessels and feet and in particular, the relationship between self-care and the development of potential problems in these areas.	Personal relevance of education and treatment plan.
36. I think that every Oh say every 2 or 3 months they should have a little class to bring you in there like classes we had some kind of a...smartening up class, a class to refresh stuff you've learned just cover that cause it's gonna leave our minds and we're gonna push our diets.	She explained her need for a refresher class every 2 to 3 months to help her maintain her motivation to stay with the diet plan. She acknowledged that this need comes from the realization that she will push the limits of her diet plan.	Extrinsic and intrinsic motivation necessary.
37. They make it sound important. They tell you it's important and that voice [educator's] is gonna leave my mind eventually...you know you're living, they're living they're having a good time why can't I? and it's gonna leave that importance.	Expression of her concern that the importance of her treatment plan will leave her as she compares herself to others who seem to be enjoying their lives. A refresher program would help her to remember the significance of following the treatment plan.	Extrinsic and intrinsic motivation is necessary. Personal relevance of education and treatment plan.

Excerpts from Transcribed Interviews	Two levels of Abstraction	
	1. Paraphrases	2. Themes.
38. I gave a couple of them [classmates] my phone number and I gave them some recipes. They were a nice bunch. I'd like to know how they're coming along...It's up to them but are they gonna forget too?	She expressed an interest and concern for her fellow classmates with whom she identified. She wondered about their motivation to adhere to their treatment plan.	Concern for others' wellbeing. Identification with classmates as a reference and support group. Extrinsic and intrinsic motivation necessary.
39. Another thing which the other people and I had in common, the hands go to sleep or the arm will go to sleep, yeah I heard them talking, does you arm ever go to sleep? yeah they do...I think there was 4 of us with those symptoms.	Similar symptoms with other class mates made her reflect more on the symptoms and their causes.	Education crucial to treatment plan success.
40. Now if I get a headache, I wonder if my blood sugar's up or down, you know, you don't blame it on stress, you blame it on diabetes which is stupid...yeah everything goes to that, yeah that's why I got this, that's why my legs are sore, my arms ache.	Questioning and worry as to which of her symptoms were related to diabetes and which were related to other illnesses.	Experiential learning paramount and demanding of time and effort
41. I think I've aged 10 years in the last year...you see all the wrinkles now, I didn't have those last year and everything seems to be different.	Recognition that the diabetes has affected her such that she feels she's aged 10 years in one year.	Diabetes induced grief.
42. I think it's up to me. I think it's up to me [while crying].	Diabetes management her responsibility.	Personal responsibility for self-care. Support integral to wellbeing

Excerpts from Transcribed Interviews	Two levels of Abstraction	
	1. Paraphrases	2. Themes.
43. Even [boss] I worked for her all of last year...I said to her I can't do three classes this year. I can't work from 7 in the morning till 10:30 at night. I can't do that this year...I said I'm gonna have to cut back...and she says why? and I said because of my diabetes, I just get tired and it runs me down and I get too hyper and I can't sleep and she says well I don't understand that...[she said] when you work..it gets your mind off yourself...she really didn't sympathize with this. This diabetes is nothing. It's only you're taking a pill and that's it.	Recognition and frustration with unsympathetic work boss who seemed to think that she should work more to get her mind off herself and was unsympathetic to Margaret's stated need for more leisure time.	Frustration with unsympathetic work boss. Permanent lifestyle change required attitude change and commitment.
44. They're all longlivers [family of origin] and they don't have diabetes either. Of course my mom never drank or smoked in her whole life. Both of them were staunch Catholics. I guess they didn't do anything except work and be good mothers and wives...You know our generation is different...We're kinda rang a tang, there's a phase you go through and I'm divorced, left on my own with 3 kids to raise and there's a lot of stress there. If I was gonna be sick, I shoulda been sick back then but you go on and on and on...I suppose once I got on my feet...I ate and I enjoyed life, could have been [that that had caused diabetes].	Reflection on the reasons for her developing diabetes as there is no family history of it. She lived her life differently from her family whereas she enjoyed her life once she had been through her period of severe adversity raising 3 kids alone with little money and little help.	Diabetes induced grief.

Excerpts from Transcribed Interviews	Two levels of Abstraction	
	1. Paraphrases	2. Themes.
45. I kinda explain things the best I could [to family] but then I say why worry them?...like my mom phoned this spring and I hadn't even been able to go down to see a doctor, that's how bad I felt and I was just sick as far as I was concerned and mom says how are you feeling? and I said not too great. I said I worked hard all winter. I think I need a bit of a rest and when I got off the phone my husband said well what do you want to worry your mom for? well you have to have someone to talk to.	Eloquent description of her suffering related to the lack of her family support for her diabetes. She explained that she wanted someone to talk to about the diabetes.	Support integral to wellbeing
46. Experience, hands on...is the best teacher, reading it is one thing. It doesn't register till it's hands on.	Definition of her learning needs which include a preference of experiential learning.	Experiential learning paramount and demanding of time and effort.
47. Somebody cared. They [educators] cared even though they put thousands of people through that hospital... I still feel like they care and this is their job...because I know I could pick up the phone and I know they'd see me. That means a lot.	Description of her feeling cared about by the educators which has helped her to adapt to life with diabetes and to cope with it.	Significance of educated support
48. [Newly diagnosed people] have to take those classes at the hospital. I couldn't put into words in a 10 minute conversation what they have to know. They have to know all those things from their eyes to their feet...and not listen to other people. Not listen like they'll say it's only a two or they'll say I'm a diabetic too but I can have angel cake with ice cream every second day, don't listen to other people because everybody's different.	Her advice to newly diagnosed people with diabetes is not to listen to other people and to participate in the education classes which she found very helpful. She stressed the individuality of each person with diabetes.	Education crucial to treatment plan success Personal responsibility for self-care.

Excerpts from Transcribed Interviews	Two levels of Abstraction	
	1. Paraphrases	2. Themes.
49. [At] the BBQ that I went to, they're diabetics, they're doing exactly what they shouldn't. No way could I take advice from them or I'd be dead or in some kind of a coma, hypered all up. I can't live like that...How come they're doing that with diabetes? how can they function? I can't function when I'm too high or too low.	She expressed how incredulous she was about individuals who didn't seem to have the same level of commitment towards their self-care and in fact they acted in very self-destructive ways.	Personal responsibility for self-care. Permanent lifestyle change involves attitude change and commitment

Table 4

Thematic Clusters of Margaret's Diabetes Experience and Generalized Description

Thematic Cluster	Generalized Description
The psychological reaction to diabetes: includes themes, Diabetes induced grief 1, 2, 4, 10, 12, 19, 31, 41, 44.	Prior to the diagnosis of her diabetes, Margaret was extremely unwell. She endured this suffering, which interfered with her daily living activities, for several months before seeking medical attention. During that time, she believed that her symptoms were due to a fatal brain tumor. Once the diabetes was diagnosed, Margaret experienced some relief that this wasn't imminently fatal. However, she did experience grief and angst related to the lifelong nature of the diabetes and related to the complexity of its management as well as the loss of her former lifestyle. This was also related in part to the guilt she felt about the lifestyle she had led which had included overeating and enjoying life. This, she felt, had played a role in precipitating the diabetes. Also following the diagnosis, she began to feel the need for greater security including more time at home, and less of a desire to eat out or to travel. This was due to her diminished self-confidence in her ability to care for herself particularly given the complex treatment plan.

Thematic Cluster	Generalized Description
Learning to cope with diabetes depends on education: includes themes, personal responsibility for self-care, worry about potential outcomes of diabetes, personal relevance of treatment plan, frustration with complexity and rigidity of diet, education crucial to treatment plan success frustration with ignorance and lack of others' discernment, frustration with unsympathetic work boss, experiential learning paramount and demanding of time and effort. 5, 6, 9, 15, 16, 18, 20, 21, 23, 25, 28, 29, 30, 32, 33, 35, 37, 42, 43, 46, 48, 49.	Margaret's attendance of the diabetes education classes played a significant part in her coping with the diabetes. During the classes she became increasingly aware of her personal responsibility for her diabetes management. The classes also emphasized the potential adverse outcomes of diabetes if it were not well managed. This served to enhance her sense of personal responsibility. Comprehension of the information disseminated in the classes was dependent upon its personal relevance to her. In addition, she identified that experiential learning was her preferred mode of learning and it was the use of experiential learning techniques that facilitated her learning. She expressed that the diet information was the most significant portion of her treatment plan and that she found this portion of her treatment plan the most frustrating because of its complexity and rigidity. Related to the diet was her frustration with her blood glucose levels which often did not ameliorate despite strict following of the diet and exercise plans. She was very clearly aware of the importance of managing her diabetes well because of its relationship to the adverse long term complications. She was also made aware, as a result of attending the classes and her own life circumstances, of the proportional relationship between stress and elevated blood glucose levels. As a direct result of her enhanced knowledge, she worried about the relationship of any ill symptoms to her diabetes. Margaret appreciated the significance of her symptoms when she found they were also experienced by her classmates. This validated her own experiences. She expressed a frustration with others who were not as knowledgeable about nor as interested in her diabetes. These people included her boss and members of the public whose nonchalance made it more difficult for her to manage her diabetes.

Thematic Cluster	Generalized Description
Adaptation to life with diabetes: includes themes, permanent lifestyle change required attitude change and commitment, mastery of treatment plan, significance of educated support, support integral to wellbeing, worry about potential outcomes of diabetes, satisfaction with meal plan, extrinsic and intrinsic motivation necessary, identification with classmates as reference and support group, concern for others' wellbeing, hope for positive future, personal responsibility for self-care 3, 5, 7, 8, 9, 11, 12, 13, 14, 16, 17, 18, 22, 23, 24, 26, 27, 34, 36, 37, 38, 39, 40, 42, 45, 47, 48, 49.	The process of Margaret's adaptation to diabetes began with her attendance at the education classes where she became aware of the need for permanent changes in her lifestyle. This was an attitudinal change that involved making healthier food selections as well as making a commitment to regular exercise. Eventually she mastered her treatment plan and expressed some satisfaction with it even though she found the resulting low blood glucose reactions very unpleasant. She wanted her family's support but it was absent. This caused her frustration and grief. Despite this, her husband was somewhat supportive of her efforts at lifestyle change. However, because of his own ill health and her concern about him, Margaret chose to shield him from the full implications of her diabetes. By making such a choice, meaningful support was absent. Instead, she received support from her classmates, with whom she identified and from the educators who expressed an interest in her wellbeing. A long time friend also provided her with meaningful support. However, his recommendations and variations in blood glucose varied from those she had been taught so she found his support limited. Margaret identified her need for frequent refresher classes to help keep her motivated. This was also one way to stay in touch with her classmates. She also began to become concerned about others' wellbeing particularly as it related to their risk of developing diabetes. She stressed to her kids the importance of eating a healthy diet free of sugar. There remained times when it seemed to overwhelm her and she became depressed as she contemplated her future with diabetes. Despite this, she attempted to use positive self-talk in order to remain hopeful for a future free of diabetes complications.

Synthesis of Margaret's Diabetes Experience

This individual experienced prolonged suffering before seeking medical attention. During that time, she attributed her symptoms to a fatal illness. Once the diabetes was diagnosed, she experienced some grief and guilt about her former lifestyle. In addition, she experienced a significant loss of self-confidence in her ability to care for herself. As a result she demonstrated a greater need for security.

Learning how to cope with the diabetes by attending diabetes education classes helped to alleviate the suffering somewhat and the frustration about the diabetes but with the enhanced knowledge came the responsibility for her self-care. Many times this individual felt burdened by this responsibility because her blood glucose levels often did not normalize despite strict following of her treatment plan. Along with this enhanced sense of personal responsibility came the awareness of potential adverse complications of diabetes. These served to motivate and burden her, by turn. Following a period of practice she eventually felt that she had achieved some mastery with regards to certain aspects of her treatment plan, most notably the diet. Despite this, she found the diet frustrating because of its rigidity and complexity.

Other facets of her learning experiences included identification with her fellow classmates as a reference group. Often symptoms she experienced were validated by other group members which imparted to her their significance. This group of people also became a significant support group for her during the course of the classes. Her need for support was very evident. It was noted that her family did not provide her with significant support, even to some extent discounting the seriousness of her disease which frustrated and saddened her. Her husband was somewhat supportive. However because of his own ill health, she chose to shield him from the full implications of the diabetes thereby lessening his ability to provide her with meaningful support. The educators at the clinic provided her with significant support and she relied upon them and trusted them implicitly about the diabetes, even more so than her physician.

She also experienced frustration with her unsympathetic work boss. This frustration was directly related to her boss' ignorance of the ramification of diabetes and of its effect upon her health and lifestyle. In addition, she complained bitterly about other individuals, who through similar ignorance about her diabetes, minimized her disease and its gravity.

The individual realized the importance the permanent nature of the lifestyle change required in managing diabetes and she took steps to help ensure that these changes would occur. Predicated upon the action was her attitudinal change about her lifestyle and the importance of her health. It was this attitudinal shift that hastened her concern for others' well-being most notably her children and grandchildren.

The presence of a long time friend who had successfully managed his diabetes to date was a primary motivator for her own success and a way to provide her with hope for a positive future, free of long term complications. Despite this, there were times when she became depressed and overwhelmed with the enormity of the tasks involved in self-care. She attempted to overcome those times with positive self-talk.

Sara

Personal Information. Sara is 39 years old, married with two teenage boys. She lives with her husband and boys in a single-dwelling home. She works as a kindergarten teacher in a nearby school. Sara's family has a strong history of diabetes although this was mostly unknown to her prior to her own diagnosis with the disease. She described her family as having a very busy lifestyle with both parents working full-time and both sons involved in several extra curricular activities. Foods consumed in this family tended to be selected primarily for their convenience. Sara admitted that prior to her diagnosis, all her family members led a relatively sedentary lifestyle.

She admitted that she had a chronic weight problem for which she had sought a lot of help over the years with a moderate amount of temporary success. Unfortunately, she had never been able to maintain the weight loss for very long. Sara was particularly interested in how her diagnosis with diabetes had affected her whole family. She emphasized the importance of her family's involvement in her diabetes care although she had chosen not to involve her family in attending the diabetic clinic with her. Sara recognized the value of support groups and had herself been involved with one called overeaters anonymous for quite a while.

What impressed her most about the diabetic clinic was the information about the relationship of 'big babies', gestational diabetes and Type 2 diabetes because she had had 2 very large babies approximately ten to twelve years ago. She repeatedly expressed her anger about not being 'checked properly' by her doctor for gestational diabetes during her pregnancies.

Table 5

Thematic Abstraction of Sara's Diabetes Experience

Excerpts from Transcribed Interviews	Two levels of Abstraction	
	1. Paraphrases	2. Themes
1. I found out [during] the first week of June this year. I went to my doctor and I was really thirsty...I could have held a hose in my mouth and I thought something's wrong here, then I went in for a vaginal infection and so from there [and] talking to the doctor. He put two and two together and I was also getting cramps in my legs...at night.	Description of the symptoms which drove her to seek medical attention. These included extreme thirst, night leg cramps and a vaginal infection.	Diabetes induced grief
2. I think it was just that it happened so fast [the diabetes onset]. I wasn't pre-warned that I had diabetes. All my symptoms seemed to come on so quickly and I had all these symptoms like the cramps and the thirst and everything.	The sudden onset of the symptoms of diabetes created her shocked reaction to it.	Diabetes induced grief.
3. He [alternate doctor] was assuming that I had type 1 diabetes and he said... come down and talk to me and we'll see what we can do so I left the school and said, sorry guys I gotta go, get a sub. I might be in the hospital this afternoon and it was quite emotional and that it hit me that something Oh my goodness, so I phoned my husband and he came and picked me up and we went off to see this doctor.	The realization that she had diabetes brought on a grief reaction and this caused her to turn to her husband for support. He offered her this support by attending the doctor with her.	Diabetes induced grief. Support integral to well being
4. We sat and waited so I went home and bought the pills and went on this strict rigid diet and it was really quite emotional. My husband and I, we didn't know if I was gonna end up in the hospital at any time.	She followed doctor's stringent measures: bought the medication prescribed and begin to follow strict diet. These measures were in attempt to avoid hospital admission.	Diabetes induced grief.

Excerpts from Transcribed Interviews	Two levels of Abstraction	
	1. Paraphrases	2. Themes
5. When I was talking to the teacher the day before I found out, she told me you know I think it's diabetes and I thought Oh no.	The realization that her symptoms may be due to diabetes filled her with apprehension.	Diabetes induced grief.
6. When the doctor phoned, it wasn't my doctor, whether that had anything to do with it. He phoned and said you have diabetes and I think maybe because my mother is diabetic, my brother in law is diabetic. I just assumed it would never happen to me.	Reflection on her reaction to the diagnosis. Sara thought it may have been due partly to the involvement of a second physician or maybe to her assumption that she would never have the disease.	Diabetes induced grief
7. I think it was overwhelming like wow, this was going to be a big change and I didn't expect myself to get emotional like that I thought I'll deal with it and I think when I phoned my husband and he was so supportive like I'm on my way and he was right there. I was getting overwhelmed. Oh man, what's gonna happen to me?	Her experience of shock was most notable as an overwhelming sensation particularly about her future outcome.	Diabetes induced grief Worry about potential outcomes of diabetes.
8. By the next day, even after I had talked to the doctor, I couldn't go back and talk to the teachers at school. I was just really emotional now whether with your blood sugar going up and down probably had something to do with it because even now if I miss my medication, like 3 or 4 hours later, I find myself getting emotional again.	Diagnosis of her diabetes was an emotional event for her such that she couldn't admit it to her fellow co-workers. She wondered if that feeling was due in part to erratic blood glucose levels.	Diabetes induced grief
9. That was the hardest part in the beginning was these emotions of these people wanting to out me in the hospital and put me on insulin right away.	Anxiety and grief about potential hospital admission and introduction of insulin injections.	Diabetes induced grief

Excerpts from Transcribed Interviews	Two levels of Abstraction	
	1. Paraphrases	2. Themes
10. When I first found out, my blood sugar was up to 34 and then I was on the pill so it was dropping quite quickly so I think everything's out of whack and you've got this kind of lightening bolt that says you've got to make changes.	Reflection on some of the possible reasons for her emotional upheaval following the diagnosis. These included the changing blood glucose levels and the realization of the necessity to make lifestyle changes.	Permanent lifestyle change required attitude change and commitment.
11. The first thing I did, like I think it was more support from family like the teacher at school...she told me to stay away from this...she was giving me little hints...so it was more of a family and friends' support system.	Identification that her first line of support and information was from a friend who gave her practical advice about food.	Significance of educated support
12. It [diabetic clinic] was wonderful. It was a real eye opening experience as far as food goes. Food and reading labels and taking time to learn what this disease is all about was a real eye opener.	Diabetes education was valuable experience because she discovered more about her diabetes and its treatment.	Education crucial to treatment plan success
13. This whole business of having big babies and diabetes in the family and getting pregnant...that I should have been monitored and tested then for gestational diabetes and I never was. Nobody ever said anything.	Recognition that her past medical treatment was inadequate because of the lack of monitoring for gestational diabetes during her pregnancies.	Diabetes induced grief
14. I guess anger because if I'd have known [about big babies and risk of diabetes I might have made alternate choices]. As soon as I found out I was on the bandwagon that I wasn't going to let this beat me. If I'd have known that 10 years ago, I would have jumped on the bandwagon then, so I guess it's a lack of knowledge about it. If I'd have understood more about the diabetes 10 years ago when I had these big babies...I wouldn't have had the big babies...If I was learning the information then, I don't think I would have packed this weight for that long.	Recognition of her anger because of her lack of knowledge about her risk of developing type 2 diabetes as a result of having gestational diabetes in pregnancy. Sara claimed that had she been aware of this risk she would have made considerable efforts to lose the extra weight.	Diabetes induced grief

Excerpts from Transcribed Interviews	Two levels of Abstraction	
	1. Paraphrases	2. Themes
15. I think once they had me leveled out like right away I know what I have to do and I know that my mother survived and my brother in law...I think by being aware of what it is, it's more what helped me through that and then it just was I wasn't gonna let it beat me so determination I guess.	As blood glucose levels normalized she became aware of people in her family who have successfully managed to live well with diabetes and began to believe that this could be true for her too. As a result she became determined to master her condition.	Hope for positive future
16. It just amazed me everytime I came out of this clinic every week and I kept notes like I've got a notebook that's full of ideas and full of information that is so important to this whole diabetes which before I wasn't even concerned about.	Enhanced awareness of diabetes and its treatment resulted from her attendance of the diabetic clinic.	Education crucial to treatment plan success
17. I've always struggled with weight problems all my life and I've gone to every diet there ever was and we talked about this at the clinic that guaranteed I lost weight on almost all of them but they weren't maintained and then you gained all that weight back plus a few pounds so you're putting on baggage after every diet and with this [diabetes] it was almost like a lightening bolt that I needed to get my life in shape like hey, you can't fool around any more.	Her long term struggle with obesity was related to her lack of commitment to the weight loss plan. Her diabetes provided her with the opportunity to commit to the long term amelioration of her obesity.	Permanent lifestyle change required attitude change and commitment.
18. Little quotes that she used in the classes that stuck and she gave samples of different people and different things that have happened and different movies on foot care like if you don't watch it you could end up losing your foot in a week with gangrene.	Sara's learning about the diabetes process was related to the personal relevance of the information. When the information was presented visually, this seemed to heighten her awareness and make the information seem even more relevant to her.	Personal relevance of education/treatment plan

Excerpts from Transcribed Interviews	Two levels of Abstraction	
	1. Paraphrases	2. Themes
19. It's a whole way of finding out what foods have hidden fats and the sugars and natural sugars and vegetables that have natural sugars and you know it just amazed me some of the things and then to carry that over into a family, like I've got 3 boys and a husband so there's five of us to eat and I'm still working on that area where you have to plan meals and set those kinds of things up.	Discovery of the contents of food has enhanced her awareness of healthy food choices for herself and her family.	Concern for other's wellbeing.
20. With the diabetes, you don't have a choice like it's either this way or you're gonna suffer the rest of your life or you could end up killing yourself and then your family suffers and like the doctor said, you wanna be around to see your kids grow up.	Sara recognized that diabetes has provided her with the incentive to permanently alter her lifestyle. This incentive comes from her knowledge that if she didn't stick with the treatment plan, she would suffer the adverse complications. This would also adversely influence her family.	Extrinsic and intrinsic motivation necessary. Worry about potential outcomes of diabetes.
21. It's an ongoing process...but as far as living with it day to day it's not gonna beat me. I'm gonna be around for a long time so I'm not thinking of it as a real illness. I just think of it as my lifestyle that I have to eat for my body...like I've lost 22 lbs since the first time I found out so that's the way I'm thinking. This is the lightening bolt I needed like you can't have it anymore so you might as well work on it.	Sara's coping strategy has been one of considering the diabetes as a necessary lifestyle change for her health. She has divorced this change from diabetes as an illness.	Extrinsic and intrinsic motivation necessary.

Excerpts from Transcribed Interviews	Two levels of Abstraction	
	1. Paraphrases	2. Themes
22. 3 months before I found out I had diabetes I joined a group called overeaters anonymous and it works on the 12 step program...and a lot of that is building up your self-esteem and...putting your whole life in perspective not just your weight problem and I think that has carried over into [my life] and then I found out I had this, well I just carried on with that and so like I have a support group for losing weight and I just tied it all together.	Diagnosis of diabetes came at a time when she had already began making permanent lifestyle changes. These included joining overeaters anonymous which focused on weight loss as a self-esteem issue. As a result she connected all issues as components of the permanent lifestyle change.	Permanent lifestyle change required attitude change and commitment.
23. You want to be around to see your grandchildren so it's up to you and they really stressed that at the clinic. It's up to you. It's not up to anybody else.	She recognized that she was personally responsible for the outcomes and management of her diabetes. This was emphasized in the education classes.	Personal responsibility for self-care.
24. I think I'm a visual learner...If I see things I remember them. If I'm just sitting and listening to a lecture, I have to take notes and read those notes over in order for those notes to sink in...like when they did labels, they brought in cartons of things and samples, the Pepsi bottle and the cubes of sugar and for me being that type of learner was how I remember.	Description of her preferred learning style which was visually oriented.	Experiential learning paramount and demanding of time and effort
25. When I found out I had diabetes, I talked to my mother and she has diabetes...she's had it for ...5 years but then she informed me that her dad had it and her two brothers had it and a niece had it so it is a lot in the family and they say statistically that one out of my 3 kids could have it so I'm working with them on nutrition.	Strong family history of diabetes caused her some anxiety and concern with regards to the risks of her children developing diabetes. In an effort to prevent this, she has introduced some discussion about health and nutrition issues with her children.	Concern about others' wellbeing.

Excerpts from Transcribed Interviews	Two levels of Abstraction	
	1. Paraphrases	2. Themes
26. My blood sugar dropped down to 3.7 last t week after a meal and my husband automatically said well you need to eat something sweet and I said no, I have to keep monitoring how many times it drops or if it is doing it steadily that I can reduce my medicine not a quick fix so like he didn't understand that whole process so I'm wishing that my family had come to the clinic and they were invited.	Sara recognized that her husband didn't have the same level of knowledge or competence about her diabetes because he didn't attend the education classes. This placed him at a disadvantage as far as being able to offer her educated support.	Significance of educated support. Mastery of treatment plan.
27. It becomes a whole family issue and they say that a lot of families...that have a diabetic person...the whole family becomes healthier so you know like my husband who doesn't usually go for walks has offered to go for walks with me and the kids will go. Oh no mom, you can't have that so they're becoming aware. I keep them talking. We keep talking about it.	She recognized that her diabetes has affected her whole family because of the lifestyle changes in which they have participated	Support integral to wellbeing Significance of educated support.
28. I was telling somebody today I think I feel better now than I have in 10 years. I think that eating healthy and the exercise and the walking and losing the weight, it makes this whole total picture seem better.	She attributed her wellbeing feelings to the positive changes she has made in her lifestyle namely in the diet and exercise	Permanent lifestyle change required attitude change and commitment
29. I teach at [an elementary school] and a few years ago we had a teacher on staff who was a type 1 diabetic and then we had a student that was type 1 so they have done just before I got there...a lot of in-school workshops explaining what happens and explaining what to do...so when I found out they were right there and it's like if you need time off, you do it.	Inservice education of her fellow co-workers about diabetes treatment has positively affected her in that her co-workers are supportive of diabetes treatment measures.	Significance of educated support.

Excerpts from Transcribed Interviews	Two levels of Abstraction	
	1. Paraphrases	2. Themes
30. I have to live with it. I have to be responsible and that's what they really stressed at the clinic to...you have to be on top of it and she [educator] really stressed that.	She recognized her personal responsibility for her diabetes management which was stressed to her by diabetes educator.	Personal responsibility for self-care.
31. I think the biggest thing is living with diabetes rather than the scientific side of it like you know I'm interested in the scientific side of it as well but I think that's not the part that you need the most, like you need to know the basics of what it is all about but how to survive day to day, you know watching for symptoms and how to give your medicines...and when you should get off the medicine, all those little things and nutrition is the most important.	Description of information she needed to learn. This information was related to her daily management of the diabetes such as what to eat, how to administer medicines, and how to make treatment plan adjustment decisions.	Personal relevance of education/treatment plan
32. I find that hard [meal planning] because...sometimes I'll arrive home at 5:30 and so my husband prepared supper last night and we're sitting at the table and he said you know I never thought about what you can eat or can't eat. It was just rush home and get something on the table and as we sat and looked at the meal, it was a very safe meal because of what he'd prepared, the vegetables and the meat and it wasn't anything that had extra sugars in it.	Sara found lifestyle changes particularly diabetic meal planning difficult to make at times because of time constraints.	Life constraints complicated diabetes management. Mastery of treatment plan.

Excerpts from Transcribed Interviews	Two levels of Abstraction	
	1. Paraphrases	2. Themes
33. There's cookbooks out there but I'm not the person that can sit and read cookbooks and plan like I learn better just trying things and that's one thing like right now I know that's gonna be hard in my life with working so it's on a weekend that I can sit and go through recipes and say figure out portions because there's five of us like how much should I have and whatever and I know that's my weakness and I'm just doing one step at a time.	She identified effective learning techniques which include experiential components. She admitted that this type of learning is time and effort consuming.	Experiential learning paramount and demanding of time and effort Frustration with complexity and rigidity of diet
34. They [educators] make up a food guide for you and ask you about your lifestyle...so they fit your food plan into your lifestyle rather than making you change everything and that made it easy like I put my meal plan on the fridge and this is what I can have and it was basically things that I have like a bowl of cereal and fruit but just that information like I now had to eat the fruit with a meal, I couldn't just have it on its own. Those little things and it was just fitting it onto my normal lifestyle that made it easy.	Recommendations for diet and lifestyle adjustments were made in accordance and with respect to her usual eating habits and lifestyle. She saw this method of recommending lifestyle changes as positive and easy to follow.	Personal relevance of education/treatment plan
35. I'm no good at doing that kind of thing [strict diet adherence]. It's a guide not a bible. I started using it as a planning guide for future meals like when I go shopping Oh well I need to have starches, I have to buy dark bread not just white bread so it helps, but it's not an extensive food or health plan.	Description of her use of her food plan and overall treatment plan. She used these as guides and as tools for planning meals. She admitted that she has difficulty adhering strictly to a meal plan.	Frustration with complexity and rigidity of diet Personal relevance of education/treatment plan Mastery of treatment plan.

Excerpts from Transcribed Interviews	Two levels of Abstraction	
	1. Paraphrases	2. Themes
36. It [the education] was 4 full days and I gather that it is quite expensive to put on this clinic but I could have used more days because I think there is so much information and you just feel saturated with all this stuff and then you go through your notes again and you say gee what do they mean here?	Description of her overwhelmed sensation with the information presented in the education classes.	Overwhelmed with quantity of information.
37. [Overeaters Anonymous] is like a support system that is making me more aware of my whole life rather than just the diabetes or a weight problem. It's putting everything in focus, like with the support system from the overeaters anonymous and meeting people there, I know I can go and talk to them about anything.	Value of overeaters anonymous was a wholistic support group that provided her with confidence to manage her life.	Significance of educated support. Support integral to wellbeing
38. Maybe not even so much the education but maybe like if it was a little support group like maybe next month your group is gonna meet together and you know I guess that's part of it like you had a place to go and talk to everybody there who had the same problem so 'twas kind of neat. Oh 'twas just sharing recipes before sitting in our little group before the instructor came in and it was like getting together.	Recognition of her need for ongoing support that she would receive from her classmates in the diabetes education classes.	Identification with classmates as reference and support group.

Excerpts from Transcribed Interviews	Two levels of Abstraction	
	1. Paraphrases	2. Themes
39. [Regarding niece's diagnosis of diabetes] I was sad. I thought boy at 4 years old...she's dealing with it but the long term complications and going through her teenage years [will be hard] and I think with that it's most important for education and for her to be educating the school with the class she's with...starting at 4 years old and going to play school and today was a Halloween day and what do you hand out? candy...I gave her a goodie bag and I put stickers and a balloon and little blowing thing in because I don't want to be handing out candy in my classroom	She realized the loss of a normal life that her niece has experienced as a result of the diabetes; for example, she recognized her niece no longer had the freedom to consume candy. She recognized the need for and the importance of education of the child's caregivers and friends. To that end, she gave the child suitable treats and realized that too holds a responsibility for educating the people in the child's environment.	Diabetes induced grief. Education crucial to treatment plan success.
40. It was different getting sick, it was just a cold...but the things you have to do are different like you have to drink a lot of fluids like you can't take a lot of medicines, antihistamines or things like that...so I had to play around with and talk to the pharmacist like what can I take? I had a sinus headache and I can't take the sinus medicine so...I have to change my lifestyle in that sense which I hadn't thought of so much because I would always got and get a cold capsule kind of thing whereas now I have to change that. You're always learning, different situations come up and Oh what do i do for that?	Recognition that the diabetes altered her treatment options for illnesses such as colds and sinus headaches. She realized that her learning was situationally dependent and she found that disconcerting.	Learning situationally dependent.

Excerpts from Transcribed Interviews	Two levels of Abstraction	
	1. Paraphrases	2. Themes
41. I find it so hard now being back to work to be able to walk everyday and I miss that and once the snow comes, I don't like walking in the snow so I have to hopefully walk at school but you know different things come up and that throws you off your schedule and once your schedule is thrown off, then you start to feel a little different, so it's something that you live with on a day to day basis.	Description of the frustrations she has experienced in implementing the prescribed lifestyle changes. These frustrations included a variety of life constraints.	Life constraints complicated diabetes management.
42. One of the ladies that came to talk to our group had it [diabetes] for 31 years and she was the one who came to talk to us about joining this group [the CDA] so I think that's where you'll get that people that have had it for a long time so that will probably be something similar where you get to see people that have been successful and that's important and that you see that you can do this.	Role of people who have successfully managed their diabetes over a long time was to provide her with motivation and hope for a similarly successful future outcome.	Hope for positive future. Extrinsic and intrinsic motivation necessary.
43. Maybe right now I'm so positive with it because it's so new. I think it's just been a real experience like it was kind of a shock and emotional right at the beginning and as I keep going I don't want to let my guard down.	Recognition that diabetes diagnosis has been shocking and has caused some emotional upheaval and her way of coping with that has been to focus on the positive aspects of the diabetes.	Diabetes induced grief.
44. With the kids like when I forgot my medicine I was getting really emotional. If they were aware of things to watch for and to happen, they would say Oh mom your blood sugar's too low or something. They would be able to watch me and see these changes when things happen and just the education of just knowing that diet is so important not just for diabetics...I think they would be more of a support system for me if they understood. They would become part of that little group that I was with.	Sara's children did not attend the diabetes education classes and as a result were not able to accurately interpret her symptoms. She admitted that if her children had this knowledge, they would be better able to support her in her diabetes management in much the same way as did her classmates. Also their enhanced knowledge would be a valuable tool in helping them to prevent diabetes from happening to them.	Significance of educated support. Education crucial to treatment plan success

Excerpts from Transcribed Interviews	Two levels of Abstraction	
	1. Paraphrases	2. Themes
45. We become a family that eats better and with my husband who has high cholesterol we can work towards becoming a whole family thing. It also made me realize how supportive my family is when I found out like I think it brought us closer together, like Oh mom has a problem like they're all wanting to help...so that was nice to know.	Recognition of the positive effect that diabetes has had on unifying the family's efforts at eating more healthfully and at offering her support in her efforts at learning to cope with diabetes.	Significance of educated support
46. If I didn't have a goal to try and lose weight, I think I would probably struggle with the diabetes more because I know if I lose weight and can get off these pills then I'm in control rather than using these pills to do things so I want to be in control.	Her weight loss goal was helpful as a way to remain in control of her diabetes and its outcomes.	Weight loss early measure of success.
47. My next goal will be getting into the cooking end and figuring things out because I don't want to ever put it back on so that's my goal right now, to do the exercise and the walking and keep losing the weight and then for me to get off the pills and then into more food management so I don't go too far off now. I have very basic meals so then later you can add desserts and deduct them from the food plan and do all sorts of things later. I don't have to worry about that now.	Description of her projected management of the diabetes: first came the weight loss then elimination of the pills and then experimentation with a variety of foods. She admitted that for the present her primary goal remained the weight loss.	Personal achievement of goals indicator of treatment plan success.
48. I don't think the public knows a whole lot like I mean I didn't. I knew that my mother had diabetes. I didn't know there was 2 types and what they meant and now people ask me and Oh well I have this type but there is also this type...I educate my colleagues and my family...but I guess if people don't have it or aren't aware of anybody that has it, it's not important to them.	Recognition of the public's ignorance abut diabetes, its various types and its management. Sara believed that the public's ignorance was mostly due to their lack of involvement with or exposure to people with diabetes.	Frustration with the ignorance and lack of others' discernment

Excerpts from Transcribed Interviews	Two levels of Abstraction	
	1. Paraphrases	2. Themes
49. Hopefully my kids are doing science fairs and I'm hoping one of them will decide to do something on diabetes this year because they will have a lot more information and they will learn from it so that they can educate their friends.	Role of education needs to be expanded beyond immediate family's boundaries to reach those of her children's school friends.	Education crucial to treatment plan success
50. [I'm] on glucophage. I know there's different kinds and basically...my body is making enough insulin but it allows the cells to open up and absorb that insulin and once I lose more weight and get down I can go off the medicine and just with diet and exercise I will use up the insulin I make so that scientific part I was figuring out and once I understood it then I know that I can't just go and buy a chocolate bar things like that, so it's interesting. I find this whole thing interesting.	Description of her understanding of the function of medication and the role of weight loss in alleviating the need for medication. This provided her with incentives to stay away from poor food choices such as chocolate bars.	Extrinsic and intrinsic motivation necessary. Education crucial to treatment plan success
51. There is so much information and you only take in so much but I find reading now, Oh right, I should be doing that...there is more information to soak in.	Recognition of the abundance of information about diabetes and her inability to absorb it all in one sitting.	Overwhelmed with quantity of information.
52. [Education] has to be ongoing and with so many new things that come out and even just reinforcement like you listen to all of these lectures like I could listen to them over and over again because you pick out things that change your lifestyle, different things that come up then you really understand what's going on so I think it has to be ongoing.	Description of her need for ongoing education to coincide with the variety of her life situations.	Learning situationally dependent.

Excerpts from Transcribed Interviews	Two levels of Abstraction	
	1. Paraphrases	2. Themes
53. Having that whole group that knows exactly what you're going through and knows exactly about all of this blood and everything even more than your spouse at that point. It made you feel good to be with those people and you don't know them from anybody. You're all just meeting them that one day so it was after 4 days of being with these people, you knew you could talk to them about anything so that support system is really important.	The value of her classmates as an effective support group came from the common knowledge and experiences these people had.	Significance of educated support. Identification with classmates as reference and support group.

Table 6

Thematic Clusters of Sara's Diabetes Experience and Generalized Description

Thematic Cluster	Generalized Description
<u>The psychological reaction to diabetes</u>: includes themes, Diabetes induced suffering, diabetes induced grief, anxiety about possible imminent hospital admission, worry about future outcomes of diabetes, mood swings accompanied erratic blood glucose levels, diabetes induced grief, shock about diabetes diagnosis, anger at physician for inadequate treatment, anger about her misinformation. 1, 2, 3, 4, 5, 6, 7, 8, 9, 10, 13, 14, 20, 39, 43.	The period of time leading up to Sara's diagnosis was marked by her illness. She suffered from several debilitating symptoms which drove her to seek medical attention and it was then that the diabetes was diagnosed. Her initial reaction to the diabetes was shock and grief particularly as the physician involved wanted to admit her to hospital. She understood that to mean that she was seriously ill. Ultimately this caused her to rely more heavily on her family and particularly her husband, for encouragement and support. Her previous experience with diabetes was limited to her mother's experiences which she assumed occurred only in old age and as such she considered herself immune from developing diabetes. This understanding contributed to her shock about her own diagnosis. In addition to this, Sara started to realize that her diagnosis would alter her life and that of her family's though at the time, she was unsure of what the changes would be. As her blood glucose levels normalized, she experienced mood swings which were partly related to the erratic blood glucose levels and partly to the emotional upheaval following her diagnosis. She remained particularly concerned about her future outcomes with the diabetes. Once she realized her risks of developing diabetes were high because of previously undiagnosed gestational diabetes, Sara exhibited anger toward her physician for his mismanagement of her condition and her misinformation. She realized that had she been treated adequately during her pregnancies and had the appropriate information she may have been able to delay or prevent the incidence of her type 2 diabetes.

Thematic Cluster	Generalized Description
Learning to cope with diabetes involves education: includes themes, Education crucial to treatment plan's success, education enhanced awareness about disease and its treatment, personal relevance of education, learning situationally dependent, preferred learning style visual, experiential learning paramount, experiential learning time and effort-consuming, overwhelmed with quantity of information, personal responsibility for self-care, frustration with ignorance and lack of discernment by public, husband's support integral to wellbeing, significance of educated support, identification with classmates as reference and support, personal responsibility for public's education, education of broader public necessary. 11, 12, 16, 18, 23, 24, 26, 27, 29, 30, 31, 33, 34, 36, 37, 39, 40, 44, 48, 49, 50, 51, 52, 53.	Sara's attendance at the diabetic clinic classes enhanced her awareness about diabetes and its treatment / management. She was specifically impressed with the significance of the effect of lifestyle behaviours such as eating, and exercising on the outcomes of diabetes. Therefore, she believed education was crucial to the success of her treatment plan. Sara became impressed with her responsibility for her self-care and as a result for the outcomes of her diabetes. This was also emphasized during the education sessions. Sara was able to recite various quotes and incidents from the education classes all of which were personally relevant to her treatment plan. She observed that she learned best when the information was presented visually and when it involved experiential components. Despite her declared learning style preference, Sara recognized that mastery of this type of learning took time and effort which at times was difficult for her to accomplish because of her variety of life constraints. She also observed that she learned best about a particular method of treatment or management when circumstances warranted this in her own life. For example, she learned about sick day management when she herself became ill. Sara identified support as an integral component of her learning to cope efforts. Though she wanted and received support from her family, co-workers, classmates and the public, she wished for educated support and was grateful when those offering her support practically or emotionally had some understanding about diabetes and its management. For that reason, her classmates were a significant support group for her during this stage. She also recognized that education of the broader public was essential to provide a diabetes-friendly environment that was supportive of people's efforts at their diabetes management.

Thematic Cluster	Generalized Description
Adaptation to life with diabetes: includes themes, Permanent lifestyle changes necessary, permanent lifestyle changes required attitude change and commitment, desire for life without diabetes, mastery of treatment plan, satisfaction with meal plan, extrinsic and intrinsic motivation necessary, other's success with diabetes provided hope, wellbeing enhanced by lifestyle change, strict diet adherence difficult, weight loss early measure of success, personal achievement of goals measure of treatment plan success, diabetes enhanced family intimacy and support, diabetes management involved whole family, life constraints complicate diabetes management, concern for others' wellbeing. 15, 17, 19, 20, 21, 22, 25, 26, 27, 28, 32, 33, 35, 37, 38, 41, 42, 45, 46, 47, 50, 53.	Sara's adaptation to life with diabetes began with her realization that permanent lifestyle changes were necessary for her to effectively manage her diabetes. She recognized that such changes required an attitude change and a commitment to carry through the changes. The particular attitudes in question were those concerning her health and her responsibility with regard to its management. Though concerned about potential adverse complications of diabetes, Sara realized that she could have a positive outcome to her diabetes by observing significant family members who had successfully managed their diabetes to date. Following the education, Sara realized that she had mastered the ability to manage her diabetes well. At times she found life constraints including time and money at odds with her desire to manage her diabetes well and consequently, she found strict adherence to the treatment plan particularly the diet difficult, if not impossible. Sara used her weight loss as an early measure of her success with her treatment plan which then became a motivator in helping her stay on track. She admitted the importance of personal treatment plan goals to keep her motivated towards her treatment plan. Her family played a significant part in assisting her in making lifestyle changes. Their support was invaluable to her and it had the added benefit of bringing the family closer together as they sought to help her manage her diabetes well. She noted that the overall effect of her lifestyle changes was positive in light of her enhanced sense of wellbeing and her concern that others among her family and friends follow suit by making positive long term lifestyle changes as well.

Synthesis of Sara's diabetes experience

The diagnosis of diabetes was sudden and followed a short but intense illness that prompted her to seek immediate medical attention. The diagnosis was a total surprise to this individual because she believed herself to be protected from what she considered 'an old person's disease'. After her diagnosis, this individual questioned her relatives and discovered that several of them had Type 2 diabetes.

The period immediately following her diagnosis was marked by tension and fear that was partly due to having diabetes and partly related to the absence of her regular physician and consequently, the involvement of fill-in physicians who seemed somewhat confused and hesitant about her medical care. During this time, she found great comfort and support from her fellow workers who had some experience with diabetes because of a former staff member's experiences with the disease. These staff members were also able to offer her practical support with regards her diet.

The individual found the diabetic clinic to be a positive experience because of the emphasis on education, support and practice. Although she attended the diabetic clinic without her family, she believed that educated support was imperative in the success of her self-care behaviours. As a result, she involved her family in her diabetes self-care as much as possible, including them in meal planning, exercise and blood testing.

She experienced some frustration and anger resulting from the knowledge that her medical doctor may not have treated her appropriately during her pregnancies some ten to twelve years previously such that she had not been screened for gestational diabetes, nor had she been warned about her risks of developing Type 2 diabetes.

During the course of her adaptation to life with diabetes, this individual became aware of the need for permanent lifestyle changes particularly with regards her diet and exercise habits. Successful role models were important to her during this time because they provided her with hope for her own successful outcomes with the disease. These role models were significant people in her life and included her mother and brother in law.

There was a recognition that these permanent changes involved an attitudinal change and certain amount of commitment to carry through these changes. It was evident that this sense of commitment was related to her belief of her personal responsibility for her self-care--a message emphasized by the educators at the diabetic clinic. It was noticeable that this individual's attitudinal shift engendered a concern for other's wellbeing including other family members who had not as yet become quite as concerned about their health and their responsibility for its maintenance. Another noticeable change in this individual's family relationships was the enhanced intimacy and support amongst family members as a result of her diabetes diagnosis.

This individual recognized and admitted the role of motivating factors in facilitating adherence to the new lifestyle behaviours. These factors included a realization of the potential adverse complications that result from poor adherence to lifestyle behaviours. Positive support from educators also became a motivating factor as was success with the treatment plan. This success included early weight loss. This ultimately led to a sense of mastery and achievement which also fostered her motivation positively.

There were definite constraints which hindered this individual's total adherence to the prescribed treatment plan and these included: time, money, her maternal role and the demands of her children on her time and efforts. This experience was particularly frustrating as she had not yet learned to balance the demands of her disease and the remainder of her life.

This individual was clearly able to identify her preferred learning style which was visual and her need for experiential learning that was relevant to her personal circumstances. She also stated that she tended to learn things as they applied to her life, that is, her learning was situationally dependent. She expressed frustration with the ignorance of the public with regards her treatment plan demands. She also recognized the need to educate the broader public about diabetes and generally speaking, its treatment demands as a way to support those like her who were attempting to adhere to difficult treatment plans.

The Shared Experience

Introduction

Twenty two themes (see table 7 p. 93) emerged from the analysis of the data provided by the three participants. The themes shared by the three participants were: "Diabetes induced grief" "Education crucial to treatment plan success" "Personal responsibility for self-care" "Personal relevance of education/treatment plan" "Experiential learning paramount and demanding of time and effort" "Support integral to wellbeing" "Significance of educated support" "Identification with classmates as reference and support" "Concern for others' wellbeing" "Permanent lifestyle change required attitude change and commitment" "Extrinsic and intrinsic motivation necessary" "Mastery of treatment plan".

Six themes were shared by two of the three participants. These were: "Overwhelmed with quantity of information" "Frustration with the ignorance and lack of others' discernment" "Hope for positive future" "Satisfaction with meal plan" "Frustration with unsympathetic work boss" "Worry about potential outcomes of diabetes". Each participant expressed some themes that were not shared by any of the others; some of these will be covered in the following discussion.

Grief

All participants expressed some grief following the diagnosis of their [illegible]. This psychological reaction included shock, denial, anger, sadness, guilt [illegible] for life without diabetes. Each participant expressed a different facet of this grief. Mark and Margaret expressed their guilt about their former lifestyle behaviours which they believed had precipitated the diabetes, whereas Sara expressed more shock because she truly believed that diabetes would not happen to her because of her youth. Both Mark and Margaret expressed some denial, initially, about their diabetes. Mark attributed his diabetes symptoms to aging while Margaret attributed them to stress and to a fatal illness. In both cases, the attribution of symptoms made both individuals delay seeking medical attention.

The sadness and the desire for life without diabetes was expressed by Margaret and Mark who both wished for their former life. Yet both of these individuals were able to comment upon the positive changes that resulted from the incidence of diabetes. Anger was expressed by Mark and Sara. In Mark's case, he directed his anger at his physician whom he felt had not warned him sufficiently about his risks of diabetes because of his obesity and strong family history of the disease. Sara also directed her anger at her physician whom she felt had mismanaged her condition particularly during her pregnancies such that she had not been adequately monitored for gestational diabetes nor had she been warned about the risks associated with gestational diabetes in terms of the development of type 2 diabetes later on in life.

Role of education

All participants concurred on the significance and the importance of education in the treatment and management of their diabetes. All three participants were unaware of appropriate lifestyle behaviours that would be conducive to effective diabetes management prior to these sessions. For example, both Margaret and Sara mentioned the significance of foot care which they had not, prior to the education classes, realized was a component of diabetes treatment. Mark, on the other hand, was particularly impressed with the importance of heart healthy lifestyle behaviours including dietary fat reduction and exercise. In all three situations, the education sessions enabled each individual to make sense of their treatment plan recommendations. However, it was interesting that two of the three participants (Mark and Sara) were overwhelmed with the quantity of information disseminated to them in the education classes.

This sense of being overwhelmed was likely derived from both of these individuals' desire to comply fully with the recommended treatment plans and from their realization that they had many lifestyle changes to implement. Interestingly, both Mark and Sara declared themselves to be visual learners.

Personal responsibility

All participants discussed their personal responsibility for their self-care. Each stressed that the successful management of their diabetes was up to them. In addition, each mentioned that this message had been brought up and stressed in the education sessions. However, the level of personal responsibility differed amongst the participants. Mark, who tended to function more independently than any of the other participants, stressed that he appreciated the support offered to him by his family and friends but he remained ultimately accountable for the outcomes of his diabetes. To Margaret, personal responsibility was an attitudinal shift in which she recognized that her lifestyle behaviours had a significant role in determining the outcomes of her diabetes. Similar to Margaret, Sara recognized the significance of her lifestyle behaviours in determining the successful outcomes of her diabetes and with that came her understanding of her personal responsibility in implementing those necessary lifestyle changes.

It was this sense of personal responsibility and the knowledge that others had successfully lived with the disease that provided Sara and Margaret hope for their positive outcomes with the diabetes. Both of these individuals knew of close friends or relatives who had successfully managed their diabetes. Mark, on the other hand, had a negative experience with family members who had diabetes. In his experience, these people had had negative outcomes with the diabetes partly through their own negligence. This had the effect of enhancing his sense of personal responsibility for his self-care and raising his level of concern and worry about his development of potential adverse complications.

Experiential learning

The theme of experiential learning as paramount and demanding of time and effort was also shared by the participants. Here the participants expressed their preference for the experiential mode of learning. All three participants commented on their greater ability to understand the mechanics of their treatment plans when this information was presented to them experientially. They also commented on the difficulty and complexity of mastering tasks presented to them experientially. In addition to the complexity, Mark commented about the expense of mastering experiential tasks such as blood glucose monitoring. The complexity of experiential tasks seemed to raise the individual's level of stress mostly because of their own expectation of task mastery.

Personal relevance

The personal relevance of education/treatment plan was also common to the three participants. Sara expressed this theme most eloquently when she described her learning as situationally dependent. In other words, information presented to her needed to be relevant to her general life situation and specific to her particular condition. For example, she discussed that she learned how to cope with diabetes in illness when she herself fell ill. Mark and Margaret expressed similar learning needs. Sara and Margaret expressed their satisfaction with their meal plans while Mark expressed satisfaction with his overall treatment plan. Their satisfaction was derived, in part, from their sense of mastery of the various aspects of their meal/treatment plans and from their realization of the personal relevance of each of their respective treatment/meal plans.

Support

All participants discussed the significance of support in assisting them practically and emotionally to live successfully with diabetes. Mark described his family's support as including their abstinence from unhealthy foods and their participation in his food and exercise plans. Sara, on the other hand, described her need for more emotional support from her family. This, she believed, further enabled her to follow through with her treatment plan. Practical support was also available to her as her husband participated in her exercise plan. Margaret's experience of support was significantly different from the other participants in that meaningful familial support was absent in her life partly because her family members were not aware of her need for their support and partly because she chose to shield her husband from the full implications of her diabetes because she received that support from her classmates. She expressed a need for emotional support around coping with her fears about diabetes and in particular her fears about developing any of the long term complications of diabetes.

All three participants expressed their desire for educated support such that all those offering them support would be at least generally knowledgeable about diabetes and its implications. Sara in particular commented on the difficulty of making her family understand certain aspects of her treatment plan because she herself was still learning how to master those aspects. For this reason, the three participants identified with their fellow classmates as a support group. These individuals had spent time together learning about their diabetes management and as such were able to offer practical as well as emotional support to one another.

Margaret identified the diabetes educators as those who offered her significant practical and emotional support because they spent a considerable amount of time teaching her how to make the lifestyle changes in her diet and in her exercise habits. They also provided her with much emotional support which consisted of encouragement and emotional space to vent her feelings about the diabetes. It was these individuals upon whom she relied quite heavily most notable because her family and work environments were unsupportive of her efforts to live well with the diabetes. Mark commented that in his experience the general public and casual acquaintances were in sympathy but lacked understanding about the diabetes, generally speaking. He noted that he often became irritated with the misinformation, even antagonism that he encountered. In his experience these people were friends or work colleagues. Mark was clear that he wanted both emotional and practical support from his family but he only wanted practical support from friends and colleagues. Both Mark and Sara experienced frustration with an unsupportive work boss/environment. In addition, they both attributed the lack of meaningful support in these environments to their bosses' ignorance about diabetes and its treatment.

Attitude change

All three participants recognized the importance of the attitudinal change required in order to implement permanent lifestyle changes. All three recognized that a certain level of commitment to making the necessary lifestyle changes emanated from their new attitudes. These new attitudes included a sense of personal responsibility for one's own health, a greater realization of one's own mortality, and a greater concern for others' wellbeing. It seemed as though the diagnosis of the diabetes was a sufficiently disorienting event to enable the shift in attitudes to take place.

Motivation

The discussion of motivating factors was as interesting as it was important in that all three participants identified various extrinsic and intrinsic factors that facilitated their adherence to their treatment plans. These factors included a desire for longevity and good health , a fear of adverse long term complications (Mark in particular), the reward of approval and support from family friends and educators (Margaret and Sara), the loss of excess weight (Sara), the ever-increasing understanding about diabetes and its treatment (Mark and Sara), and the enhanced sense of wellbeing that resulted from the knowledge that the job had been done well (Sara).

Table 7

Definitions of the Themes Abstracted From the Interviews

1. Diabetes induced grief: A psychological reaction to the diagnosis of diabetes and to the loss of the former lifestyle. This reaction included denial, anger, guilt, shock, fear, sadness, depression and withdrawal, a reflection on the possible causes of the diabetes and a sense of blame of others who may have been able to prevent its incidence.. A physical suffering accompanied this psychological reaction including pain and overall malaise.
2. Education crucial to treatment plan success: A realization that education about diabetes and its treatment essential in order to enable individual to learn how to manage the diabetes successfully. Education also included the validation of symptoms previously not ascribed to diabetes and an awareness of the need for education of the broader public.
3. Personal responsibility for self-care: A sense that the successful management of the diabetes was more or less totally in the hands of the individual.
4. Personal relevance of education/treatment plan: A recognition that the individual's most significant learning occurred when the information presented was personally relevant to the recipient of that information whether in the prescribed treatment plan or the actual life circumstances of the individual. In this process there was a questioning of recommendations made. Relevance of information was related to its method of presentation.
5. Learning situationally dependent: A sense that the learner came to understand concepts of self-care as situations where application of those concepts occurred in the learner's life.
6. Experiential learning paramount and demanding of time and effort: A realization that hands on experience was the primary way to facilitate transfer and integration of the material. This method of learning demanded considerable amounts of time and effort before mastery was accomplished. An example of this type of learning is blood glucose testing. Some frustration was experienced because of the time involved in practice and in the unpleasantness of certain experiences such as low blood glucose reactions and a concern about the relationship of other symptoms to the diabetes.
7. Overwhelmed with quantity of information: A sense that materials to be learned exceeded the learner's ability to comprehend them.
8. Support integral to wellbeing: A realization that the positive support of significant family members, co-workers, educators, friends, and ones self was important in establishing a climate where the prescribed diabetes treatment plan regimens were accommodated in an atmosphere of cooperation, caring, reassurance and confidentiality. This atmosphere was conducive to the whole family's involvement in the treatment plan but the individual remains ultimately responsible for his/her own treatment plan.
9. Significance of educated support: A realization that sympathy alone expressed by significant others was insufficient in providing an atmosphere of cooperation. These individuals needed to be knowledgeable about the diabetes as well as about the particular treatment plan. Supportive relationships positively motivate individuals towards their self-care.

10. Identification with classmates as reference and support: A sense of commonality in the learning processes and stages of adaptation to diabetic life between the learners who attended the same education classes. This sense of commonality in learning processes facilitated the formation of a support group.

11. Frustration with complexity and rigidity of diet: A sense of frustration with oneself because of the difficulty in adhering to the prescribed diet as a result of its complexity and lack of flexibility in accommodating the individual's lifestyle preferences.

12. Frustration with the ignorance and lack of others' discernment: A sense of frustration with others who appear/act ignorant of the individual's needs for cooperative support in adhering to the prescribed treatment plan. This frustration contributes additional stress

13. Concern for others' wellbeing: A realization that significant others particularly family members were at some risk for developing diabetes and/or its complications as a result of their lifestyle behaviours.

14. Permanent lifestyle change required attitude change and commitment: A realization that successful management of the diabetes meant permanent lifestyle changes were essential. These required a positive attitude of support and commitment towards those lifestyle changes.

15. Extrinsic and intrinsic motivation necessary: A recognition that extrinsic and intrinsic motivators were essential for the successful management of the diabetes. These motivators were both positive and negative in nature such as the positive support of educators, positive self-talk and the fear of long term adverse complications.

16. Hope for positive future: A sense that the individual's disease outcomes would be positive in the long term.

17. Mastery of treatment plan: A sense that the individual had mastered all aspects of the prescribed treatment plan both physically and emotionally and is achieving some success such as in weight loss.

18. Satisfaction with meal plan: A sense that the individual experienced satisfaction with their meal plan. This became an indicator of the individual's adaptation to life with diabetes.

19. Worry about potential outcomes of diabetes: A fear that the adverse outcomes of diabetes were in the person's future. This led to worry about the person's life, family and work if the complications became a reality.

20. Frustration with unsympathetic work boss: A sense of frustration with the individual's work boss who was unsupportive of the individual's needs including time off to attend to the prescribed diabetes treatment plan.

21. Optimal learning conditions included intellectual, experiential and emotional components: A recognition that the individual's optimal learning was achieved when the teaching included rational information, hands on practice and emotional space to vent one's feelings about life with diabetes.

22. Life constraints complicated diabetes management: A recognition that life constraints including time, money and other circumstances interfered with the individual's ability to adhere strictly to the prescribed treatment plan despite the individual's best intentions.

CHAPTER V

Discussion

Introduction

I began this study with the objective of gaining an understanding of the lived and learning experiences of people with type 2 diabetes and with a desire to explore the value of these experiences in the development of diabetes education programs. I wanted to know if by gaining an insider's perspective to the diabetes experience, my understanding of the diabetes education process would be enriched and expanded. I believe that the participants have illuminated the experience profoundly. They have answered my questions well and have in fact helped to raise more questions that can be pursued in further research.

I will conclude this thesis by, first highlighting the collective experience as determined by this study, while reviewing some of my own thoughts as a diabetes educator and integrating them into the ramifications of the collective experience on the educational processes. From this I will demonstrate a learning model that encapsulates the collective learning process described by the study participants. This will be followed by a discussion of several key issues that have emerged, namely: the psychological reaction to diabetes, learning to cope with diabetes, and adaptation to life with diabetes. Finally, I will discuss the implications of these findings on further research and diabetes education practice.

Grief

In looking back at what was presented earlier in the literature review concerning patients' experiences of diabetes, the grief reaction figured rather prominently (Quint 1969). Quint's study was done with families of children with Type 1 diabetes and it was the first of its kind that examined patients' perspectives of their disease. Quint (1969) identified the cause of the grief reaction as the result of its interference with the social order of the family.

Certainly, the participants in this study all experienced a grief reaction following their diagnosis of diabetes. The nuances of the grief reaction varied from one participant to the next ranging from denial to guilt, shock, and anger.

> Sara: ...I left the school and said, sorry guys I gotta go, get a sub. I might be in the hospital this afternoon and it was quite emotional and that it hit me that something (pause) Oh my goodness.
>
> Margaret: There's no diabetes in the family whatsoever...I don't know if I'll hand this down to my kids...yet I've got this so maybe it's the way I've lived. It's stressful. It just happened to me.
>
> Mark: I thought I didn't want to go [for medical attention] because I'd been having trouble with my eyes and I don't want to get glasses. Maybe it's just vanity or growing older.
> He [doctor] told me that time that I would have to go to the adult daycare centre which didn't thrill me. I didn't know exactly what it was but it didn't sound very nice.

It was the theme of loss of a former lifestyle which interfered most directly with the social order of the families of the participants. This was most evident when the prescribed treatment plan interfered with already established roles and activities such as the selection and preparation of foods particularly if these were family favourites or the introduction of an exercise regimen to an otherwise sedentary family.

> Mark: It [the diagnosis] was shocking. I think my wife took it more than I did. It was very difficult for her but, you know, because I know it would require a lot of change. Maybe it's time for a life change. I don't know.
>
> Margaret: We used to eat out a lot...now when we're going downtown, I think well where would we go?...I'd rather come home and eat something I know I can have...
>
> Sara: It's a whole way of finding out what foods have hidden fats and...natural sugars...and you know it just amazed me some of the things and then to carry that over into a family, like I've got 3 boys and a husband so there's five of us to eat and I'm still working on that area.

It was also evident that some of the family members of the participants had some difficulty adjusting to the new lifestyle. This caused some tension and frustration amongst the family members. Clearly, the diagnosis of the diabetes was a major disorienting event for both the participants and their families.

It was particularly interesting to note the themes of denial, anger, and guilt brought out by the study participants. Though these were not mentioned directly by Quint (1969), I understood, albeit by inference, that denial and anger were integral components of the grief reaction. What was particularly interesting about these two emotions was, in both cases (Mark and Margaret), these were associated with a delay in seeking medical attention and a general unwillingness to pursue learning about diabetes management.

> Margaret: I was down south and I was sick all winter not knowing what was wrong. I had achy joints, my mind would go. I couldn't think straight. I was irritable with people...I was sick to my stomach and couldn't keep anything down. I lost 22 lbs and that was just nerves or something...I thought I had a brain tumor and I went all winter [like that].
>
> Mark: [Doctor] said it was for counseling and it's for my diabetes and how to handle that and I still didn't think it sounded very nice.

During this time Mark, in particular, believed the diabetes education to be irrelevant and repeatedly questioned the value of attending the diabetic clinic. Clearly, the initiation of an educational process at such a time must be carefully weighed against the risks of doing so. As a diabetes educator, I have come face to face with individuals who were clearly not ready to learn about diabetes management and yet by virtue of their attendance, were coerced to participate in the educational program.

The theme of guilt was peculiar to all three of the study participants. This was not mentioned by Quint (1969) at all, most likely because the incidence of Type 1 diabetes was not associated with former lifestyle behaviours unlike the incidence of Type 2 diabetes which was partly related to lifestyle behaviours such as poor dietary habits, obesity and inactivity. Here again, it was the role of guilt in the adjustment to life with diabetes that is of some significance. In all three cases it was associated with regret and a seemingly genuine desire for life without the diabetes or 'another chance' at reforming their former lifestyle. Furthermore, it was associated with a sincere concern for others' wellbeing particularly other family members and friends who may themselves be at risk of developing diabetes and/or their complications.

> Mark:...I've always been fairly good about getting a yearly checkup but this time it had been about 3 years and I had put on a lot of weight so I didn't want to go. [My family] make popcorn, they like butter, they just smear it all over there...I think why are they doing this? They don't need that.
>
> Sara: If I had known that 10 years ago that if you don't do something now, 10 years from now you're gonna have Type 2 diabetes from being overweight...I would have done something different back then.
> [Diabetes] is a lot in the family and they say statistically that one our of my three kids could have it so I'm working with them on nutrition.
>
> Margaret: We're kinda rang a tang. There's a phase you go through and I'm divorced left on my own with 3 kids to raise and there's a lot of stress there. If I was gonna be sick I shoulda been sick back then but you go on and on...I suppose once I got on my feet and got going again, I ate and enjoyed life. Could have been that [that caused the diabetes].
> I got grandkids, you know and my daughter I told her to get checked. I told her not to feed my granddaughter too much sugar.

Formal diabetes education

All three participants essentially began to learn to cope with their diabetes when they attended the diabetic education classes. The classes were of major significance for several reasons; these included meeting the participants' intellectual, emotional and experiential learning needs concerning the diabetes. In addition, the class participants formed a reference and support group for another. This support group was of great significance in facilitating the participants' adjustment to life with the diabetes. These findings are in keeping with those reported by Wikblad (1991) concerning patients' needs for basic knowledge about daily life with diabetes and their need for behavioural reinforcement and emotional peer support directed both to the patients and those closest to them.

> Margaret: [New diabetics] should go through that 4 week course...I mean there's no getting around it because what will happen is you're gonna run into people like

> I was talking about at the BBQ. If they went to that course, there's no way they'd be doing that There's just no way. They don't realize the damage. You just shorten your life.
>
> Sara: [The diabetic clinic] was wonderful. It was a real eye opening experience as far as food goes. Food and reading labels and taking time to learn what this disease is all about was a real eye opener.
>
> Mark: In some ways [the education classes were] overwhelming. I'm glad they stretched it over 4 days. I wish in some ways I had more handouts. I took lots of notes and I have to review things and to remember things.

It was Mark who directly reported his intellectual learning needs. He explained that scientific, and logical information helped him to understand the rationale behind the treatment plan. Sara, on the other hand, wanted to learn the basic knowledge about daily life with diabetes. She was more interested in how to manage her diabetes in a variety of situations such as when she was sick, or chose to eat out in a restaurant rather than a scientific explanation of the physiology of the disease or the rationale behind the treatment plan.

Similarly, Margaret was interested in learning how to cope with diabetes in her life including how to manage it when experiencing undue stress. She was not particularly interested in the scientific or treatment plan explanations. Margaret's learning needs appeared to be more emotional and experiential in nature. She repeatedly expressed her frustration and grief with the lack of familial emotional support.

Experiential learning needs were expressed by all participants. These included the ability to perform blood glucose monitoring adequately, to select appropriate foods from a menu or a grocery store shelf, and to carry out exercise activities with confidence. What was particularly significant about these experiential tasks was that they required effort, time, and practice in order to master. Even though the diabetes educators did attempt to meet these experiential needs by providing the participants with repeated opportunities for blood glucose monitoring practice, all three participants expressed some frustration with the effort and time required to master certain experiential tasks. Mark also expressed his frustration with the expenses incurred during these learning endeavours.

> Mark: I guess it all comes with time, knowing where to hit and how to hit and it's still frustrating to me to put blood on the tab and have the machine say, nothing happened. You got to do it again. That's frustrating. That's a buck you're throwing in the garbage just like that.
>
> Sara: I know I can have tomatoes and a cup of vegetables and meat the size of a deck of cards...you know I can picture what I should have and follow it that way but I know in order for me to continue to lose weight and keep up the exercise, I really have to watch, so that's my learning area. I'd love to take a cooking class for diabetics because I could see what they're doing and be able to cook that meal rather than just look at books.
>
> Margaret: I find it [the diet] frustrating like they're saying half a cup, well half a cup of this, well that's frustrating to me because I don't like that stuff so I want a whole cup of this...and it doesn't work that way...It's measuring and getting used to measuring.

However, opportunities to select appropriate foods and to carry out exercise activities were limited because of the organizational structure of the classes. In addition, these experiential needs appeared to be related to the participants' ability to perform these tasks outside of the classroom and in their daily lives. As a diabetes educator, I have noted repeatedly patients' desire to share their successes and trials concerning their diabetes with me and with each other. I think this must be related to these experiential learning needs and in particular to the process leading to the treatment plan mastery. The significance of this finding lies in the provision of 'real-life' experiential learning opportunities for the participants of diabetes education classes as well as opportunities to share these experiences within the classroom. These 'real-life' opportunities must be drawn from the participants' own life experiences. I also think that diabetes educators must explain the need for patience and practice with regards to treatment plan mastery as one attempt to circumvent some of the frustrations experienced by those expecting early mastery of their treatment plan.

Support

In terms of the formation of a reference and support group, the study participants expressed differing viewpoints with regards to the importance and function of such a support group in their lives. Sara was the most vocal about the importance of her classmates' support. She had, however, been involved in at least one other support group prior to beginning the diabetes education classes which may have predisposed her favourably towards belonging to this support group. In her estimation, the purpose of the support group was to provide her with a discussion forum regarding her diabetes and its management. She clearly wanted her classmates input into her daily decisions about her diabetes.

> Sara: ...If it was a little support group like maybe next month your group is gonna meet together and you know I guess that's part of it, like you had a place to go and talk to everybody there who had the same problem so it was kind of neat. Oh it was just sharing recipes before sitting in our little group before the instructor came in and it was like getting together...you need a group to share and make sure you're doing the right thing...I think you really kind of bond with that group. It's scary when you first go like I've got this disease and you realize that yeah you can all survive.
>
> Margaret: I gave a couple of [classmates] my phone number and I gave them some recipes. They were a nice bunch. I'd like to know how they're coming along cause a couple of them were really bad, really bad...yeah it would be nice to get together.
>
> Mark: I don't need a support group...to hold my hand through this so I don't think I would seek them out for that area. I think the area I would want is the information.

Mezirow (1991) described this dialogical process as inherent to transformational learning because it involved critical reflection, in this case, of the prescribed diabetes treatment plan, an exchange of ideas as well as a sharing of feelings among the group's participants. This process of critical reflection was a crucial element in fostering Sara's transformation of meaning perspective about the disease because it afforded her the opportunity to examine her underlying assumptions about such issues as the incidence of

Type 2 diabetes in one so young as her. Sara believed that her youth protected her from Type 2 diabetes because her mother had developed Type 2 diabetes late in life.

Margaret used her classmates for emotional support. Even though she did not believe that they had similar life experiences, she did recognize the significance of their common experiences in the classroom. I believe Margaret received validation and a sense of belonging from her classmates. This spirit of acceptance and of mutual respect became a safe environment and was also described by Mezirow (1991) as essential to transformation because it was in this atmosphere that Margaret began her examination of her underlying assumptions about diabetes namely, her role in its development. Here again this process involved critical reflection.

Mark used his classmates for practical support and as a way to gain insight into the lives of others with diabetes. This was his attempt to validate his own experiences. What he wanted most from the group was information about their experiences. His critical reflection was concerned with the value of other people's diabetes experiences in the management of his own condition. This process was also transformational in nature because Mark's attitudes about the final outcomes of the diabetes were altered dramatically as a result. He no longer believed in the dire outcomes of diabetes as a matter of course despite his strong family history of severe and debilitating complications.

The whole issue of support was of major significance to the study participants. It was particularly interesting because it involved several dimensions. These included defining the variables of meaningful support which were, from the participants' perspectives: a spirit of caring, compassion and sharing, practical knowledge about the diabetes and the individual's treatment plan, guidance and criticism where appropriate, and cooperation. Though each of these dimensions was important, their relative importance varied from one participant to the next and even within the same participant from one point in time to the next.

Mark: 1. You know our family is quite heavy and they're quite pleased to walk with me and so I'm really quite pleased. I think [family support] is really a key thing. My family's fairly supportive. However, they still don't sympathize in some ways and I realize they can have what they want too.
2. Yeah, you know you can live with this. You're not going to lose both legs tomorrow and that I could be disciplined enough to control this, you know you can have control over it. It doesn't have to control you.

Sar..: 1. My blood sugar dropped to 3.7 last week after a meal and my husband automatically said well you need to eat something sweet and I said no, I have to keep monitoring how many times it drops...[so] that I can reduce my medicine not a quick fix, so like he didn't understand that whole process, so I'm wishing that my family had come to the clinic and they were invited.
2. I would find that very lonely like you're trying to master this whole thing and learn about it and if you don't have people to share and talk it through that would be hard, whereas I have a whole support group.

Margaret: 1. I don't think they [family members] know the seriousness of it. I wanted them to come to some of the classes and they just don't know the things that can happen; your eyes can go, your feet can go or your legs can go. They don't realize that stuff, you know even though I tell them that. They go, Oh mom!
2. Somebody cared. They cared even though they put thousands of people through that hospital...I still feel like they care and this is their job and they still care because I know I could pick up the phone and I know they'd see me. That means a lot.

Mark initially wanted guidance and practical knowledge about his diabetes. He wanted this form of support from diabetes educators and his physician. Later as he learned to master his treatment plan, he wanted more cooperation, sharing and caring from family members and his work boss and less guidance from diabetes educators. Margaret, on the other hand wanted caring and compassion immediately following her diagnosis, then practical knowledge and guidance. She wanted these types of support from the diabetes educators and her physician. As she learned to master her treatment plan, she wanted more cooperation as the primary form of support from her family members and work boss. Her reliance on diabetes educators continued even as she mastered her treatment plan. She relied on these people for caring and guidance.

Sara initially wanted caring and compassion from her family members. She then wanted more guidance and practical knowledge from the diabetes educators. As she learned to master her treatment plan, she wanted more cooperation and sharing from work colleagues, friends, and family members. It was evident that all participants predominantly wanted guidance and practical knowledge from the diabetes educators while they wanted more cooperation, caring, sharing and compassion from family members and friends. In addition, and with the exception of Margaret, their reliance on diabetes educators for guidance and practical knowledge dwindled as they learned to master their own treatment plan and their attention shifted to establishing a cooperative environment at work or at home.

As a diabetes educator, I have often wondered about the value of the support I have provided to patients. I now think that it is imperative to determine what type of support people require from diabetes educators. This appears to be dependent upon the strength of their personal support network and their stage of adaptation to life with the diabetes. This is in keeping with Nyhlin's (1990) findings in which she reported that her study participants expressed a need for a comprehensive health care education system that included considerations about their situations in their families, work, and society.

Perspective Transformation

It was interesting that all participants recognized the importance of their attitudinal shifts in order to accommodate their new lifestyle. The theme of personal responsibility for self-care was an inherent component of this attitude change and it was clear that this attitude of personal responsibility governed the participants' behaviours and actions.

> Sara: 1. I have to live with it. I have to be responsible and that's what they really stressed at the clinic too...you have to be on top of it and she really stressed that.
> 2. I think for me like I've always had a weight problem and you know like I've tried every diet and everything and nothing was followed through like you'd go on maintenance for a while and then you're back to your old eating habits so I think with the diabetes you don't have a choice like it's either this way or you're gonna suffer the rest of your life.
> 3. We become a family that eats better and with my husband who has high cholesterol we can work towards becoming a whole family thing.
>
> Mark: 1. It's probably a more healthy lifestyle. There are things that I have wanted to do for the last while and changes that we wanted to make. It's still I think some things could become crowded again and I don't know if I can handle them.

> 2. I have my log I've been keeping my blood monitoring in so I've also included a column on there and I keep track of my weight and I've also been taking my blood pressure every night so I have other information on hand that I can look at and see whether things are settling down or not.
>
> Margaret: 1. You think about it but then when you start worrying about it, you know it's in my hands. I've gotta do something about it. It's up to me to stay on this diet and to exercise and eat proper foods and if I do everything in my power then it's gonna work for me and I gotta think that way.
> 2. Like there's people there who took insulin that would go out and have a sundae and go back and take a shot of insulin and that is you;re killing yourself as far as I'm concerned, who are you fooling?

Sara, for example, recognized that prior to her diabetes diagnosis she had been unconvinced of her need for permanent habit changes in order for her to achieve permanent weight loss. Instead, her weight had fluctuated up and down in line with her momentary motivations and whims. However. after the diabetes diagnosis, the need for lifelong habit changes became abundantly clear to her as did her understanding and acceptance of her personal responsibility for making those changes.

Similarly, Margaret had not considered her attitudes about her health and her responsibility for its maintenance prior to the diabetes diagnosis. Instead, her attention had been focused on her husband's health and her work. Once she realized that she was personally responsible for the maintenance and achievement of her health, her self-care became a priority for her and even though she remained quite concerned about her husband's health, she became less concerned with her work. In Margaret's case, her understanding of personal responsibility for her self-care effectively altered her viewpoint about a number of other significant life events. This in turn altered her choice of behaviours which ultimately affected her work and family relationships.

Mark on the other hand, began his course of adaptation to life with diabetes with a sense of doom and hopelessness most likely because of his strong family history for severe diabetes complications. Once he realized the possibility for his positive diabetes outcomes, he became more adjusted to the concept of his personal responsibility for his self-care. Without doubt, his attitude of hope for a successful future was intertwined with his attitude of personal responsibility. This in turn affected his behaviours regarding his self-care and his attitudes about the personal responsibility of his family members towards their own wellbeing and health.

The role of education in facilitating this attitudinal shift was fascinating. Over and over again, the participants reported that the personal responsibility for their self-care was emphasized by the diabetes educators throughout the diabetic education classes. In addition, opportunities were given to the class participants to take personal responsibility and to report the consequences of the same back to the group. It was apparent that these opportunities occurred informally during the breaks and in between the structured educational sessions.

As a diabetes educator, I have often wondered how best to communicate to persons with diabetes their level of personal responsibility for the diabetes management. I now think these discussions are best facilitated by the educators as an inherent rather than incidental component of the education process, because all three participants in this study at times confused personal responsibility for self-care with personal responsibility for diabetes outcomes. In reality, diabetes outcomes, positive or otherwise, do at times occur irrespective of self-care behaviours. What appeared to be missing in these people's understanding was the level with which they could realistically predict diabetes outcomes as a result of their self-care behaviours. It remains unclear to me specifically how to do this but I am certain that people who believe that their diabetes outcomes are solely their responsibility can and do become overly burdened with guilt and remorse if and when adverse outcomes happen. A fair discussion of their level of responsibility appears to be warranted.

Perspective transformation was experienced by all three participants particularly with regards to their attitude about their health and their sense of personal responsibility for its maintenance. This ultimately affected all aspects of their lives including their work and family relationships. Mezirow (1991) described the meaning making process of perspective transformation as consisting of the following phases: (1) a disorienting dilemma, (2) self-examination with feelings of guilt or shame, (3) a critical assessment of assumptions, (4) recognition that one's discontent and the process of transformation are shared and others have negotiated a similar change, (5) exploration of options for new roles, relationships and actions, (6) planning a course of action, (7) acquiring knowledge and skills for implementing one's plans, (8) provisionally trying out new roles, (9) re-negotiating relationships and negotiating new relationships, (10) building competence and self-confidence in new roles and relationships, and (11) a reintegration into one's life on the basis of conditions dictated by one's perspective" (pp. 168 - 169).

Clearly, all participants experienced the diabetes as a disorienting dilemma and while only two of the three participants experienced guilt, all three experienced some grief and proceeded to examine their role or that of significant others' roles such as physicians, in the incidence of their disease.

> Sara: I guess anger because if I'd have known about big babies and the risk of diabetes, I might have made alternate choices. As soon as I found out I was on the bandwagon that I wasn't going to let this beat me. If I'd have known that ten years ago, I would have jumped on the bandwagon then, so I guess it's lack of knowledge.
>
> Mark: When I did go to the doctor and had the physical done...there didn't seem to be anything wrong except that I had gained a lot in the past 5 or 6 years after my brother died. It was careless I guess.
>
> Margaret: Two years ago my husband had a heart attack and I started feeling funny then and the stress was very heavy and I thought I was gonna lose him...and I got feeling bad then...and I'm wondering would all that stress could that have brought this on?...That could very easily have been the breaking point...from then on I was never normal again.

Once the process of education began, all participants began to realize that their current attitudes and behaviours governing their health were questionable and in fact were in need of modification. During that time significant family members or friends who themselves had diabetes were treated as role models or at the very least, were looked to for consideration of the disease's outcomes.

It was also during that time that significant relationships were formed between members of the group attending the same education classes. These relationships, as has been outlined earlier, were supportive in nature. Acquisition of knowledge and skills followed. This process was time and effort consuming because it required both reflection and practice. From there, the participants began to examine how the rest of their lives fit in with the diabetes. This included family relationships, work, and other roles. In all instances, there was a transition period during which time, some relationships became easier, such as in Sara's case where her diabetes helped to create greater family intimacy and support, while others became clearly more difficult, such as in Mark's and Margaret's cases with their antagonistic and unsympathetic work bosses. All three participants achieved some mastery with regards to their self-care behaviours and all commented that they felt reasonably confident in their ability to care for themselves. Margaret for example, commented on the new-found importance of her health particularly over her work while Mark expressed his confidence in carrying out several self-care behaviours and in asking for the time and space to carry out such tasks from his family and co-workers. In terms of the previously mentioned stages, I believe Mark and Margaret achieved stage 10 (building competence and self-confidence in new roles and relationships) and were in fact in the process of reintegration into their lives. Sara, on the other hand, I believe clearly achieved stage 9 (re-negotiating relationships and negotiating new relationships).

Motivation

The theme of extrinsic and intrinsic motivation as essential to treatment plan success was peculiarly interesting because it highlighted the participants' need for ongoing motivation to help them maintain their newly acquired behaviours. It is difficult to assess with certainty if the motivating factors permanently changed with the individual's increasing adaptation to life with diabetes, because these participants had all been diagnosed with their diabetes within two to six months prior to my interviewing them for this study and therefore the diabetes was a relatively new experience. I suspect that motivation is time, task, life-stage and disease-stage specific. However the data in this study did not clearly indicate this.

Mark's primary motivation to maintain his newly acquired habits was his fear of the adverse diabetes outcomes particularly heart disease and limb amputations. As he learned to master the diabetes management tasks and gained confidence in his abilities, his motivation became the desire to live well with the disease and to continue to accomplish and to achieve things in his life as well to gain longevity for his own sake and for that of his loved ones, particularly his two teenage children.

> Mark: It wasn't necessarily the knowledge that I gained from the classes but the knowledge of what's happened in our family before, you know with my uncle dying...the knowledge that this is serious and don't mess around with it.

Sara's primary motivation to maintain her newly acquired habits was her desire to maintain some semblance of control over the disease and its outcomes. In this manner, she could predict the outcome of her disease. As she became more proficient with her diabetes management tasks, she became motivated by her desire to live well with the disease and to gain longevity for her own sake and for the sake of her family. Sara noted that daily success with her treatment plan, that is the knowledge that her daily choices were positive, was also rewarding and positively motivated her to maintain her newly acquired behaviours. Sara, in particular, appeared to require daily motivational considerations.

> Sara: 1. It was just very emotional like somebody else was taking charge of what I have to do but it didn't take long before it became like get on top of it.
> 2. I don't feel that different if I'm eating properly and exercising. I don't feel like I have anything. It's just, yeah you have diabetes.

Margaret's primary motivation was very similar to Mark's and that was her fear of the adverse outcomes of the diabetes. This remained her primary motivation throughout the period of time that she participated in this study. She also required regular motivational considerations to help her stay committed to her treatment plan. These considerations included frequent interactions with diabetes educators who helped to remind her of the importance of adhering to, and of the consequences of not adhering to her treatment plan.

> Margaret: You can't tell me a two isn't that serious and like she says, the twos are the ones that have the heart attacks, the twos are having the strokes because they pushed it that one little step cause they say I'm not that serious. It's not the twos that push it over the edge and I believe that. I believe that.

What was particularly interesting in all three cases was the role that the educators and the educational processes played in these individuals' motivation towards their self-care behaviours. Clearly, the provision of information was important as was the provision of reassurance, guidance and opportunities for practice and feedback. The acquisition of skills and the development of self-confidence in the conduct of those skills were also imperative components of the educational process. Evidently then, two types of learning took place: instrumental learning and communicative learning (Mezirow 1991).

Instrumental learning (Mezirow 1991) which involves the acquisition of skills and competencies, is by and large recognized as primary in affecting behaviour, in this case, the selection of foods, the monitoring of the blood glucose and the performance of exercise activities. Communicative learning, on the other hand, involves "identifying problematic ideas, values, beliefs and feelings, critically examining the assumptions upon which they are based, and testing their justification through dialogue and making decisions predicated upon the resulting consensus" (pp. 79 - 80). In this situation, the participants took part in communicative learning when they developed their self-confidence and other reflective activities related to their self-care.

Personal relevance of education/treatment plan

The participants learning preferences included the themes: personal relevance of the education/treatment plan and the theme of learning as situationally dependent upon the learners' life circumstances. Mark reported that he wanted the information presented to him to be personally relevant to his life circumstances and in fact, he assessed the usefulness of the information on the basis of its personal relevance. Margaret, on the other hand, identified that her comprehension of any information presented to her in the classes was dependent upon the personal relevance of the information. In other words, she seemed unable/unwilling to take in information that was not personally relevant to her life circumstances. Finally, Sara explained that she was able to recall information presented to her in the classroom based on its personal relevance. She, in effect, tuned out irrelevant information. It was Sara who identified most clearly that she learned new information best when it was applicable to her particular situation. For example, she learned how to cope with sick days when she herself was sick. It was as though the specific situation helped to bring the need for that appropriate information into sharp focus.

> Mark: I understand the process of the small blood vessels and how important that is to have that weight reduction because of the small blood vessels in the feet or the heart or the kidneys cause I wondered why everybody had all these problems. You know why don't you get cancer of the pancreas instead of a heart attack? I didn't understand what the correlation was and now I have understanding.
>
> Sara: It was different getting sick, it was just a cold but the things you have to do are different like you have to drink a lot of fluids and like you can't take a lot of medicines antihistamines or things like that...I have to change my lifestyle in that sense which I hadn't thought of so much before. You're always learning, different situations come up and oh what do I do for that?
>
> Margaret: They showed pictures of things that can happen...and I think everything she said registered to me. It stayed in my mind and always when I eat, it goes through my mind, how are you gonna spend this? I'll have that extra whatever but how are you gonna spend it?

Certainly the theme of personal relevance is a well known adult learning principle (Brundage & Mackeracher, 1980). As a diabetes educator, I have repeatedly wondered how to make my teaching appropriate for each of the learners. Certainly using the learners' own life experiences as models and case studies may be one way. However, in a group situation, it is more likely that program activities need to be designed such that they allow all group members to "discover, acknowledge, and accept the learning needs of other learners and to understand that each learner's needs must be connected, in some way, to the objectives of any group activity" (Brundage & Mackeracher, 1980, pp. 103). The implication here is that serious attention be given to conducting meaningful and functional learner needs assessments as well as communication of those learning needs to the assembled group of participants.

Constraints

The final cluster of themes brought out by one of the study participants was: life constraints complicated diabetes management. It was Sara who commented most directly about this when she discussed time, money, and her maternal role within her family as constraints which impeded her adherence to her treatment plan. She expressed her frustration because she certainly did wish to conform fully with her prescribed plan. Margaret also expressed this same frustration but in a rather more indirect fashion. She stated her frustration with the rigidity of the diet as prescribed because, as she described it, it did not accommodate all of her preferences particularly for sweets.

> Margaret: I'm slowly losing weight which is OK. Sometimes I'm hungrier than ever. I just get so hungry. Other times I couldn't care less if I eat so losing weight isn't that hard for me really. Somedays I get really hungry and I make myself a hot bun. No I feel if I work hard at it, I may be able to take less than my 3 pills.
>
> Sara: I find meal planning hard because sometimes I'll arrive home at 5:30 and so my husband prepared supper last night and we're sitting at the table and he said you know I never even thought about what you can eat or can't eat... so if I'm not figuring things out, I'll try and eat a small meal but I find that part is the hardest.
>
> Mark: We have teenagers...we're extremely busy in our lifestyle and...I realize that it's our lifestyle you know they have their meat, their potatoes and their vegetables and it's all nice but we have the goulash or the spaghetti or the pizza and how do you figure that?

Undoubtedly this is similar to Roberson's (1992) findings where her study participants reported that variables such as money, social concerns such as the ability to eat and drink as others and so on, impacted participant's diabetes self-management. She concluded that health providers needed to gain a better understanding of their clients' perspectives of their health as a way to further facilitate the clients' diabetes self-management.

Yet another theme that related to life constraints which complicated diabetes management was that of frustration with the ignorance and lack of others' discernment. It was Mark and Margaret who expressed this theme most eloquently. Mark found that people around him were often in sympathy with him but lacked some basic understanding about diabetes in general and his diabetes in particular. Subsequently, they gave him inappropriate foods as gifts and generally became more of a nuisance to him. Margaret found that her family members were quite ignorant of the ramifications of her diabetes on her health and on their family life. As a result she became quite frustrated particularly when she seemed unable to explain the ramifications fully to them.

> Mark: I also find people in sympathy but not understanding. I have been given sugarless candy with sorbitol and I don't like chocolate but somebody bought me a box of dietetic chocolate from Purdy's...it's just all very high in fat and all the other things that are to be avoided.
>
> Margaret: 1. They say a number two is not that serious. Well God I don't know how a number one feels if they have mood swings and they feel as lousy as I feel sometimes, they must feel terrible cause I don't feel that great most of the time.
> 2. I kinda explain things the best I could but then I say well why worry them?...well you have to have someone to talk to.

As an educator, I have often thought that education of the individual alone about their diabetes is insufficient in facilitating that person living well with their disease. Clearly, immediate family members must also be included. Beyond that, I suspect educators bear some responsibility for creating a cooperative and supportive environment for the individual with diabetes and their family within the community.

Education programs

In looking back at what was presented earlier in the literature review concerning the practice of diabetes education, the expectation was that the development of alternate diabetes education programs based on educational and psychological theories of learning would be more appropriate for people with diabetes because of the chronic nature of the disease and because of its emphasis on behavioural and lifestyle change (Dunn 1990).

This is in contrast to education programs based on the traditional medical model with its emphasis on the treatment and management of the disease.

Certainly, the participants in this study described their educational experiences in terms of learning to live well with the disease which was an educational process that lent itself very well to Mezirow's (1991) psychological and educational transformational theory of learning. Participants were able to identify both the factors that promoted and impeded their achievement of their goal --learning to live well with diabetes. For each participant, as might be expected, these factors were different.

> Margaret: I wanna live and I wanna live without taking insulin as long as I can. Also I think a big thing was the classes that I took at the hospital. Those voices are in my head and they echo. It's up to you.
>
> Mark: I saw something on the buffet table and it was wonderful so there was a choice that I could make and be intelligent about how much and not have to worry that maybe there's something here that I really shouldn't be eating.
>
> Sara: I think once they had me leveled out like right away I know what I have to do and I know that my mother survived and my brother in law hasn't changed his lifestyle a lot so I think by being aware of what it is, it's more what helped me through that and then it was just that I wasn't gonna let it beat me, so determination I guess.

However, the process leading to their adaptational success was similar for all three participants and was marked by three definitive stages. The first stage was the psychological reaction to the diabetes in which the participants began their process of self-reflection and dialogue. The second was the formal teaching/learning stage where the participants learned the rudiments of diabetes self-management and, in effect, learned to cope with the diabetes. The third stage was marked by some sense of mastery and a transformed set of beliefs about one's own health. This stage was an adaptational stage where the participants proceeded to integrate what was learned in the second stage with their own life.

Learning model

The following is a learning model that incorporates the three learning stages described above and also uses Mezirow's theory of transformational learning

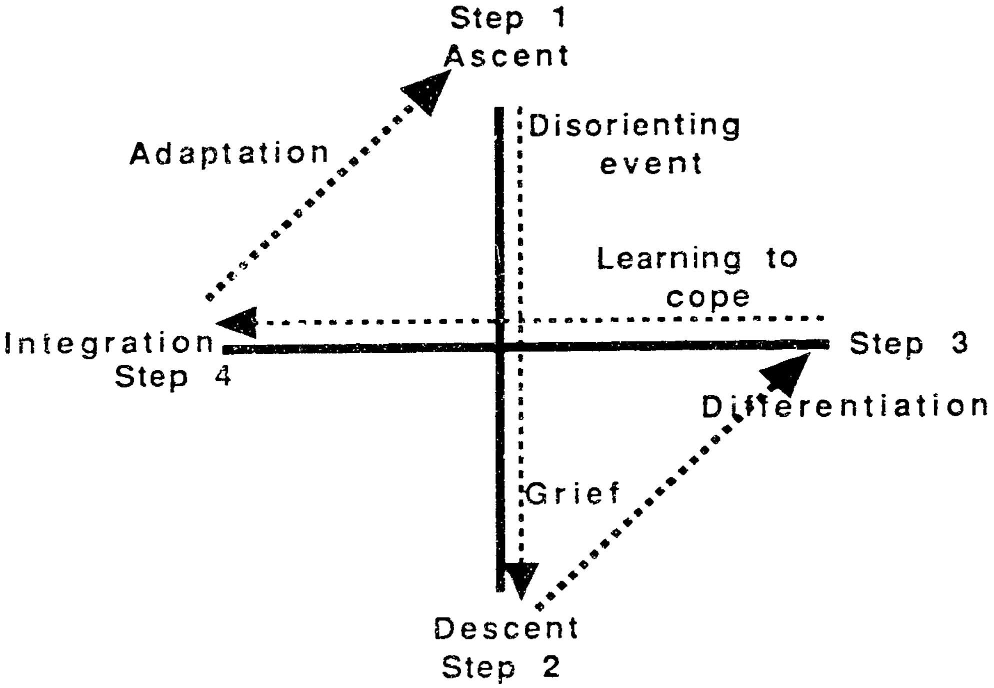

Figure 1: Transformational model of learning depicted by study participants

Note. Adapted from Transformation in Consciousness. Conventional and contemplative perspectives on development (p. 80) by K. Wilber, 1986, Boston: Shambhala.

This is a dynamic dialectical model which encompasses the learning experiences described by this study's participants. Here the participants continuously assessed the value of the formal diabetes education information against their personal life circumstances which included their social, emotional, intellectual, and economic situations. This ongoing process was sequential in nature and consisted of a realization that the status quo was no longer suitable in accommodating the current life circumstances (Step 1). From there the individual experienced grief as the realization that the release of former habits and attitudes had become essential (Step 2). During this time, the individual began the process of self-reflection. The third step was marked by a differentiation process where the individual began to learn to cope with the diabetes. Significant relationships were formed during this stage with classmates and diabetes educators who helped to foster the inter-and intrapersonal reflective dialogue. The final step (Step 4) was marked by a sense of mastery and efforts to integrate the newly learned materials with the individual's life.

It appeared that this sequential process occurred gradually over time and was affected by the individual's ability to cope with the changes. This coping ability included the strength of their support network. This process was not, at least in these participant's cases, strictly a rational process. This is opposed to Mezirow's (1991) theory that posits that perspective transformation is a rational process that occurs within the ego. Clearly, in these individuals' cases, there was some soul searching when they were forced to face and to come to terms with their own mortality. Certainly, there were cognitive elements in this adaptational process such as learning how problem solve, how to monitor one's own blood glucose and so on but by no means were these the only significant learning processes.

Margaret, for example, experienced an enhanced need for security shortly following her diagnosis. This meant she wanted to spend more time alone and more time in her home.

> Margaret I wanna stay home. There's security here. It's stupid when you think about it cause you're taking your two pills and you can go downtown...but I feel better at home. I don't look any different. People don't know you've got diabetes...I don't know what it is. I just don't have the confidence.

It was evidently during this time that she did some in-depth reflection on her life and her life circumstances because following this period of voluntary isolation, her priorities changed drastically; she became more concerned with her health and less concerned with her work. She became more fragile and focused more on her own life rather than being extroverted and outgoing and concerned with the lives of others.

> Margaret: Things bother me more than they used to; something the family will say or do. Before I'd say that's life, not now it goes right to the heart, I don't know why. I talk myself out of it and go and do something else but that's only been in the last year. It's quite an effect that it has.

Similarly, Sara experienced an episode of soul-searching, also shortly after her diagnosis. During that episode, she spent a considerable amount of time in and around her home and in fact declined to travel with her family on their summer vacation. Sara took that time to explore the meaning of diabetes to her. In addition, she practiced the various aspects of her treatment plan in a safe and well known environment.

> Sara: I just said I'm not going anywhere this summer we're going to be spending it at home and I'm going to walk. If I didn't have that this summer and I didn't walk and I didn't feel successful losing the weight then it could have been a different story.

Evidence of descent / regression was less apparent in Mark's case, however, it was present shortly after his diagnosis when he experienced guilt about his former lifestyle and a desire to blame his physician for his diabetes. Mark did not report periods of solitude or isolation that typically depict regression or descent but he did report taking a substantial amount of notes during the education classes. He also reported reading these notes over and over again and reflecting on how to apply this information to his life.

> Mark: In some ways it was overwhelming. I'm glad they stretched it [the classes] over four days. I wish in some ways I had more handouts. I took lots of notes and I have to review things and to remember things...it's so difficult to remember everything.

In this way, the participants were able to make personal meaning of the information presented. Learning became the product of the interaction between the formal education and the individual's personal life circumstances. This process was dependent upon critical premise reflection and the achievement of task mastery. The dynamic between ascent, descent, differentiation, and integration continued until a perspective transformation had taken place. This new perspective consisted of the knowledge that the individual had a serious disease which threatened one's health and required continual attention and care. This was in contrast to the former perspective which consisted of the assumption that one's health required no particular care or attention because one was essentially healthy.

Implications for diabetes education

The implications of this study for diabetes education practice are numerous. However, it must be noted that the small number of participants in this study naturally precludes the broad generalizability of the findings rather the study's generalizability is empathic.

1. Contextual learning needs of the participants clearly influenced their learning endeavours and to some extent their ability to follow/comprehend the formal diabetes education process and therefore the assessment of learners' contextual learning needs is warranted in the development of a diabetes educational program.

2. Considerations for program development and delivery should consider the adaptational stage that the participant is experiencing. The participants' educational needs in this study appeared to differ during each of the three stages mentioned above.

3. Careful consideration should be given to the inclusion of significant family members and/or friends in the educational endeavour. These participants, despite their well intentions, seemed unable to learn about their own self-management and communicate that in a coherent fashion to their family members.

4. The significance of educated support needs to be carefully considered, whether that support is obtained from an organized support group or from friends. These participants clearly benefited when their environment was cooperative and supportive.

5. The role of educators in helping to create a supportive environment in the community, such as in the individual's workplace or school needs to be explored.

6. Opportunities for experiential learning and technique mastery should be maximized in an effort to develop self-confidence as well as competence. Provision of these opportunities within the classroom appeared to positively support the development of treatment plan mastery.

7. Opportunities for problem-solving discussions about the various life constraints would be quite useful. Suggestions could come from the group which would help to enhance group cohesion, as well as from the educators. These participants created such opportunities for themselves during the breaks and in between the formal sessions.

8. Frank discussions about the individuals' level of responsibility with regards to the outcomes of the diabetes are essential. These participants, as has been mentioned, felt that they had total control over their diabetes outcomes which is not strictly true.

Implications for further research

As far as this study's implications for future research, I think there are several: I think the study of specific contextual learning needs warrants a closer examination. For example, what effect, if any, do contextual learning needs have on the ability of the individual to learn and to master treatment plan tasks? How can these contextual learning needs best be assessed by diabetes educators? and which of them are appropriate to address in the formal diabetes education process?

I think the issue of support and the role of educated support warrants a closer examination as well. For example, what type of support does the individual require over the course of their disease and what role do educators have in this process? Furthermore, what responsibility do educators have for the development of a cooperative and supportive environment in the community?

Finally, because the participants in this study had all been diagnosed relatively recently, it would be interesting to know what effect the passage of time would have on any of the major themes found in this study including, support, motivation, learning endeavours, and daily self-management.

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Appendix one

Interview Guide

1. What was it like when your first found out that you have diabetes? Can you describe how you felt? what was happening then ?
2. You've known about the diabetes for ---- do you feel any different now after all this time? Why is that? Can you describe how this process came about?

3. Can you describe how you learned to take care of yourself with the diabetes? Were there any particular people who helped you , or those who didn't? Were there any particular events that helped you or didn't help you?

4. If I had been there when you were learning to take care of the diabetes, what would I have seen?

5. If diabetes were a person sitting across a table from you, what would want to say to it? Why?
6. How does having diabetes affect you?

Appendix two

Research activities schedule

Sept 1993	Informed consent: physicians and participants; recruit participants; conduct 1st interviews
Oct 1993	Conduct 2nd and third round of interviews
Jan 1994-March 1994	Data analyses
April 1994 - May 1994	Final report writing

Appendix Three

Consent Form

Thesis Title:	**The Lived Experiences of Type 2 Diabetes**
Researcher:	**Nadia Najjar** **University of Alberta** **Faculty of Education** **Department of Adult Career and Technology**

This is to certify that I agree to participate in the above study. Having been contacted by the researcher, a graduate student in the Department of Adult Career and Technology, I understand that:

1. The purpose of this study is to gain an understanding of people's experiences and learning experiences of diabetes.
2. My name will not be disclosed at any time during this study or used in the resulting thesis.
3. Any information I provide to the researcher will be kept confidential and used solely for the purposes of this research study.
4. I am participating in this study on a purely voluntary basis. Therefore, I have the right to quit or refuse to participate at any time.
5. The results of the study will be made available to me if I so request.
6. I have been fully informed as to the nature of the study and my involvement in it.
7. The thesis this study leads to will be available for examination at the University of Alberta Library.

Signature of participant ______________________________ **Date** ________________

END

17-01-95

FIN