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QUALITY OF LIFE AND CONTROL IN NON-INSULIN-DEPENDENT DIABETES MELLITUS

BY

MJ WIERSEMA

A THESIS
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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 "Quality of life and control in non-insulin-dependent diabetes mellitus" submitted by MJ Wiersema in partial fulfillment of the requirements for the degree of Master of Education in School Psychology.

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Abstract

Type II diabetes affects hundreds of thousands of Canadians. Yet, little is known about how diabetes may impact quality of life or about how quality of life may in turn affect glycemic control. Both of these issues were addressed in this study.

Subjects were 26 men and 32 women attending a large metabolic clinic. All had been diagnosed with type II diabetes for at least ten years. Quality of life was operationally defined in terms of four components: (a) physical well-being as indicated by the physical scale of the Sickness Impact Profile, (b) psychological well-being as indicated by the Index of General Affect and the depression and anxiety scales of the Basic Personality Inventory, (c) social well-being as indicated by psychosocial scale of the Sickness Impact Profile, and (d) subjective life satisfaction as indicated by the Overall Life Satisfaction Scale. Control was operationally defined by the results of a glycosylated hemoglobin assay.

There were several major findings. First, despite functional limitations in both physical and social activities, most long-standing, type II diabetics seem to experience the same psychological health and life satisfaction as the rest of the population. Other researchers have interpreted similar results to mean that many persons are capable of adapting to the lifestyle restrictions of a chronic disease. Second, with the possible exception of depression, there was little evidence for a relationship between any of the quality of life variables measured and glycemic control. Third, the range of scores was exceptionally wide. This suggests that there may be many ways of coping with diabetes. Fourth, there was a significant correlation between scores on a subscale measuring alertness behavior and scores on the glycosylated hemoglobin assay. In addition, these alertness behavior scores were unlike those obtained from populations suffering from other chronic diseases. These two findings taken together provide limited support for an accelerated cognitive aging effect of diabetes.

Recommendations include implementing a psychosocial component into current educational programs, treating enhanced quality of life and improved metabolic control as separate goals, designing individualized treatment plans, and teaching compensatory strategies to overcome any memory and concentration difficulties.

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I. INTRODUCTION

A. Background

The Canadian Diabetes Association (1989) reports that six hundred thousand Canadians suffer from diabetes. Epidemiologists suspect that an additional six hundred thousand may be undiagnosed (Harris, Hadden, Knowler, & Bennett, 1987). And these numbers are rising. Two factors are responsible: (a) the increased prevalence of diabetes among the elderly (Harris, et al., 1987) and (b) the increasing number of elderly persons in the population (Statistics Canada, 1988). Thus, in terms of sheer numbers, diabetes is a cause for concern.

Eighty to ninety per cent of diabetics suffer from type II or non-insulin-dependent diabetes mellitus (NIDDM). This is a metabolic disorder characterized by insulin resistance. The cause is unknown. If left untreated, blood sugar levels increase causing a wide range of symptoms. Risk factors include age (greater than forty), genetic predisposition, and obesity. Treatment is primarily the patient's responsibility. It includes a complex regimen of diet, exercise, and blood and/or urine testing. Frequently, insulin injection or oral hypoglycemic medication is necessary to achieve glycemic control. Despite treatment, most NIDDM patients eventually develop serious secondary complications including retinopathy, neuropathy, nephropathy and/or vascular diseases. Serious manifestations may include blindness, sexual dysfunction, amputation, kidney failure, myocardial infarction, and/or stroke.

Little is known about how the individual type II diabetic patient experiences this disease. Such quality of life questions represent a relatively new field of endeavor. Furthermore, most of the existing studies have been performed on insulin-dependent (type I) diabetics. Because the two forms of diabetes are now seen as both pathologically and etiologically distinct (King & Zimmet, 1988), these results cannot be generalized. It would be especially dangerous to apply these results to persons with long-standing, type II diabetes. This latter group is likely to be elderly. Consequently, they may be simultaneously coping with the limitations of advancing age, other medical ailments, and multiple drug therapy (Bohannon, 1988). Thus, there is a need for research into the quality of life of long-standing, type II diabetics.

Another area of current concern is blood sugar control. Although genetic predisposition may play a role in the development of secondary complications of diabetes, recent studies have also implicated long-term blood sugar levels (Raskin & Rosenstock, 1986). Thus, achieving glycemic control has become a major goal of diabetic treatment. This has been described as a "problem of many things: of behaviour, attitudes, stress control and family support as well as metabolism" (Shillitoe, 1988, p. 242). Currently, the psychosocial factors are receiving a lot of attention. Many researchers have called for further study into the relationship between psychosocial variables and metabolic control (eg. Fisher, Delamater, Bertelson, & Kirkley, 1982; O'Connor, Fragneto, Coulehan, & Crabtree, 1987). Quality of life is one such psychosocial variable.

To summarize, type II diabetes affects hundreds of thousands of Canadians. Yet, little is know about how this form of diabetes may impact quality of life or about how quality of life may in turn affect blood sugar control. This study addressed both of these issues.

B. Overview

This is an exploratory, descriptive study designed to investigate the long term impact of NIDDM on an individual's life and to explore the possible relationship between quality of life variables and control. It is hoped that by gaining knowledge into how diabetes impacts an individual's quality of life, health practitioners will be better able to meet both the short and long-term needs of individual patients. Quality of life variables were also investigated as a possible avenue through which improved glycemic control may be achieved.

C. Purpose of Study

The purpose of this study was two-fold:

1) To explore the impact of non-insulin-dependent diabetes mellitus on the quality of life of persons having had the disease for ten years or more.

2) To investigate the possibility of a relationship between quality of life as assessed by a self-report questionnaire and glycemic control as measured by the glycosylated hemoglobin assay (HbA1).

D. Definition of Terms

1. Quality of Life: A composite measure of an individual's physical, psychological, and social well-being plus a measure of his/her subjectively experienced life satisfaction.

2. Non-insulin-dependent diabetes mellitus (type II): A disease characterized by elevated plasma glucose concentration. Individuals are

not ketosis prone and the HLA types and islet cell antibodies characteristic of insulin-dependent diabetes are not usually found.

3. Insulin-dependent diabetes mellitus (type I): A disease characterized by elevated plasma glucose concentration. Individuals are dependent on insulin to prevent ketosis. This disease is associated with the presence of certain HLA types and islet cell antibodies.

4. Glycemic control: The degree to which blood glucose levels fall within the normal range. In this report "glycemic control" is used interchangeably with "blood sugar control" and also with the broader term "metabolic control."

5. Hypoglycemia: A state in which an individual's blood sugar level is below the range considered to be normal.

6. Hyperglycemia: A state in which an individual's blood sugar level is above the range considered to be normal.

7. Glycosylated Hemoglobin: A term for hemoglobin molecules which have combined with glucose. The extent to which this chemical reaction occurs depends on the concentration of glucose in the blood.

8. Glycosylated Hemoglobin (HbA1) Assay: A procedure which provides a measure of glycemic control over the previous 6-8 weeks. Unlike other measures of blood sugar levels, it is independent of time of day, recent food intake, or activity levels. For this study, values of 4.9 - 8.0 mmol/l are considered to be within the normal range (see appendix A)

II. REVIEW OF THE LITERATURE

A. Quality of Life

1. Rationale for studying quality of life

"'Improved health' is an undisputed, universal goal of health practitioners" (Jette, 1980, p. 567). Traditionally, health referred to an absence of disease. Consequently, health measures were limited to morbidity and mortality statistics. However, today's definition of health usually includes a component of general well-being (eg. Aaronson, Calais da Siva & de Voogt, 1988; Spitzer, 1987b). Therefore, any current measurement of health is incomplete without some measure of quality of life.

The first reason for the shift is demographic: our population is aging, bringing with it an increasing prevalence of chronic disease. In Canada, the percentage of the population over the age of 65 has increased from 7.7% in 1959 to 10.6% in 1986 (Statistics Canada, 1988). Epidemiological studies indicate that older persons are more likely to suffer from chronic diseases. For example, a Swedish group of researchers (Ohlson et al., 1987) reported that among a cohort of 855 men born in 1913 the prevalence of diabetes rose from 1.5% at age 50 to 7.6% at age 67 and Harris et al. (1987) reported a rise from 2.0% among persons aged 20-44 to 17.7% among those aged 65-74. Since there is no "cure" for chronic diseases such as diabetes, health practitioners are limited to improving quality of life. Thus, research into quality of life is necessary to meet the needs of a large and increasing proportion of the population.

Second, the cost of medical treatment is spiralling. In 1986, Canadians spent 24 million dollars on insulin alone (Lemay, 1988) and American authors have suggested that diabetes may cost that nation as much as twenty billion dollars annually (eg. Krosnick, 1988). Society can no longer afford to spend an infinite amount of money providing the maximum amount of health care that technology can offer. Furthermore, the situation is expected to worsen with further medical research and tighter government budgets (eg. Sisk, 1987). Quality of life studies may play an important role in helping health administrators make difficult resource allocation decisions (Drummond, 1987; Jonsson, 1987).

In addition, it is becoming apparent that the cost of chronic disease not only involves the direct costs of medical care but also the indirect costs due to the loss of functional capacity (Lubeck & Yelin, 1988). Therefore, quality of life variables must be studied before any true estimate of the cost of diabetes can be made.

Third, medical technology often offers a variety of treatment alternatives. Quality of life measures may be used to help judge relative advantages and disadvantages. With respect to diabetes, quality of life variables have been used to help judge the efficacy of pancreas transplants (Nakache, Tyden & Groth, 1989; Schreiber, Norman, Cosimi, Rubin, & Nathan, 1989), continuous subcutaneous insulin infusion (Levy & Czernichow, 1988; Shapiro, Wigg, Charles, & Perley, 1984; Meize-Grochowski, 1989), multiple injection with blood glucose monitoring (Mazze and Shamoon, 1982) and various physician-patient interactions (Kaplan, Greenfield, & Ware, 1989).

Fourth, the treatments currently available for chronic diseases often involve unpleasant side effects. Several researchers have put forward the question: "What is quantity of life without quality?" (eg. Gill, 1984). Results from several studies demonstrate that patients will not follow a treatment plan unless the perceived benefits outweigh the perceived costs (eg. Ockene, Sorensen, Kabat-Zinn, Ockene, & Donnelly, 1988; Testa, 1987). This issue is especially cogent for diabetics because most of the onus for treatment rests on the individual. Estimates of adherence among diabetics are notoriously low. For example, in a study of 208 NIDDM diabetics, Ary, Toobert, Wilson, and Glasgow (1986) reported that half of the time these persons either failed to diet or neglected to exercise. Furthermore, Cerkoney and Hart (1980) studied insulin-treated diabetics and found that only 2 out of 30 persons followed all of the 45 items that the investigators believed to be necessary for good diabetic control. Perhaps if the medical profession were more conscious of quality of life considerations, satisfactory compromises could be negotiated and adherence improved (Uhlmann, Inui, Pecoraro, & Carter, 1988).

Fifth, there is an increasing trend towards humanizing the entire medical field (Levine, 1987; Schipper, 1987). Health practitioners are beginning to move away from a model based solely on beneficence and towards a model which incorporates principles of autonomy (McCullough, 1984). In fact, some physicians are beginning to encourage the patient to participate in making treatment decisions. This is an important development because it is evident that physician and patient views may be very different. For example, in one study of hypertensive medication, physician ratings indicated 100% improvement, patients ratings indicated 48% improvement and friends and relatives' ratings indicated 2% improvement (Jachuk, 1882). In another study, Pearlman and Uhlmann (1988) compared physician and patient evaluations of quality of life and found physician judgments to be significantly lower. Slevin, Plant, Lynch, Drinkwater, and Gregory (1988) did a similar study of 108 cancer patients and concluded that "the doctors could not accurately determine what the patients felt" (p. 109). In fact, both Croog et al. (1986) and Schipper (1983) comment that physicians are seldom even aware of the effect various therapies can have on quality of life. Finally, in a study of 30 IDDM patients Pendleton, House, and Parker (1987) reported similar discrepancies between physician and patient judgments regarding the difficulty of adhering to various therapeutic regimens.

Treatment goals may also differ. In reviewing insulin pump therapy, Jornsay, Duckles, and Hankinson (1988) wrote that while health practitioners are interested in improving metabolic control, patients are more interested in improving lifestyle. Furthermore, many outcome studies measure the number of work days lost (eg. Nakache et al., 1989) even though it has been demonstrated that patients are more concerned with their ability to maintain relationships (Lubeck & Yelin, 1988). All of the above discrepancies point to a need for quality of life studies which illuminate the impacts of disease and treatment from a patient's perspective.

Sixth, quality of life variables have been recognized as important predictors of mortality. For example, Ruberman, Weinblatt Goldberg, and

Chaudhary (1984) studied 2320 male survivors of myocardial infarction and discovered that even after other prognostic factors were controlled, persons suffering either stress or social isolation had a four fold higher risk of death.

Lastly, the reliability and validity of psychosocial measuring instruments has vastly improved over the past few years. Thus, quality of life can now be assessed in a more meaningful way. (Tarlov, 1983; Ware, 1984b)

In summary, quality of life studies have become more numerous and relevant because they: (a) help establish important goals in treating the increasing numbers of elderly people suffering from chronic disease, (b) are useful in assessing different treatment plans, (c) provide doctors with information on the patient's perspective, (d) incorporate newly established, reliable, valid measuring instruments, and (e) help explain mortality patterns.

2. Historical Background

One of the first medical studies to formally incorporate quality of life variables was that undertaken by Karnofsky in 1948. He designed a functional status measure and then used it to help determine the therapeutic value of nitrogen mustards in treating cancer (Karnofsky, Abelmann, Craver, & Burchenal, 1948; Karnofsky & Burchenal, 1949). This instrument, now called the Karnofsky Index, is still in use today (Mor, Laliberte, Morris, & Wiemann, 1984). Another major step forward was taken by Sidney Katz when he devised the Index of Independence in Activities of Daily Living (Katz & Akpom, 1976). This instrument covers functional capacity in the areas of bathing, dressing, going to the toilet, transferring, continence and feeding. It is also still in use today (Kaplan, 1988).

Currently, there are many researchers devoting their energies to studying quality of life. According to one popular computer literature search (Medline) there were 667 articles published on this topic in 1987 alone. Thus, most chronic diseases and their respective treatments are now being assessed from a quality of life perspective. Some examples include: hypertension (Croog et al., 1986), cardiovascular disease (Kaplan, 1988), end-stage renal disease (Evans et al., 1985), and cancer (Padilla, 1983). In fact, numerous organizations (eg. National Cancer Institute) and many individual researchers are now calling for the incorporation of quality of life measures in all clinical trials (eg. Friedman, Furberg, & DeMets, 1985; Katz, 1987).

3. The Problem of Definition

Despite the rapid growth in quality of life as an outcome variable, there is still no consensus with respect to definition. Some social scientists look at need fulfillment. For example, the report of the Panel on the Quality of American Life (1980) conceptualized quality of life in terms of growth needs which were based on Abraham Maslov's needs-hierarchy theory. Similarly, Campbell et al. (1976) wrote of the discrepancy between expectations and achievements. However, within the context of medicine, reviewers have described quality of life as a complex, multidimensional concept (eg. Pearlman & Uhlmann, 1988; Vetter, Jones, & Victor, 1988). One reviewer tried to summarize some of the commonly assessed dimensions. The list included "physical activity, social and leisure activity, work, symptoms, loss of income, cognition, emotional adaptation, self-esteem, interpersonal relationships, impotence, incontinence, and overall satisfaction with life" (Bergner, 1989, p.S149). It seems that many investigators deduce their own study-specific definitions. Sometimes the term is not defined at all (vanDam, Somers, & vanBeek-Couzijn, 1981; Miettinen, 1987).

In addition, there is no direct way of measuring quality of life (Schussler & Fisher, 1985). Many researchers devise their own study-specific indicators (eg. Diabetes Control and Complications Trial Research Group, 1988). Consequently, there is a plethora of measuring instruments. Reviewers conclude that this haphazard state of affairs has hampered cross-study comparisons and hindered progress in the field (Friedman et al., 1985; Spitzer, 1987b).

The traditional starting point for medical studies of quality of life is the World Health Organization's (WHO) definition of health: "Health is a state of complete physical, mental, and social well-being" (World Health Organization, 1947, p.1). However, there are many critics. For example, Spitzer (1987a) believes that this definition is more of a slogan for happiness than a definition of health. In addition, several researchers have criticized the social well-being portion of the definition as being irrelevant to medical outcome studies. Ware et al. (1981) ask if "one of two persons enjoying the same level of physical and mental health would be considered less healthy if that person resided in a strife-torn community or was separated from family members" (p.621).

At the same time it is difficult to totally discount the social well-being aspect of quality of life. Numerous studies illustrate how central this concept is to how most persons judge their quality of life. Vetter et al. (1988) interviewed 1066 persons over the age of seventy and found that the principal determinants of life satisfaction were finances and family. Flanagan (1982) surveyed 3000 adult Americans using a critical incident technique and reported that the most frequently reported determinants of quality of life were health and children. In ranking activities, a group of 300 arthritis patients and 100 controls rated activities that maintain social relationships as being the most valuable (Lubeck & Yelin, 1988). Finally, in a study of 126 elderly persons, Pearlman and Uhlmann (1988) found these persons gave the highest ratings to health, interpersonal relationships, and finances.

Thus, the question becomes one of distinguishing health-related quality of life issues from those arising out of the social conditions of the world (Levine, 1987). Some researchers attempt to do this by including instructions which direct patients to only check off only those items which are true because of their health. This is the approach taken by the measure of social well-being which was used in this study.

Another definitional issue involves how to best capture a global integration of the individual's quality of life experience. Many reviewers recommend that this be done by assessing general well-being or life satisfaction (eg. Levine & Croog, 1985). This is the philosophy behind the Life Satisfaction Scale which was used in this study.

Thus, several researchers in quality of life research have advocated a twofold approach to measuring quality of life in which both the patient's subjective perception of life satisfaction and well-being and the patients objective functional status in the three dimensions outlined in the old WHO definition of health are used (eg. Croog et al., 1986; Evans et al., 1985; Spitzer, 1987b). This is the conceptual framework which was used in this study.

B. Diabetes and Quality of Life

Although conceptualizing disease impact in terms of quality of life is a recent development, researchers have been evaluating the various physical, psychological, and social implications of diabetes for many years.

1. The Physical Component

Numerous studies demonstrate the serious physical consequences of diabetes. In Canada, in 1986, over three thousand deaths were directly attributed to diabetes mellitus (Statistics Canada, 1988). If deaths due to indirect causes were included this figure would be considerably higher. In fact, the authors of one epidemiological study report that having diabetes doubles the risk of death at all ages (Kleinman, et al., 1988). Some researchers have even claimed that diabetes is a form of accelerated aging (Kent, 1976; Lipson, 1986).

Studies show that serious secondary complications commonly occur 10-15 years after diagnosis (Santiago, 1986). Often a person with diabetes will develop more than one complication. The following are some of the major epidemiological studies of the prevalence of retinopathy, nephropathy, neuropathy, and vascular disease among persons with diabetes:

First, in regards to retinopathy, one group of researchers studied a group of 1370 older onset diabetics (mostly type 11) and reported that 2.9% became blind over a period of four years (Moss, Klein, & Klein, 1988). This was considered to be an underestimate since the subjects omitted from the study because of mortality would have been more likely to suffer blindness. From the perspective of prevalence, a World Health

Organization (WHO) multinational study of 6695 diabetics aged 35-54 revealed that "only 32% of the men and 38% of the women with diabetes of long duration were without eye disease" (Diabetes Drafting Group, 1985, p. 637). A Swiss group of researchers found that among a group of 159 later onset, insulin-treated diabetics, the prevalence of retinopathy sixteen years after diagnosis was 60% (Teuscher, Schnell, & Wilson, 1988).

Second, with respect to nephropathy, Ballard et al. (1988) found that 20 years after diagnosis, 25% of a sample of 1031 persons with NIDDM had kidney damage as demonstrated by protein in the urine. Parving et al., (1988) studied a sample of 957 persons having had IDDM for at least five years and found an incidence of microalbuminuria of 22%. Microalbuminuria is predictive of the later development of nephropathy. Finally, in a review of the topic, Herman and Teutsch (1985) conclude that "after 15 years of diabetes one-third of persons with IDDM and one-fifth of persons with NIDDM have developed nephropathy" (p. XIV-1).

Third, with respect to neuropathy, reliable prevalence estimates are difficult to find (National Diabetes Data Group, 1985). Neuropathy may affect the somatic and/or autonomic nervous systems causing a wide variety of symptomology including pain, loss of sensation, cardiac deinnervation, constipation, diarrhea, and/or incontinence (Bays & Pfeifer, 1988). Dyrberg, Benn, Christiansen, Hilsted, and Nerup (1981) tested 75 consecutive insulin-dependent diabetic males attending a hospital outpatient program and discovered that 27% suffered from autonomic neuropathy as measured by an abnormal response in beat to beat variation during forced respiration. A group of reviewers estimate that symptoms such as abnormal pain and touch sensation are present in about 10% of all patients and that abnormal nerve conduction velocities are found in almost all diabetics (Clements & Bell, 1985).

Some researchers believe that neuropathy may also cause sexual dysfunction. Impotence has been reported by many diabetic men and insufficient lubrication has been reported by some diabetic women (eg. Jensen, 1981). Few objective studies have been performed. In an older but often quoted study, the prevalence estimate for sexual dysfunction among diabetic men is 49% (Kolodny, Kahn, Goldstein, Barnett, & Boston, 1974). The corresponding figure for women is 35% (Kolodny & Boston, 1971). Jensen (1981) compared 80 diabetic men and 80 diabetic women to 80 controls by using a self-administered questionnaire. He reported that 44% of the diabetic men as compared to 12.5% of male controls indicated sexual dysfunction. The corresponding figures for women were 27.5% and 25%. For both men and women sexual dysfunction was significantly correlated with peripheral neuropathy. In a more recent study which separated type 1 and type 11 diabetic women, Shreiner-Engel, Schiavi, Vietorisz, & Smith (1987) report that diabetes had little impact on the type I diabetic women but had a negative impact on the sexual desire, orgasmic capacity, and lubrication of the type II diabetic women. They suggest that the developmental stage of life at which the diabetes is diagnosed has a substantial influence on how it affects sexuality. Finally, in a more recent study of diabetic men, Cavan, Barnett, & Leatherdale (1987) surveyed a population of 412 men attending a diabetic clinic. Results from 292 persons indicated that

27% were impotent as compared to 9% of a sample of nondiabetic outpatients.

Fourth, with respect to vascular disease, the researchers of the World Health Organization study (Diabetes Drafting Group, 1985) found that the overall prevalence of large vessel disease in their sample of 35-54 year old diabetics was 28% for men and 36% for women. These vascular complications have been associated with mortality. In a major review, Harris and Entmacher (1985) estimates that heart disease is implicated in 60% of diabetic deaths and cerebrovascular accidents in about 25%. These figures are higher than those taken from studies of more general populations. For example, Barret-Connor and Wingard (1983) compared 343 diabetics with 2104 non-diabetics and found a risk ratio for death from ischemic heart disease of 2.5 for diabetic men and 3.4 for diabetic women. This is consistent with a Swedish study of 341 patients with myocardial infarction. Malmberg and Ryden (1988) report that not only were a disproportionate number of the victims non-insulin-dependent diabetics (23%) but that these persons had a much higher mortality rate, usually due to reinfarction.

Finally, peripheral vascular disease also occurs with increasing prevalence among diabetics. In studying hospital discharge data, Most and Sinook (1983) found that 45% of all lower extremity amputations are performed on persons with diabetes. With respect to prevalence, Palumbo and Melton (1985) report that after 20 years 45% of all adult diabetics have diminished arterial perfusion to the legs and feet.

According to the Canadian Diabetes Association (1989) the situation is similar in Canada. They report that the complications of diabetes make it the third leading cause of death in Canada, the leading cause of new cases of blindness, and the indirect cause of 50% of all strokes and heart attacks.

These complications obviously impact the physical component of quality of life. Little has been written as to how diabetes may affect an individual's day to day functioning, his or her ability to move around within the home or community, or to take care of his or her own body. In a major review of disability in diabetics Drury (1985) reports that adult diabetics experience two to three times more bed days and work loss days than the rest of the population. Mattler, Falck, Ronnemaa, and Hyyppa (1985) administered a questionnaire to 33 type 2 diabetics and 32 controls and concluded that diabetes has a significant impact on day to day activities such as lifting, running, airing carpets, making beds, and vacuum cleaning. This study included measures designed to address these types of issues in more detail.

2. The Psychological Component

Physicians have long linked psychological problems with diabetes. In 1679, Thomas Willis wrote that diabetes was "sometimes caused by sadness" (p. 253, cited in Major, 1948). Two hundred years later the same conclusion was reached by Menninger (1935) who wrote that "diabetes may be the direct result of psychological disturbances" (p. 11)." One of the first scientific studies of diabetes was conducted by Hinkle and Wolf (1952). They related observations of life stress with blood sugar levels in a group of 64 diabetics and concluded that "psychological factors may have an important influence on the onset and course of the disease" (p. 520). Researchers today continue to study the psychological sequelae of diabetes.

a) Neuropsychological Variables

An important line of research today concerns the possible neuropsychological sequalae of diabetes. There is some evidence that early onset of insulin-dependent diabetes mellitus is associated with minor cognitive deficits (still within the average range). In a study of 27 early onset diabetic children, 24 late onset diabetic children, and 30 sibling controls, Rovet, Ehrlich, and Hoppe (1987) found that the early onset diabetics performed significantly lower on tests of visuospatial ability. This was particularly true of the girls. In a study of 40 adolescents compared with demographically matched controls, Ryan, Vega, and Longstreet (1984) found significant differences on measures of verbal intelligence, visuomotor coordination, and critical flicker threshold. Similar results have been found with adult diabetics. Skenazy and Bigler (1984) compared 39 diabetics to both a nonneurological chronically ill group and a healthy group of subjects and found that the diabetics scored significantly lower on tasks that required visual and motor efficiency or somatosensory discrimination. Furthermore, these decrements were associated with severity of disease. This has led some researchers to hypothesize neuropathy as the causal agent. Support for this hypothesis is found in studies which correlate hypoglycemic episodes or other signs of neuropathic damage to differences in cognitive impairment. For example, in the Rovet et al. (1987) study the number of hypoglycemic convulsions was significantly associated with lower scores on tests of spatial ability and arithmetic.

Similar results were obtained in a study of 27 diabetic men: Those in poor control scored significantly lower on the Wechsler Adult Intelligence Test scales of Information and Vocabulary than those in good control (Holmes, 1986). Furthermore, in a longitudinal study, Golden et al. (1989) found that frequent episodes of hypoglycemia were correlated with lower abstract/visual reasoning scores among a group of 23 children diagnosed with diabetes before the age of five. However, the test performance decrements found in all of the above studies are small. Furthermore, some investigators have failed to find any differences between their populations of diabetics and controls or any correlation between neuropathy and intellectual status (eg. Lawson et al., 1984). Methodological issues surrounding subject selection, matching, and instrument sensitivity may account for differences among studies.

Results from studies comparing the neuropsychological performance of persons with NIDDM with their peers are even less clear. Mooradian, Perryman, Fitten, Kavonian, and Morley (1988) found decreased performance on measures of serial learning and visual memory for 43 elderly non-insulin-dependent diabetic men as compared with 41 age-matched controls. Similar findings are reported by Perlmuter et al. (1984) who studied a 140 non-insulin-depedent persons aged 55-74. However, Mattler et al. (1985) compared 33 male and female type II diabetics aged 45-64 and found no significant differences on any portion of a neuropsychological battery of tests. This discrepancy may be explained by the age differences. The lack of any significant findings in a longitudinal study of 52 older type II diabetic men

(Robertson-Tchabo, Arenberg, Tobin, & Plotz, 1986) is harder to explain. Perhaps the clinical populations of the Mooradian et al. (1988) and the Perlmuter et al. (1984) studies were more severely affected by their diabetes than the more random sample of Robertson-Tchabo et al. (1986). Alternatively, the matching procedures may have varied. With respect to the etiology of these cognitive deficits some researchers have suggested that the secondary complication of neuropathy may affect the central nervous system (Shillitoe, 1988, p. 18). However, as with the type I diabetics, research evidence is mixed. The Perlmuter et al. (1984) study found a correlation between peripheral neuropathy and decreased cognitive performance. However, the Mooradian et al. (1988) did not. Instead, the latter group of researchers found some differences in EEG patterns which they believe suggests "there may be a central neural pathologic condition associated with diabetes" (p.2369). One potential problem with all of these studies is that some of the neuropsychological changes may be too subtle to detect with the currently available measures. Other problems which confound experimental findings include the number of additional factors which affect cognitive performance, the small sample sizes used, and the complex interactions between various diabetic complications.

b) Personality Variables

A second line of research concerns the possibility of a "diabetic personality". Results from some early studies suggested that diabetics differed from other persons along a variety of personality dimensions (eg. Murawski, Chazan, Balodimos, & Ryan, 1970). Furthermore, when a group of 300 diabetics were interviewed 25% of them agreed to the statement "Having diabetes over a long period changes the personality" (Dunn, Smartt, Beeney & Turtle, 1986). However, the concept of a specific "diabetic personality" has not been supported by recent studies (eg. Ivanyi, Gyimesi, Hanyecz, & Kallai-Szabo, 1988; Jenkins & Webb, 1980) and many reviewers now conclude that the "diabetic personality" is a myth (eg. Dunn & Turtle, 1981).

c) Psychiatric Variables

Many studies point to an association between diabetes and an increased incidence of depression and anxiety. For example, using clinical examinations and DSM-III criteria, Popkin, Callais, Lentz, Colon, and Sutherland (1988) found that 51% of potential pancreas transplants received at least one psychiatric diagnosis, the most common being depression and/or anxiety. Using similar criteria, Lustman, Griffith, Clouse, and Cryer (1986) reported lifetime prevalence figures of 33% for depression and 41% for anxiety for a clinic population of diabetics. In a British sample of 194 insulin-dependent diabetic outpatients, Wilkinson et al. (1988) used the General Health Questionnaire and found the prevalence of psychiatric morbidity to be 18%. In another British study, Robinson, Fuller, and Edmeades (1988) used a psychiatric interview to determine that 27.7% of a group of 70 NIDDM and 60 IDDM patients had experienced symptoms of depression in the month prior to the interview. The authors suggest that their estimates are lower than Lustman's because of the stricter criteria used in their measuring instrument. Finally, Surridge conducted psychiatric interviews with 50 insulin-dependent diabetics and found a "marked reduction in energy level, increased fatigue and irritability, depression, and delayed psychosexual maturation" (Surridge et al., 1984, p. 269). Because each of the above researchers sampled from a different population pool and used a different instrument, an overall prevalence figure can not be determined. Furthermore, none of the studies were limited to persons with NIDDM.

Recent studies suggest that increased psychiatric morbidity may be characteristic of any chronic disease and is not specific to diabetes (eg. Skenazy & Bigler, 1985). Cross-sectional studies of different disease populations support this hypothesis. For example, vonAmmon Cavanaugh (1986) reports that depressive symptomology is common among most hospital inpatients. In a large study of a community sample, Murrell, Himmelfarb, & Wright (1983) found that levels of depression among diabetics were not significantly higher than those of other persons. Likewise, Wells, Golding, and Burnam (1988) studied a community sample of 2,554 persons and concluded that while chronic disease and psychiatric disorder may occur concurrently this is not especially true for diabetes. Finally, Cassileth et al. (1984) studied 758 persons with 6 different chronic diseases and concluded that psychological distress is associated with the severity rather than the type of chronic illness. Interestingly, they also found that the overall psychological health of the chronically ill was similar to that of the general public.

To summarize, there is some indication that diabetics may suffer from mild neuropsychological and/or psychiatric symptomology. There is a lack of research with respect to psychiatric symptomology among non-insulin-dependent diabetics. Therefore, this study included measures to assess this important aspect of the psychological component of quality of life.

3. The Social Component

Few studies have addressed the social impact of diabetes. Deleterious social effects are potentially dangerous because researchers have found an association between social well-being and mortality (Broadhead et al., 1983). This relationship appears to be independent of baseline physical health, various sociodemographic data, or health practices (Berkman & Syme, 1979). It is especially true of elderly populations such as the one in this study. Blazer (1982) administered questionnaires to a stratified random probability sample of 331 persons aged 65 and over in North Carolina and a 30 month follow up revealed that the mortality risk for impaired perceived social support was 3.40 and the risk for impaired roles and available attachments was 2.04. Thus, any indication that diabetes adversely affects an individual's social well-being must be taken seriously.

First, Wilkinson et al. (1988) found that according to the self-report questionnaires of a sample of 194 persons with IDDM 45% of the men and 39% of the women were currently experiencing major social problems. Unfortunately, these authors do not give any baseline measure by which these results can be compared to a non-diabetic population. Second, in interpreting the Minnesota Multiphasic Personality and Picture Frustration Tests given to 53 insulin-dependent diabetics Ivanyi et al. (1988) found the following: "tension, uncertainty in orientation in new situations, decreased self-confidence, feeling of inferiority, diminished sociability and sensation of being exposed to danger and socially defenceless" (p. 113). Unfortunately, these authors do not give enough information to judge whether or not these conclusions are justified. Finally, Davis, Hess, and Hiss (1988) surveyed 343 non-insulin-dependent diabetics and collected mortality data four years later. Their survey included questions in the areas of work, activities, and going out. They concluded that "patient-reported social impact of a chronic disease (in this case diabetes) appears to be substantial and is related to mortality" (p. 542).

There is also anecdotal evidence to suggest that diabetes may have a substantial impact on an individual's social well-being. For example, Schwartz (1988) writes of a sense of isolation the detailed treatment plan can elicit and the guilt that other family members may experience.

If diabetes adversely affects social well-being, one might expect these persons to benefit from social learning programs. However, as judged by improvements in diabetic control, the evidence for the efficacy of such programs is mixed. In a study of 21 IDDM adolescents at a diabetes summer school, Kaplan, Chadwick, and Schimmel (1985) report that after four months those participating in social-learning exercises had significantly lower HbA1 levels. However, in a study comparing nutrition education alone, nutrition education and social learning, and wait-list control subjects, Glasgow, Toobert, Mitchell, Donnelly, & Calder (1989) did not find any added benefit to the addition of the social learning intervention. Neither investigator reported any measure of improved social well-being. Finally, in a review of the effects of eight different educational and psychosocial interventions in the treatment of diabetes, Padgett, Mumford, Hynes, & Carter (1988) reported that social learning interventions had the second strongest effect, surpassed only by diet instruction.

In summary, there is some indication that diabetes may have adverse effects on the social component of an individual's quality of life. This study included measures to further investigate this issue. Information regarding social well-being is especially pertinent because of its putative effects on mortality and morbidity.

4. The Subjective Satisfaction Component

Although anecdotal reports abound, researchers do not appear to have investigated how diabetics rate their quality of life according to a global type of rating scale. Since many researchers now believe that this type of subjective judgment should be included in any quality of life judgment (eg. Wenger, Mattson, Furberg, & Elinson, 1984), an item assessing life satisfaction was included as part of this investigation.

C. Glycemic Control

1. Introduction

During the late 1970's the glycosylated hemoglobin assay became available for widespread use as a measure of long term (6-8 weeks) glycemic control. Research began lending support to what many had suspected for a long time: long periods of hyperglycemia are associated with the onset and development of secondary complications, especially retinopathy and nephropathy. For example, in reporting on a study of 4,400 unclassified diabetic patients, Pirart (1978) concluded that "poor control assessed cumulatively over the years is definitely related to a higher prevalence and incidence of neuropathy and microangiopathy, particularly of severe retinopathy" (p.168-169). In another study, Chase et al. (1989) found that among 230 patients with IDDM those in poor control had 3.6 times the prevalence of kidney damage and 2.5 times the prevalence of eye disease. Klein, Klein, Moss, Davis, and DeMets (1988) studied 987 older onset (type 11) and 891 younger onset (type 1) diabetics and reported that glycemic control was correlated with the incidence and progression of retinopathy for both groups. Numerous other studies lend further support to the association between glycemic control and complications. However, tighter control is not without its side effects and until it can be demonstrated that hyperglycemia is a causal factor in the onset/development of secondary complications, there will still be critics. For example, one reviewer cites accelerated retinopathy, hypoglycemic encephalopathy, and local abscesses at the needle site as some of the possible short term risks (Unger, 1982). Although some very recent research indicates that this accelerated retinopathy is only an initial reaction which soon levels off (Kroc collaborative study group, 1988), the potential for damage caused by hypoglycemic episodes remains a serious concern. To gain more conclusive evidence into this whole issue a large scale longitudinal study assessing the effects of improved glycemic control on the development of early vascular and neurological complications is currently underway. The study, entitled the Diabetes Control of Complications Trial (DCCT) involves the testing of a cohort of 1400 insulin-dependent diabetics assigned to either standard or intensive insulin therapy for a period of up to ten years. After the first year of therapy, results confirm only a significant weight gain in the group treated with intensive insulin therapy (DCCT research group, 1988). Conclusive results regarding the relationship between control and secondary complications are not expected for several years. In the interim, normalization of blood glucose has become an important therapeutic goal of most diabetic programs (National Institute of Health, 1987) and researchers have sought to sort out the many complex variables which may influence glycemic levels. Because the diabetic plays such a central role in his/her own treatment, it has become apparent that achieving control is more often a behavioral rather than a physiological problem. Self-control is critical. Thus, research into psychological factors affecting control has been especially extensive.

2. Psychological Factors and Glycemic Control

In insulin-dependent diabetes glycemic control has been associated with health beliefs (Brownlee-Duffeck et al. 1987), negative life events (Jacobson, Rand, & Hauser, 1985), hassles (Cox et al. 1984), impaired personal relationships, (Spiess, Sachs, Gisinger, & Schernthaner, 1988), anxiety and depression (Mazze, Lucido, & Shamoon, 1984), perceived stress (Peyrot, & McMurry, 1986), negative mood (Dobbins, & Eddy, 1986), and an attitude of personal responsibility (Deprez, Anderson, Pennell, & Beisswenger (1984). For children and adolescents better control has been associated with psychological health (Evans, & Hughes, 1987), self-care behavior and social skills training (Kaplan et al., 1985) and higher activity levels, greater regularity in routines, milder reactions, distractibility, and negative mood (Rovet, & Ehrlich, 1988).

However, there have also been attempts to relate psychological variables to metabolic control that have failed. For example, there was no significant relationship found between control and the emotion profile index (Mazze et al., 1984), a measure of the type A personality (Stabler et al., 1988), various measures of the quality of family life (Kovacs, Kass, Schnell, Goldston, & Marsh, 1989), self-reports of major social problems (Wilkinson et al., 1988), a measure of depression (Robinson et al., 1988), and Jackson's Personality Research Form (Jenkins & Webb, 1980). To further complicate the picture there are some researchers which have reported opposite findings. For example, Kaplan et al., (1985) found that among 21 adolescents with IDDM, high scores on a measure of social problem-solving ability corresponded to poor rather than good diabetic control. In addition, Fonagy, Moran, Lindsay, Kurtz, and Brown (1987) described a study of 50 children in which psychological disturbance was predictive of low rather than high glycolsylated hemoglobin assay results. They suggest that anxious persons may be more diligent in following their treatment plans. To summarize, it would seem that poor control in persons with IDDM may be associated many, but not all psychological and social problems.

Few studies have looked at the relationship between glycemic control and various psychological variables in the non-insulin-depende diabetic. However, the available studies seem to present a similar picture. In a study of 93 men, Harris & Linn (1985) found that health beliefs were strongly associated with metabolic control. Kaplan and Hartwell (1987) used the social support questionnaire and found that social support satisfaction was positively associated with better metabolic control for women and negatively correlated for men. On the other side, in a study of 184 NIDDM patients Wilson et al., (1986) found that psychosocial variables such as stress, depression, anxiety, social support, and diabetes-specific health beliefs were not significant predictors of glycemic control.

There are many potential reasons for this seemingly contradictory evidence. Variations in the instruments used, the subjects selected, and the constructs measured make direct comparisons across studies extremely difficult. Furthermore, it is possible that different causal factors operate in the different patient groups. Finally, the possibility of a type 11 error is high in all these studies. Frequently, sample size was small, the patients homogeneous and/or the instruments relatively insensitive. Far more research is needed before any firm conclusions can be drawn.

3. Relationship Between Psychological Variables and Control

Nonetheless, in reviewing the above studies most researchers conclude that psychological problems are associated with poor control (eg. Williams, Pickup, & Keen, 1988). However, the relationship is extremely complex. It is possible that improved control directly affects a person's feeling of well-being. Limited support for this hypothesis is found in Siegler, Citron, and Reeves's (1982) study of ten IDDM persons who experienced significantly improved scores on measures of depression and anxiety after implementation of a program of tighter control. However, in this case, the effects of experimental participation can not be ruled out as a possible confound. Another explanation of the relationship between glycemic control and psychological variables is that some third variable such as various life events affects both psychological well-being and control.

However, by far the most popular approach is to postulate that psychological variables cause poor control. This could occur either directly via neurohormonal routes or indirectly through adherence to treatment plans. There is some evidence to suggest that both are involved.

a) neurohormonal hypothesis

With respect to the neurohormonal hypothesis, most psychological variables cause stress and stress may impact blood sugar levels directly through its effects on the body's hormonal levels. Stress is known to stimulate both sympathetic nervous system and adrenal activity. This results in the release of catabolic hormones which cause a subsequent increase in blood glucose. Presumably this response is exaggerated or somehow altered in diabetics and this would account for the link between psychological variables and glycemic control. Support for this hypothesis comes from several sources. First, Shamoon, Hendler, and

Sherwin (1980) found that IDDM patients have an altered responses to the stress hormones epinephrin and cortisol. Second, animal studies confirm that stress can directly affect blood sugar levels. For example, using genetically obese mice as a model, Surwit, Feinglos, Livingston, Kuhn and McCubbin (1984) found that blood sugar levels increased in response to the stress of immobilization and shaking. Also using mice, Mazelis et al. (1987) found that stressful housing acted synergistically with streptozotocin to cause hyperglycemia. Third, in a study of 93 adolescents Hanson, Henggeler, and Burghen (1987) discovered that stress had an impact blood sugar control which was independent of adherence. Finally, relaxation therapy is thought to be effective in treating NIDDM patients because it enables them to compensate for this putative sensitivity to stress (Surwit & Feinglos, 1983). However, Surwit and Feinglos selected only those subjects who reported "variation in diabetes control as a consequence of stressful events" (p. 176). Therefore, these latter results must be viewed cautiously.

On the other side of hypothesis which postulates that the relationship between psychosocial variables and glycemic control is mediated by a neurohormonal mechanism, Carter et. al. (1985) found that neither playing pacman nor taking caffeine caused any significant blood sugar changes in 21 IDDM patients. Furthermore, Kemmer, et al. (1986) found that despite changes in catelcholamines (stress hormones) there were no changes in circulating levels of blood glucose in 18 IDDM patients after the stress of public speaking or mental arithmetic. They concluded that "metabolic control in insulin-treated diabetic patients is not jeopardized . . . by the common stressful events of daily life"

(p. 1083). It is possible that these apparently contradictory findings result from the use of different stressors or that the stress may not have reached some critical threshold. Alternately, some researchers have suggested that individual response to stress is highly idiosyncratic and experimental results may be determined by the subject pool selected (eg. Cox et al., 1984) Furthermore, both of the above studies were restricted to type I diabetics and the Kemmer et al. (1986) also excluded all patients with secondary complications. Surwit and Feinglos (1988) have suggested that stress may be a more potent factor among type II diabetics. Others have suggested differences between type A and type B personalities. Finally, there the perennial question as to whether the stress experienced under the conditions of a laboratory is applicable to the stress of daily living.

Several related findings are also interesting to note. First, several studies have also implicated stress as a possible trigger for the onset of diabetes (eg. Carter, Herrman, Stokes, & Cox, 1987; Kisch, 1986). Second, some researchers have hypothesized that the sympatho-adrenal system that mediates the body's response to stress may also mediate the damage caused by NIDDM (Feldburg, Pyke, & Stubbs, 1985).

To summarize, it seems evident that the neurohormonal pathways are capable of influencing blood sugar control in response to stress under some conditions. The details of such a relationship await further study.

b) <u>adherence model</u>

Support for the hypothesis that psychological variables affect adherence which in turn affects control comes from numerous sources. First, it makes intuitive sense that an individual who is feeling psychologically unwell might be less likely to deprive him/herself of the comfort obtained through eating forbidden foods and less conscientious about keeping a rigorous schedule of treatment, meals, and testing.

Second, there are many studies which directly associate psychological or social variables with non-adherence. Hanson, et al. (1987) found that among a group of 93 adolescents, family relations and knowledge about diabetes affected adherence to the treatment plan. Other quality of life type variables which have been linked to adherence among type I diabetics include self-efficacy expectations and environmental support (McCaul, Glasgow, Schafer, 1987), belief in the value of treatment, costs involved, and support of significant others (Delany, 1982), and job characteristics (Nord, Heins, Hill, Arfken, 1989). Similar results are found from studies of mixed groups of diabetics. Schatz (1988) linked high levels of compliance to perceptions of the health care delivery system and knowledge about diabetes and Kouris, Wahlqvist, and Worsley (1988) associated adherence to a diabetic diet with health and dietary perceptions. Finally, results from studies limited to non-insulin-dependent diabetics once again yield similar results. For example, Wilson et al. (1986) administered a battery of tests to 184 diabetics and found that psychosocial measures of health beliefs and social support consistently predicted self-care behaviors. Similar results were reported from the Harris and Linn (1985) study of 93 type II diabetic men. Findings for older type II diabetics are much the same. Among 77 retirement community residents with NIDDM, Connell, O'Sullivan, Fisher, and Storandt (1988) found that the best predictors of self-reported adherence were perceived social support and morale as measured on a scale of life satisfaction. To summarize, it is clear that quality of life types of variables are related to the degree of adherence to a diabetic regimen.

Third, there are many studies which indicate that non-adherence is in turn related to poor metabolic control (eg. Brownlee-Duffeck et al., 1987; Korhonen, et al. 1983). In addition, one interesting study directly related poor adherence with the development of secondary complications. Sinzato et al. (1985) found that the 37 diabetics with severe complication of retinopathy had neglected their treatment regimens for significantly longer periods of time than those without such sypmptomology. Presumably this effect was mediated through poor glycemic control.

Reasons commonly given for non-adherence include situational factors such as being too busy or eating out, (Ary et al., 1986), forgetfulness and stress (Owens, 1980), personal preferences for certain foods (Kouris et al. 1988), and established patterns of overeating (Levine, Shah, Bill, & Ritchie, 1986). Some researchers view adherence within the context of the health belief model originally put forward by Becker in 1975 (Becker & Maimon, 1975). According to this model an individual's personal beliefs determine his/her adherence. As Sjoberg, Carlson, Rosenqvist, and Ostman (1988) explain "patients are more likely to comply with recommendations if they: perceive their disease as serious; feel vulnerable to it; experience treatment as 'cost-effective'" (p. 450). Evidence for this hypothesis has been presented by Cerkoney and Hart (1980) and Harris and Linn (1985). Both groups of researchers found perceived severity of the disease to be an especially strong predictor of compliance.

4. Summary

To summarize, the recently available glycosylated hemoglobin assay has made it possible to measure long term glycemic control among diabetics. Because there appears to be a link between blood sugar control and the onset/development of secondary complications, many researchers are focussing their efforts on identifying factors which are related to diabetic control. Most reviewers concede that many of these factors are psychosocial in nature. Although it is still unclear as to whether the relationship is one of cause or consequence, many researchers presume that a causal relationship is more plausible. Two hypotheses have been presented to explain how psychosocial variables could potentially affect glycemic control. One involves neurohormonal pathways and the other involves the degree of adherence to the therapeutic regimen. There is evidence to suggest that both hypotheses are correct.

Thus, a study of the quality of life of NIDDM patients is relevant not only not only in and of itself, but also for whatever light it may shed on glycemic control. Judging from the amount of contradictory evidence in the literature much work needs to be done to elucidate the psychosocial factors influencing glycemic control, particularly among non-insulin-dependent diabetics.

D. Quality of Life and Glycemic Control

Few studies have directly addressed the relationship between quality of life and glycemic control. First, Mazze et al. (1984) used the Mooney Problem Checklist as a measure of quality of life for 84 persons with IDDM. They found a significant difference in scores between those individuals with good control and those persons with HbA1 scores greater than 11.9%. However, the conceptualization of quality of life in terms of a problem checklist is unusual.

This same group of researchers (Mazze & Shamoon, 1982) addressed the problem from a different perspective when they tested 40 IDDM patients assigned to multiple injections of insulin with self-monitoring of blood glucose. They determined that a deterioration in control was associated with a decrease in the quality of life. However, improved control had no effect on quality of life. Not only are these findings confusing but there are many alternate explanations. For instance, the disappointment of having "failed" in a new experimental procedure easily affect many dimensions of quality of life.

On the other side, Holstein, Jorgensen, and Sestoft (1986) studied 65 patients with type I diabetes, aged 15-52, and reported that according to their questionnaires there were no psychological or social factors differentiating those in good control with those in poor control. In terms of quality of life they report that there were few problems regarding daily living. However, they found many psychological problems including "perceived disability, fatigue, fear, anger, strain, bad conscience, and perceived discrimination" (p. 165). Similar findings were reported by Pecoraro, Carter, and Andreson (1986). These researchers used the Sickness Impact Profile to measure the health status of 48 outpatients with stable NIDDM and reported that there was no correlation between glycemic control and health status.

Clearly, this is an area requiring further research.

III. METHOD

A. Subjects

Subjects for this study were selected from a larger research project designed to compare the impact of diabetes among those newly diagnosed (less than one year) with those having had the disease for ten years or more. Patients having been diagnosed for less than one month were excluded from the larger study because the diabetologist felt that some of the questionnaire items might cause them unnecessary distress. In addition, three other patients were omitted because the nurses judged them as being too disturbed to appropriately respond to the questions. Finally, nine persons were eliminated from the study because they were not comfortable with the English language. The remainder of those persons attending the diabetic and metabolic centre of the Edmonton General Hospital between July 21 and August 29, 1988 and on Tuesdays between September 6 and November 15 and meeting the above criteria were asked to participate. In all 154 persons were asked. Of these 136 agreed, giving a response rate of 88%. Fifty-eight of these fell into the long-standing, non-insulin-dependent diabetes mellitus group reported in this study.

B. Procedure

The study was explained as a research project to investigate the impact of diabetes on an individual's life. Information was given regarding the types of questions asked, the format of the questionnaire, and the time commitment involved. Patients were given the option of completing the questionnaire in the hospital or mailing/returning it at a later date. Those agreeing to participate were then asked to sign a consent form. Verbal instructions were given regarding the completion of the questionnaire. Similar written instructions preceded each set of questions. The same individual administered the tests in the same order to all persons. Time required to complete the questionnaire varied from thirty-five minutes to two and one-half hours. For those choosing to complete the questionnaire in the clinic, the administrator was available to answer any questions. These subjects often shared anecdotal information with the examiner.

Information regarding age, sex, employment, date of diagnosis, treatment, blood sugar level, obesity, and various secondary complications was copied from the medical charts.

C. Study Design

This was an exploratory study using questionnaire and demographic data to describe the quality of life of long-term, type II diabetics and to explore the possible relationship between various quality of life factors and control. Variables were operationally defined as follows:

1. The physical component of quality of life was measured by the physical scale of the Sickness Impact Profile.

2. The psychological component of quality of life was measured by the Index of General Affect and by the depression and anxiety scales of the Basic Personality Inventory.

3. The social component of quality of life was measured by the psychosocial scale of the Sickness Impact Profile.

4. The subjective dimension of quality of life was measured by the Overall Life Satisfaction Scale.

5. Control was measured by the glycosylated hemoglobin assay (HbA1).

D. Ethical Considerations

All patients signed a consent form indicating that they understood what was required of them and granting the investigator access to information in their medical records (see appendix C). They were told that they were free to withdraw from the study at any time. When requested, patients were mailed a letter describing some of the findings from their individual protocols. Any person scoring greater than two standard deviations above normal on the anxiety or depression scales was mailed a general letter explaining that people often have difficulty coping with diabetes and offering free counselling services through the University of Alberta Educational Clinic. The diabetologist at the Edmonton General Hospital was given the names of these individuals. At the completion of the study a letter was mailed to each participant thanking him or her and explaining some of the results of this study (see appendix D).

E. Design Considerations

The recommendations of several researchers were implemented in the design of this experiment:

1) The experiment was quantitative. Although studying quality in terms of quantity may seem inherently contradictory, at least one reviewer believes that the problem is one of methodology. Julius (1988) writes that the contradiction can be resolved through the use of questionnaires comprised of quantitative scales. This is the approach

taken on both the Index of General Affect and the Overall Life Satisfaction Scale.

2) The study included more than one aggregate measure of quality of life. This is because it is impossible to predict the many ways in which a disease such as diabetes may impact an individual's life. Researchers have concluded that just as no one biomedical measure can capture all possible physiological effects so no one quality of life measure can capture all possible health effects (Wenger et al., 1984).

3) Already established, well-standardized, reliable, and valid instruments were used. This allows for cross-study comparisons, reproduction of results, integration of knowledge, and progress in the field. Reviewers have frequently criticized the lack of methodological consistency in quality of life research (eg. van Knippenberg, & de Haes, 1988) and Spitzer (1987) bemoans the futility of reinventing the wheel.

4) General as opposed to disease-specific instruments were selected. In comparing these two approaches Temkin, Dikmen, Machamer, and McLean (1989) conclude that "little benefit is likely to be obtained from creating disease-specific psychosocial measures" (p. S44). Furthermore, as Kaplan (1988) points out, disease-specific measures may overlook the more general impact of a disease.

5) Both objective (behaviorally based) and subjective (evaluative) instruments were selected. Several researchers have underlined the fact that the relationship between these two measures is not yet understood and have recommended that quality of life studies always include both (eg. Levine & Croog, 1985; Ware, 1984a; Ware et al., 1981).

6) Self-administered questionnaires were used. Storstein (1987) writes that this method is more reliable than that obtained by physician interview. Furthermore, 70% of the participants of Rand's Health Insurance Experiment indicated that they preferred a self-administered questionnaire to other methods of data gathering (Ware, 1984b).

F. Analysis

All protocols were marked according to the directions in the respective manuals. Secondary complications and obesity were coded by the nurses according to the criteria found in appendix A. Modality of treatment was defined as insulin-treated or non-insulin treated.

A Hoetelling's t-test was used to compare the six quality of life variables with published normative data. Hoetelling's t-tests were also used to compare subscale scores within these measures to published normative date. In addition, either t-tests or hoetelling's t-tests were used to compare differences between the sexes and differences between those fulfilling test manual criteria for faking and the remainder of the sample. Finally, a 6 x 2 multivariate analysis of variance was performed to investigate whether there were any differences in the quality of life between those scoring in the normal range on the HbA1 and those scoring in the above average range.

G. Instruments

Because this study was part of a larger research project, subjects were administered Campbell's scales of well-being, the Sickness Impact Profile (SIP), Jackson's Basic Personality Inventory (BPI), Wallston's Health Locus of Control and a self-efficacy measure. For this study only first two measures plus the anxiety and depression scales of the BPI were analyzed.

1. Campbell's Scale of Well-Being

These scales were originally designed to measure both cognitive and affective aspects of the quality of life of the American people. This general sense of well-being was considered to be an important component of the quality of life experience as a whole (Campbell et al., 1976).

There are three indices: The Index of General Affect is comprised of eight bipolar items: boring vs. interesting, miserable, vs. enjoyable, useless vs. worthwhile, lonely vs. friendly, empty vs. full, discouraging vs. hopeful, disappointing vs. rewarding, and doesn't give me a chance vs. brings out the best in me. The Overall Life Satisfaction is comprised of a single question asking persons to judge how satisfied they are with their life as a whole. Lastly, the Index of Well-being is a composite of the other two scales giving slightly more weight to the former. All questions are marked on a seven point likert scale. Only the endpoints are marked. The composite Index of Well-Being was not used in this study.

In 1971 these scales were administered to a probability sample of 2,164 American persons. There was an 80% response rate. The alpha coefficient of reliability for the Index of General Affect was .89. Because the Overall Life Satisfaction consists of a single question the only reliability coefficient available is a test-retest reliability of .43 for a subsample of 285 persons reinterviewed eight months later. The authors acknowledge that this figure is low but point out that real changes in life satisfaction can occur over this length of time

(Campbell et al., 1976). Although the methodology used for this standardization did not involve self-administration to a relatively homogeneous population as is the case with this study of diabetics, Bremer and McCauley (1986) compared both methodologies and concluded that neither reliability nor validity were affected.

This measure has been used to assess the quality of life in other chronically ill populations including those with terminal and nonterminal illnesses (Reed, 1987), and those with end-stage renal disease (Simmons & Abress, 1988). Several authors recommend its use for quality of life studies (eg. Johnson, McCauley & Copley, 1982). This measure is especially valuable because of the extensive care with which the initial probability sample was taken. This allows for more conclusive comparisons between various subject groups and the general population of the United States.

2. The Sickness Impact Profile

This is a behaviorally based self-report questionnaire which was designed to assess the functional status of physically ill persons. It is especially recommended for use with chronically ill populations (Bergner, 1984). The twelve subscales include ambulation, mobility, body care and movement, emotional behavior, affective behavior, social interaction, communication, sleep and rest, eating, home management, work, and recreation and pastimes. A physical score can be obtained from a combination of the first three measures and a psychosocial score from the next four measures. All twelve scores are combined to give the total SIP score. Patients are asked to check off only those items which apply to them that particular day and are a result of their health (in this case the diabetes). Time taken to complete this questionnaire ranges from 20 minutes to one-half hour.

According to the authors (Gilson et al., 1975) the final 136 items were selected from over 1000 statements obtained from patients, care-givers, health-care professionals and healthy individuals. Other assessment instruments were also reviewed. Field trials were conducted on a variety of inpatients, outpatients, and nonpatients. Finally, weightings for each of the items were given by a team of 25 judges comprised of health professionals and nursing and medical students. Thus, items such as "I stay lying down most of the time" and "I isolate myself as much as I can from the rest of the family" affect the overall score more than do items such as "I change position frequently" or "I am doing fewer community activities."

Test developers report the internal consistency correlation as .94 and the test-retest reliability as .92 (Bergner, Bobbit, Carter, & Gilson, 1981). Validity has also been demonstrated. In a sample of 278 subjects with a variety of medical conditions the authors found that the SIP correlated .54 with a self-rating of illness, .49 with a clinician assessment of dysfunction, .46 with the Activities of Daily Living Index, and .61 with the National Health Interview Survey (Bergner, Bobbitt, Pollard, Martin, & Gilson, 1976).

This scale has been widely used in researching many different conditions and how these impact quality of life. For example, in the past year alone it has been used to assess quality of life in persons with head injury (Temkin et al., 1988), end-stage renal disease (Julius et al., 1989), Alzheimer's-type dementia (Krenz, Larson, Buchner, &

Canfield, 1988), chronic obstructive airways disease (Traver, 1988), angina therapy (Fletcher, McLoone, & Bulpitt, 1988), multiple sclerosis (Zeldow & Pavlou, 1988), burn rehabilitation (Questad et al., 1988), and in residents of a nursing home (Rothman, Hedrick, & Inui, 1989). Several prominent reviewers have recommended its use for quality of life studies. Jonsson (1987) cites it as an example of a well-developed instrument, Kaplan (1988) refers to it as "one of the most important and best-developed quality of life measures" (p.384), and Spitzer (1987b) suggests that the authors of this measure "have a sufficiently long head start that they deserve support from all the rest of us" (p. 470).

3. Jackson's Basic Personality Inventory

This questionnaire was designed to measure common psychopathology as well as to provide an overall profile of some of the major dimensions of personality functioning. Statements describe activities, interests, and behavior. Each is marked true or false and the authors claim to have kept the vocabulary at a grade five level (Jackson, 1988).

According to the test developer (Jackson, 1988) the constructs of this instrument are based on a canonical factor analysis of the Minnesota Multiphasic Personality Inventory and the Differential Personality Inventory. A minimum-redundancy item analysis was conducted to maximize scale intercorrelations. Furthermore, to help minimize distortion from response style, each of the twelve scales contains ten true keyed and ten false keyed statements.

For this study only the results of the depression and anxiety scales were used. These have been the most widely studied in the literature on diabetes and are frequently considered to be indicative of psychological well-being (eg. Burton, Conley, Lindsay, Wai, & Richmond, 1981). Examples of items giving points on the depression scale include true responses to "My present situation is hopeless" and "I often have trouble sleeping because I feel so sad"; and false responses to "I enjoy just about everything I do" and "I live a very satisfying and rewarding life." With respect to the anxiety scale, points are given for positive responses to items such as "Although I really try, I cannot stop feeling tense" and "Little things often upset me"; and negative responses to items such as "I don't worry over what might happen to me" and "Even at the end of a hard day, I remain relaxed and at ease." According to the scale descriptions in the manual (Jackson, 1988) persons scoring low on the depression scale report feeling confident and cheerful while high scorers tend to be despondent and pessimistic. Persons scoring low on the anxiety scale are reported to be calm and controlled while high scorers are easily frightened.

Norms are based on a sample of 1237 American and Canadian adults. According to the manual test-retest reliabilities are .85 and .78 for the depression and anxiety scores respectively. The alpha coefficients reported by Holden, Fekken, Reddon, Helmes, and Jackson (1988) are .87 for depression and .82 for anxiety. In addition, these researchers established convergent and discriminatory reliability among a psychiatric population by correlating test scores with ratings of clinical staff members (depression r = .74, anxiety r = .61).

The BPI is recommended for health related research. Although it is only recently developed, this measure has already been used in studying a wide variety of research topics. These include renal failure

(Richmond, Lindsay, Burton, Conley, & Wai, 1982), psychopathology (Jackson et al., 1986), rheumatoid arthritis and fibrositis (Scudds, Rollman, Harth, & McCain, 1987), alcohol abuse (Skinner, 1981), and eating attitudes (Chandarana, Helmes, & Benson, 1988). Finally, in comparing the Minnesota Multiphasic Personality Inventory, the Millan Clinical Multiaxial Inventory, and the Basic Personality Inventory, Helmes and Barilko (1988) conclude that the BPI is superior with respect to the ability to discriminate between the absence and presence of psychopathological symptomology.

IV. RESULTS

A. Introduction

First, the subject characteristics will be described. Second, the four aspects of quality of life as defined in this study will be discussed. These are: physical well-being as measured by the physical dimension of the SIP; psychological well-being as measured by the Index of General Affect, and the depression and anxiety scales of the BPI; social well-being as measured by the psychosocial dimension of the SIP; and subjective life satisfaction as measured by the Overall Life Satisfaction scale. Third, additional findings from some of the subscales, from anecdotal records, from a comparison between the sexes, and from a correlational analysis will be described. Finally, results concerning the relationship between quality of life and glycemic control will be outlined.

B. Subject Characteristics

The 32 female and 26 male subjects ranged in age from 38 to 86 years (M = 61.71, sd = 11.16). Nearly half (47%) of the participants were retired. One quarter (25%) lived outside of the greater Edmonton area. All had been diagnosed with non-insulin-dependent (type II) diabetes at least ten years prior to the study (M = 15.88, sd = 6.00). In addition, all were participants of a large hospital outpatient program: 55% were present for a usual 6 month follow-up examination and 45% were attending a four day educational program. Many of the subjects (91%) were more than 10% above ideal body weight and over half (54%) were more than 20% above ideal body weight (based on Metropolitan Life Insurance Company tables for men and women of medium frame). In addition, most (81%) were insulin treated. Secondary complications of diabetes were observed in 74% of the subjects with 39% of the subjects exhibiting signs of vascular disease, 15% of retinopathy, 63% of peripheral neuropathy, and 29% of nephropathy. There was evidence of satisfactory glycemic control for many of the subjects ($M = 7.77$, $sd = 1.73$).

The Basic Personality Inventory contains two scales designed to identify persons trying to fake good or fake bad. According to the manual (Jackson, 1988) persons with t-scores greater than 60 on the denial scale and low scores on the other measures may have tried to fake "good" while those with high scores on a scale of deviance and high scores on the other scales may have tried to fake "bad". A typical question on the denial scale is "I am never cross with a loved one" (keyed positive) and a typical question on the deviance scale is "I would enjoy watching someone suffer great pain" (keyed positive). There were 11 people in the subject pool which satisfied these criteria. However, despite an overall level of significance on a Hoetelling's t-test, $F(6,47) = 2.55$ $p<.05$, there were no significant differences between the suspected fakers and the remainder of the sample for any of the univariate analyses performed on the means of the six quality of life variables measured (see table 1). Likewise, there were no significant differences between the two groups with respect to glycemic control, $t(52) = .36$, $p>.05$, secondary complications $t(48) = -.04$, $p>.05$, or duration of diabetes $t(56) = .97$, $p>.05$. Finally, although the relationships between control and the quality of life variables were stronger among the persons not suspected of faking, the overall pattern of results was the same for both groups. Therefore, all persons tested were included in the data analysis.

Table 1

Mean Scores of Persons Suspected
of Faking and the Remainder of the Sample
(according to BPI test manual criteria)

variable	suspected "fakers"	"non-fakers"	F	P
physical (SIP)	8.0	7.0	.02	1.00
psychosocial (SIP)	5.0	11.0	.48	.82
depression (BPI)	4.0	7.6	1.19	.33
anxiety (BPI)	2.4	3.9	.22	.97
General Affect	6.1	5.2	.65	.69
Life Satisfaction	5.8	4.9	.55	.77

C. Quality of Life

1. The Physical Component

According to the physical scale of the SIP, diabetes impacts the physical well-being of the subjects in this study. As can be seen from table 2 the mean score of the individuals with NIDDM is significantly higher than that reported from a study of a more random sample of individuals. The same pattern of differences is evident for the individual subscale scores (see table 3). However, these effects were not universal. Fifteen of the 58 subjects reported that diabetes did not affect their behavior on any of the 45 items tested.

The overall pattern of physical functioning appears to be similar to several other groups of chronically ill patients (see table 4). In particular, scores were comparable to those obtained by patients with myocardial infarction, rheumatoid arthritis, or end-stage renal disease. In contrast, elderly persons and individuals with multiple sclerosis appear to suffer greater restrictions in day to day activities.

An analysis of individual items provides additional insight into the effects of long-standing, type II diabetes on daily physical functioning. First, with respect to bodycare and movement, the two most frequently endorsed statements were "I stand for only short periods of time" (33%) and "I kneel, stoop, or bend down only by holding on to something."(28%) None of the subjects reported needing help to bathe or to dress. Second, restrictions in mobility appeared to occur in about 17% of the subjects. These persons indicated that because of their diabetes they tend to "stay home most of the time", and/or go "to places with restrooms nearby" and/or not use public transportation. Thirdly, diabetes was reported to affect ambulation by 60% of the subject pool. 45% checked off the statement "I walk more slowly", and 31% checked "I go up and down stairs more slowly." Although no one indicated that they were unable to walk 14% admitted that they had some difficulty, "for example, limp, wobble, stumble, have stiff legs." Finally, 24% endorsed the statement "I keep rubbing or holding areas of my body that hurt or are uncomfortable." Although this latter statement comes from a scale of emotional behavior, it could also be interpreted as part of the physical symptomology of diabetes.

Table 2

Comparison of Diabetic and General Population Means

variable	type II diabetics	general population	F	P
physical (SIP)	7.4 (8.8)	1.8*	3.14	.01
psychosocial (SIP)	10.0 (9.8)	3.9*	2.78	.02
anxiety (BPI)	6.9 (4.0)	6.2 (3.5)+	.23	.96
depression (BPI)	3.7 (3.9)	3.1 (3.3)+	.14	.99
general affect	5.4 (1.2)	5.7 (1.1)++	.38	.89
life satisfaction	5.1 (1.4)	5.5 (1.3)++	.80	.58

* estimates from data cited in Deyo, Inui, Leininger, & Overman (1982)

\+ from Jackson (1988)

++ from Campbell et al. (1976)

Table 3

Comparison of Diabetic and General Population Scores on the Sickness Impact Profile

variable	type II diabetics (age 38-86) (n = 58)	general population (age 18-74) (n = 624)*
<u>Physical Scale</u>	7.4 (8.8)	+
ambulation	11.1 (13.3)	3.1 (7.0)
bodycare and movement	6.2 (8.0)	1.0 +
mobility	6.5 (11.3)	2.7 (7.3)
<u>Psychosocial Scale</u>	10.0 (9.8)	+
emotional behavior	10.3 (12.7)	3.8 (9.6)
social interaction	9.4 (10.7)	5.2 +
alertness behavior	16.0 (18.2)	4.0 (8.7)
communication	4.7 (9.5)	1.1 (3.6)
<u>Other Scales</u>		
sleep and rest	20.0 (20.2)	7.2 (13.2)
home management	29.1 (11.7)	5.4 (12.5)
work	8.6 (20.3)	8.5 (19.4)
recreation/pastimes	19.3 (21.6)	10.2 (15.8)
eating	4.8 (5.7)	1.6 (3.3)
TOTAL SIP SCORE	10.8 (8.2)	3.6 (5.3)

* from data cited in Deyo et al. (1982)
\+ statistics were unavailable

Table 4

Sickness Impact Profile Scores for other Chronically Ill Groups

Variable	Diabetes	RA	MI	ESRD	MS	Elderly
ambulation	11.1	10.5	7.7	11.7	32.9	26.3
bodycare and movement	6.2	8.6	2.4	5.0	22.7	17.9
mobility	6.5	3.9	4.2	6.2	20.6	22.4
emotional behavior	10.3	12.8	6.1	7.5	20.0	25.9
social interaction	9.4	8.0	6.3	8.4	16.7	16.4
alertness behavior	16.0	7.1	6.5	7.6	21.5	26.9
communication	4.7	2.9	2.9	3.1	11.9	13.2
sleep and rest	20.0	16.0	11.5	16.5	21.1	21.0
home management	29.1	13.5	12.1	16.8	34.9	31.1
work	8.6	4.2	17.0	39.4	13.4	0.5
recreation/pastimes	19.3	18.0	15.2	18.3	37.8	33.1
eating	4.8	2.9	6.8	7.6	4.2	6.7
PHYSICAL SCALE	7.4	7.7	4.0	6.8	24.6	20.8
PSYCHOSOCIAL SCALE	10.0	7.7	5.6	7.0	17.4	19.8
TOTAL SIP SCORE	10.8	9.2	6.9	10.2	21.1	19.7

Note.

RA: 147 Swedish women with rheumatic disorders (aged 38-72), from Sullivan, Ahlmen, Archenholtz, and Svensson (1986).

MI: 308 survivors of myocardial infarction (mean age = 61.5), from Bergner, Hallstrom, Bergner, Eisenberg, and Cobb (1985). Results from survivors of cardiac arrest were not included because one of the figures looked like a misprint.

ESRD: 770 persons with non-diabetic end-stage renal disease, from Evans et al. (1985) and Evans (personal communication, March 6, 1989).

MS: 81 persons with multiple sclerosis, from Zeldow and Pavlou (1988).

elderly: 30 people attending a geriatric day hospital (mean age = 74.5), from McKinnon (1983).

2. The Psychological Component

a) Index of General Affect: An average of the eight semantic differential scales yielded an overall score (x=5.422, sd=1.82). This mean is not significantly different from that of the large norming sample tested by Campbell et al. (1976) (see table 2). This finding is also consistent with figures reported from other studies of chronically ill persons. (see table 5).

Similar results were obtained from an additional Hoetelling's t-test conducted on the eight individual items comprising the Index of General Affect. There were no significant differences between the scores of this sample of diabetic persons and that of the American sample tested by Campbell, et al. (1976) with respect to their judgments of life in terms of words such as interesting, enjoyable, worthwhile, friendly, full, hopeful, rewarding, or bringing out the best (see table 6).

Table 5

Comparison of Mean Scores on the Index of General Affect
and the Overall Life Satisfaction Scale

Sample	Affect	Life Satisfaction
Diabetes	5.42 (1.18)	5.14 (1.43)
ESRD	5.35 (1.26)	5.18 (1.86)
kidney transplant	5.07 (1.74)	5.32 (1.64)

Note.
ESRD: 770 persons with non-diabetic end-stage renal disease, from Evans et al. (1985) and Evans (personal communication, March 6, 1989).
kidney transplant: 40 kidney transplant patients undergoing conventional immumosuppressive therapy, from Simmons and Abress (1988).

Table 6

Comparison of Diabetic and General Population Means for the Individual Subscales of the Index of General Affect

variable	diabetics (n = 58)	population* (n = 2,164)	F	P
boring vs. interesting	4.98	5.52	.63	.75
miserable vs. enjoyable	5.19	5.74	.83	.58
useless vs. worthwhile	5.83	5.87	.01	1.00
lonely vs. friendly	5.72	5.85	.04	1.00
empty vs. full	5.43	5.79	.36	.94
discouraging vs. hopeful	5.57	5.77	.11	1.00
disappointing vs. rewarding	5.36	5.60	.13	1.00
doesn't give me a chance vs. brings out the best in me	5.29	5.18	.04	1.00

* from Campbell et al. (1976)

b) Depression and Anxiety In order to determine psychological well-being in terms of psychiatric symptomology the depression and anxiety scales of the Basic Personality Inventory were analyzed. The Hoetelling's t-test on the six quality of life measures used in this study did not reveal any significant differences between the test norms and the diabetics in our study (see table 2). Table 7 allows for a comparison between groups of persons with NIDDM and persons with other chronic diseases.

Table 7

Comparison of Mean Scores on the Depression and Anxiety Scales of the Basic Personality Inventory

Sample	Depression	Anxiety
Diabetes	3.7 (3.9)	7.0 (4.0)
Home Dialysis	4.9 (3.9)	N/A
Rheumatoid Arthritis	4.0 (3.6)	7.0 (2.5)
Fibrositis	5.6 (4.0)	8.0 (3.1)

<u>Note</u>.
Home Dialysis: 204 persons still surviving home dialysis after at least 18 months (mean age = 46.6), from Wai, Burton, Richmond, and Lindsay (1981).
Rheumatoid Arthritis: 20 persons (mean age = 45.3) from Scudds et al. (1987).
Fibrositis: 20 persons (mean age = 43.7) from Scudds et al. (1987).

3. The Social Component

According to the psychosocial scale of the SIP, diabetes also impacts the social component of quality of life of the subjects in this study (see table 2). Again there was a wide range of scores with 10 of the 58 persons reporting that diabetes does not affect their behavior on any of the tested items. With respect to the individual subscales 74% of the subjects reported some impact on social interaction, 64% on alertness behavior, 53% on emotional behavior, and 29% in the area of communication. As with quality of life in the physical sphere, quality of life in the social sphere appears to be similar to that of other chronically ill groups (see table 4). An examination of this table reveals that functioning in the areas of social, emotional, and communication behavior appear to be similar to persons with end-stage renal disease, myocardial infarction, or rheumatoid arthritis.

A possible exception is evident from the scores on a scale measuring alertness behavior. This scale is comprised of items assessing cognitive behaviors such as concentration, memory, and reaction time. For example, 50% of the subjects endorsed the statement "I forget a lot, for example, things that happened recently, where I put things, appointments." An examination of table 4 reveals that diabetes seems to have a greater impact on these behaviors than do other chronic diseases with otherwise similar profiles. Scores on this alertness behavior scale were not significantly correlated with age ($r = .061$, $p>.05$).

An analysis of the individual statements on the other psychosocial scales provides additional insight into the effects of diabetes on day to day social functioning. First, with respect to the scale of social interaction, the items most commonly attributed to diabetes include "I am going out less to visit people" (30%), "I often act irritable toward those around me, for example, snap at people, give sharp answers, criticize easily" (31%), "I often express concern over what might be happening to my health"(19%), and "My sexual activity is decreased" (33%) The latter item was endorsed by both sexes: 58% of the positive responses came from men and 42% from women. Second, communication does not seem to be a problem for the majority of the subjects although small numbers of subjects did check off items such as "I am having trouble writing or typing," (14%) "I carry on a conversation only when very close to the person or looking at him," (10%) and "I do not speak clearly when under stress." (12%) Finally, on the emotional behavior scale a substantial number of persons reported that because of their diabetes they "laugh or cry suddenly," (17%) "act nervous or restless," (22%) and "act irritable or impatient" (19%).

4. The Subjective Satisfaction Component

When asked to use a seven point likert scale to judge how satisfied they were with life as a whole, 93% of the sample responded with either a neutral or a positive response ($X = 5.03$, $sd = 1.39$). This is not significantly different from the original random probability sample of 2,164 American adults tested by Campbell et al. (1976) (see table 2). An examination of the frequency distribution reveals that 23% of the diabetics indicated complete satisfaction and 2% indicated complete dissatisfaction. The comparable value for the general population are 22% and 1%. As can be seen from table 5 these results are also similar to those obtained from studies of other physically ill persons.

D. Additional Findings

1.Other Scales

Although not included in our definition of quality of life several other items on the SIP measure are relevant in describing the impact of diabetes. First, 45% of the subjects found that because of their diabetes they "sleep less at night, for example, wake up too early, don't fall asleep for a long time, awaken frequently." Overall, 78% of the subjects reported that diabetes interfered with their sleep and rest patterns. This interference with sleeping seems to be characteristic of most chronic diseases. (see table 4) Second, diabetes seems to have a substantial impact on home management. Forty-three per cent of the subjects reported they were doing "less of the regular daily work around the house" and 36% reported working for short periods of time or resting often. Third, with respect to employment, five percent of the sample were unable to work and sixteen percent indicated that they had retired for health reasons. Of the remainder, 10% find that they do not accomplish as much as usual. Finally, with respect to recreation 33% reported "going out for entertainment less often" and 19% reported not doing any of their usual physical recreation or activities.

2. Anecdotal Evidence

Unfortunately, research notes from the larger study did not include information as to whether the persons expressing the following thoughts were diabetics of early onset or long duration. However, most of the subjects did fall into the long-standing, type II diabetes group. Also, the researcher can not recall any differences between the groups in terms of types of problems encountered or approaches to coping. Therefore, all of the data are included in the following descriptions.

Overall, the researcher was struck with the extreme variety of experiences with diabetes. Many persons, both of recent onset and of long duration said that diabetes had little effect on their lives. Several elderly persons expressed gratitude that it was "only" diabetes and not cancer. Many seemed to take it all in stride, as if these things were to be expected as one became older.

On the other side of the coin, some persons experienced diabetes as devastating. One gentleman attributed his marriage breakdown to the impotence caused by his diabetes. He described diabetes as a "terrible, terrible disease." An elderly nun was on the verge of tears as she explained how diabetes had totally changed her character. Instead of being kind and good-natured she found herself becoming increasingly impatient and irritable, particularly when her blood sugar levels were "out-of-control." Others also found that irritability often accompanied low blood sugars. Some persons experienced guilt. For example, one woman said that for many years she believed that her diabetes had caused the medical problems that resulted in her son's death. Another person spoke of experiencing sudden frights regarding all the potential secondary complications of diabetes.

Comments with respect to adherence to diet are consistent with the low rates of compliance reported in the literature (eg. Ary et al., 1986). Many persons freely admitted to cheating. Some even claimed to eat whatever they desired. For example, one gentleman said that eating was his greatest joy in life and that he would rather die than change his eating habits. Another said that his only concession had been to give up sweets. One patient complained that she could not afford to buy the type of food necessary to follow the diet. Nonetheless, most of the subjects seemed to follow at least some aspects of the diet. Several expressed the feeling that it was a small price to pay relative to some of the limitations of other chronic diseases. Finally, most persons seemed relatively knowledgeable with respect to the consequences of nonadherence. For example, several acknowledged that if they would strictly follow their diet they might not need insulin.

A final comment concerns the program at this particular hospital. Many patients gave the staff and program high praise. Typical comments included "the best program in the city," "they really care," and "they try to give you a diet that you can actually follow." One patient attributed the hospital program with saving her life. She said that she had been "borderline" diabetic for twenty years and had never understood how to take care of herself. Finally, a couple of people said that they would benefit from some kind of self-help group, that the program at the centre was great but they needed continued support and encouragement.

3. Differences Between the Sexes

Using t-tests there were no significant differences in means between men and women with respect to the demographic variable of age, or the biomedical variables of duration of diabetes, glycemic control, presence of secondary complications, or treatment modality. Likewise, neither composite quality of life measures nor individual subscale scores were significantly different (see table 8).

Table 8

Average Scores Listed by Sex

variable	men (n = 25)	women (n = 29)	T	P
physical (SIP)	6.9	7.9	-.41	.69
psychosocial (SIP)	9.0	10.8	-.70	.49
depression (BPI)	3.5	3.9	-.40	.69
anxiety (BPI)	6.0	7.7	-1.61	.11
General Affect	5.6	5.3	.90	.37
Life Satisfaction	5.2	5.1	.28	.78
age	61.6	61.8	-.08	.94
years since diagnosis	15.9	15.9	.01	1.00
glycosylated hemoglobin (in mmol)	7.8	7.7	.08	.94

4. Correlational Analysis

Life satisfaction is closely related to other components of quality of life. Significant correlations were found between this measure and the physical SIP score, the psychosocial SIP score, the Index of General Affect and the BPI scales of depression and anxiety. With respect to the twelve individual subscales of the SIP the highest correlations were obtained with the perceived impact of the disease on emotional behavior, home management and recreation and pastimes. Thus, persons expressing the least amount of satisfaction with their lives were more likely to check off items such as "I act nervous or restless."; I am doing less of the regular daily work around the house than I would usually do."; and "I am going out for entertainment less often."

A similar pattern was noted for the other five variables used to measure quality of life (see table 9). The anxiety scale was a partial exception. There was no association between the physical and social impacts of diabetes and anxiety. Finally, as expected, the three variables used to measure psychological well-being were closely associated.

Table 9

Correlation Matrix of the Quality of Life Variables

	physical	psycho-social	anxiety	depression	affect	satis-faction
physical	----	.56*	.00	.40*	-.29*	-.22*
psycho-social	.56*	----	.10	.53*	-.41*	-.24*
anxiety	.00	.10	----	.36*	-.36*	-.34*
depression	.40*	.53*	.36*	----	-.74*	-.50*
affect	-.29*	-.41*	-.36*	-.74*	----	.74*
satis-faction	-.22*	-.24*	-.34*	-.50*	.74*	----

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* $p<.05$

E. Control and Quality of Life

A 2 x 6 multivariate analysis of variance did not reveal any significant differences between those with scores on the glycosylated hemoglobin test between 4.9 and 8.0 mmol/l and those with scores greater than 8.0 mmol/l, $F(1, 47) = .93$, $p>.05$ (see table 10). However, a univariate analysis revealed a significant difference between the two groups with respect to depression $F(1, 47) = 4.17$, $p<.05$. An examination of the individual raw scores reveals that four out of the five persons scoring highest on the depression scale had high blood sugar levels. The one exception had a profile suggestive of psychosis with the additional probability of having faked bad (her score on the deviation scale was six standard deviations above the norm). Thus, there may be a relationship between depression and glycemic control, especially among severely depressed persons. This finding must be viewed cautiously because the use of univariate analyses increases the chance of making a type one error.

Consistent with other findings (eg. Pirart, 1978), results from this study suggest a relationship between the presence of secondary complications and high blood sugar levels. In particular, a significant correlation was found between neuropathy and the glycoslylated hemoglobin assay ($r = .27$, $p<.05$).

Table 10

Comparison of Persons With Average and High Blood Sugar Levels

variable	average (n = 28)	high (n = 21)	F	P
physical (SIP)	6.4	7.2	.09	.76
psychosocial (SIP)	7.5	12.3	2.55	.12
depression (BPI)	2.6	4.9	4.17	.05
anxiety (BPI)	6.8	7.2	.08	.78
General Affect	5.6	5.1	1.99	.16
Life Satisfaction	5.3	4.9	.86	.36

Finally, two other findings are worthy of note. First, there was a significant correlation between high blood sugar levels and scores on the SIP subscale measuring the impact of diabetes on alertness behavior. ($r=.249$, $p<.05$). Thus, persons with hyperglycemia were more likely to respond affirmatively to items such as "I have more minor accidents, for example, drop things, trip and fall, bump into things"; "I forget a lot, for example, things that happened recently, where I put things, appointments"; and "I have difficulty doing activities involving concentration and thinking." Age was not significantly related to either variable.

Secondly, there was a significant correlation between high blood sugar levels and low scores on SIP subscale measuring the impact of diabetes on eating behavior ($r = -.26$, $p<.05$). Thus, persons who indicated that they were not eating any less than usual and/or were not eating special foods were more likely to have high blood sugar levels. This is consistent with numerous studies which find that poor control may often be mediated by non-adherence (eg. Harris & Linn, 1985).

V. DISCUSSION

A. Discussion of Major Findings

1. Introduction

The purpose of this study was two-fold: (a) to describe the impact of diabetes on the quality of life of persons diagnosed with NIDDM for ten years or more, and (b) to determine whether there is any relationship between quality of life variables as assessed by questionnaire and control as measured by the glycosylated hemoglobin assay. The following conclusions were made by the investigator:

2. Quality of Life

According to the measures used in this study diabetes impacts quality of life. However, the effects seem to be limited to objective behavioral measures. More subjective areas of evaluation appear to be unaffected.

With respect to physical quality of life, 74% of this sample of persons with long-standing, type II diabetes report adverse impacts on day to day living. As compared to the more general population samples cited in the literature, these diabetics appear to have more difficulty standing, moving around, and generally getting out of the house. This is not surprising given that the prevalence of secondary complications is 71%. Social quality of life was also assessed in objective behavioral terms and again, adverse effects were noted. Long-standing, type II diabetics seem to find that diabetes makes them more irritable, affects their social interactions, and/or impairs their memory, concentration, and reaction times.

In contrast, scores on all scales requiring subjective judgments of quality of life are close to population norms. Long-standing, type II diabetes does not seem to affect how a person judges his/her life in terms of affective words such as worthwhile, interesting, and hopeful. Likewise, the disease does not appear to cause an increased incidence of depression or anxiety. Finally, diabetes did not seem to affect global judgments of life satisfaction.

Thus, findings from this study suggest that despite restrictions in functional capacity, long-standing, type II diabetics experience the same psychological health and life satisfaction as the rest of the population.

Nonetheless, a correlational analysis revealed a significant relationship between these objective and subjective measures of quality of life. The most obvious interpretation of this correlation would be that the functional limitations of diabetes adversely affect psychological well-being. However, this hypothesis is difficult to support given the lack of a discrepancy between the mean subjective quality of life scores of the diabetics and those of the more general population. Therefore, it is more plausible to argue that the relationship between functional impairment and psychological well-being holds true for only a subgroup of the population. For example, it is possible that only the severely impaired experience psychological distress in response to diabetes. This was the conclusion reached by Cassileth et al. (1984) in their study of 758 chronically ill persons. An alternate hypothesis would be that those experiencing psychological distress are either more cognizant of their functional limitations, or more likely to report them. Conclusions in this matter await further study.

3. Control and Quality of Life

This study provides little evidence for the hypothesis that psychosocial variables affect blood sugar control. One possible exception is depression. Univariate analysis yielded a significant difference between persons with normal HbA1 values and those with higher values. The difference was particularly evident among persons scoring at the high end of the depression scale. This latter finding may partly explain some of the discrepant results reported in the literature. Different studies use different subject pools. If depression must reach a certain threshold in order to affect glycemic control, only those researchers sampling heterogeneous populations would be likely to find significant results. Another major problem with this research is that there are many potential confounds affecting both control and psychological well-being. Unless very sensitive measures are used on very large samples the putative relationship is unlikely to be found.

4. Alertness Behavior

There were two interesting findings with respect to alertness behavior. First, there was a significant relationship between alertness behavior and blood sugar levels. Second, alertness behavior was the only scale for which diabetics differed significantly from other populations of chronically ill persons (see table 4). Because the inclusion of the twelve scales of the SIP introduces so many more statistics to the analysis, either of these findings taken alone might be dismissed as spurious. However, taken together these findings suggest that diabetes may have a physiological effect on the central nervous system causing some persons to experience difficulty with memory, concentration, and reaction time tasks. This interpretation is consistent with what some researchers have referred to as the "accelerated cognitive aging effect" (Robertson-Tchabo et al., 1986, p.459). Support for this hypothesis comes from various sources. Several researchers have found evidence for cognitive performance deficits in elderly non-insulin-dependent diabetics as compared to matched controls (eg. Mooradian et al., 1988; Perlmuter et al., 1984). Furthermore, in clinical examinations of 75 type I candidates for a pancreas transplantation, Popkin et al. (1988) reported that the incidence of organic mental disorder was similar to that found in older populations. Finally, in the Surridge et al. (1984) study of type I diabetics, reports from relatives indicated that 8 out of 50 persons with IDDM had difficulties with concentration and memory for recent events.

5. Variability

Another prominent feature of this study is the wide variation in how long-standing, type II diabetics experience their disease. The degree of impairment seems to range from absolutely devastating to virtually nonexistent. This was evident from both casual conversations with the subjects and the large standard deviations obtained on each of the twelve SIP scales (see table 3). In addition, although 15 persons reported no impairments in physical functioning and 10 persons reported no impairments in psychosocial functioning, there was no overlap. This is not merely an artifact of this particular measuring instrument: Eight of the remaining 78 persons in the larger study reported no impairments in either area. Thus, it appears that although the majority of long-standing, type II diabetics experience some impact of the disease on day to day function, these effects are extremely varied.

6. Construct Validity

This study offers some evidence for the construct validity of a quality of life concept. With the exception of anxiety, all of the measures were correlated with each other. Furthermore, scores on the psychological measures more strongly associated with each other than with the physical well-being or life satisfaction scores. Interestingly, in contrast to the Campbell et al. (1976) claim that the satisfaction scale represents a cognitive judgment and not an emotional state, findings from this study suggest that life satisfaction is most closely related to psychological well-being.

B. Findings from Cross-study Comparisons

First, the findings from the depression and anxiety scales suggest that the incidence of psychiatric morbidity among long-standing, type II diabetics is no higher than that of the general public. This is in contrast to the higher figures quoted by Lustman et al. (1986) and Popkin et al. (1988). However, neither of these groups of researchers sampled from a general diabetic population. Lustman et al. (1986) admitted to sampling persons who were relatively ill and Popkin et al. (1988) used nephropathy as a criteria for inclusion in the study.

Second, the pattern of SIP scale scores is remarkably similar to many other chronic conditions. With the possible exception of alertness behavior, long-standing, type II diabetics report roughly the same functional disabilities as do non-diabetics with end-stage renal disease or patients with angina. This suggests that many of the impacts of a chronic disease are general and not specific to a particular disease.

These general impacts could potentially arise from symptoms which cut across many disease categories. For example, fatigue is a common complaint which could potentially mediate many functional limitations. Jensen (1986) reported that 49% of a sample of 101 diabetics indicated that they were chronically tired. Likewise, Surridge (1984) conducted a psychiatric interview with 50 insulin-dependent diabetics and reported that 62% complained of fatigue. It seems obvious that this might result in true responses to items such as "I sit during much of the day" or "I am going out less to visit people" or "I walk more slowly" or "I am doing less of the regular daily work around the house than I would usually do." Similar results might be found for other chronic diseases.

Third, the discrepancy between objective and subjective quality of life is also similar to that reported from other studies of patients with chronic disease. For example, Evans et al. (1985) administered the SIP, the Index of General Affect, and the Overall Life Satisfaction Scale to a group of 859 patients with end-stage renal disease. They discovered that while day to day functioning was impaired, the subjective experience of quality of life was no different from that of the general population. This was interpreted to mean that their sample was "able to adapt to very adverse life circumstances" (p.558). Results from this study of persons with NIDDM could be similarly interpreted.

Finally, it is interesting to note that this discrepancy between objective and subjective quality of life is opposite to what was reported from a study of 65 newly diagnosed insulin-dependent diabetics. According to Holstein et al. (1986) there were few problems in day to day living whereas there were many psychological problems. Similar results were noted in the Cassileth et al. (1984) of six different chronic diseases. Patients diagnosed for three months or less suffered from increased anxiety and depression, a loss of control, and poorer overall mental health. One possible explanation is that people adjust to having a chronic disease by lowering their expectations so that they are satisfied with a more limited lifestyle. Campbell et al. (1976) interpreted the findings of their major survey to suggest that while an initial deterioration in life circumstances decreases life satisfaction, ongoing deleterious circumstances cause a decrease in aspirations and a subsequent increase life satisfaction. In studying cardiovascular disease, Fletcher, Hunt, and Bulpitt (1987) write that "disabled patients who are chronically ill may have high quality of life scores due to an adjustment of their expectations to a more limited lifestyle" (p. 560). This explanation could apply to diabetes as well.

C. Summary of Major Findings

There are several major findings from this study. First, long-standing, type II diabetes seems to impact both physical and social aspects of day to day functioning. However, neither psychological well-being nor perceived life satisfaction appear to be similarly impaired. Second, with the possible exception of depression, there was little evidence for any relationship between the quality of life variables measured and glycemic control. Third, limited support for the accelerated cognitive aging hypothesis was provided by: (a) the significant relationship between alertness behavior and glycemic control as well as (b) the discrepancy between the scores of diabetics and the scores of other chronically ill persons on the alertness behavior scale. Finally, the extreme variability in scores indicates that diabetes affects different people in different ways.

A cross-study comparison suggests that, with the possible exception of alertness behavior, the functional limitations found in this study may not be specific to diabetes but characteristic of chronic diseases in general. Furthermore, the discrepancy between the objective and subjective aspects of quality of life may be interpreted as evidence that many persons can adapt to a chronic disease such as diabetes.

D. Possible Confounds

Before attributing any differences in quality of life between this sample and that obtained by more general samples of the population to the presence of diabetes several other possible differences between our sample and others must be considered.

1. Obesity

Besides being diabetic most of the persons in this study sample (92%) were at least 10% overweight. It might be argued that the functional limitations attributed to diabetes are actually caused by obesity. However, a six by three manova conducted on the three categories of obesity and six quality of life variables did not yield any significant results F(2,37) = 1.2, p.>05. Furthermore, in using the SIP to measure the quality of life of 63 obese women, Sullivan, Sullivan and Kral (1987) did not find any significant differences between the obese women and a reference group from the general population. Thus, obesity is unlikely to account for the differences in functional status found between this study sample and samples of the general population.

2. Age

In addition to being obese, many of the subjects were older than those in the general populations to which they were compared. Studies of the elderly indicate that considerable functional impairment is common among all aged persons (eg. McKinnon, 1883). Therefore, it could be argued that the functional limitations found in this study are due to age and not diabetes. There are two defenses against this argument: First, patients were asked to check off only those items which were true because of their diabetes. This would eliminate any of the impacts which were obviously due to age. Second, there were no significant correlations between age and any of the six quality of life measures assessed. Thus, age is unlikely to be the sole cause of the differences found between this study sample and those cited in the literature.

E. Limitations

1. Our subject pool may also have differed from several of the other studies of diabetics. The most obvious difference is in blood sugar control. The average HbA1 score for the diabetics in this study was 7.7 +/- 1.7. This is much lower than that reported by most other researchers. This could account for the lack of significance between various psychological factors and control. Homogeneity of subjects makes it more difficult to demonstrate a significant correlation. Furthermore, from a visual inspection of the data it seems that the putative relationship between some psychological variables and glycemic control may be especially true for people with extreme scores. Another

factor to consider is that most studies are done on either American or British populations. Possibly only the more severe or poorly controlled diabetics attend hospital outpatient programs in these countries.

However, our subject pool may not have been any more representative of the general population of long-standing, non-insulin-dependent diabetics. Almost half of our subjects were from weekly educational programs and some researchers have reported that these classes favor the attendance of "the urban dweller who is unemployed, disabled, retired, hospitalized, a student, or a homemaker" (Cerkoney & Hart, 1980, p. 596). This concern is somewhat mitigated by the fact that a large proportion of the general population of long-standing, type II diabetics are also retired. Another concern lies with the fact that many of our subjects were referred by their general physician. This could also have introduced some degree of bias. Therefore, although there is no reason to believe that results would be different for any other group of long-standing, type II diabetics, generalizations must be made cautiously.

2. There was no control group. Although results from this sample were compared with published scores from other samples, stronger conclusions could have been reached had a matched control group been used.

3. The study was limited to self-report. The conclusions reached by this investigator were based solely on what the subjects chose to reveal about themselves. The role that denial may have played is unknown. However, this is the only methodology that allows researchers to examine events from the patient's perspective.

4. Several persons complained about the use of double negatives in the Basic Personality Inventory (BPI). It is possible that some persons became confused and unintentionally misrepresented themselves. This was exacerbated by the fact that the BPI was given last and many persons were fatigued.

5. There was no correction made for the number of correlations calculated. This increases the chance of making a type one error, that is finding significance when there is none. Partial justification is provided by the exploratory nature of the study. In addition, this investigator was unable to find any related research which made use of such a correction.

6. This survey was hampered by a lack of power. Several statistics were probable at about the .10 level. This makes it difficult to draw any firm conclusions. Many psychosocial studies are plagued with this problem and efforts to develop more sensitive measures and better controlled designs must continue.

F. Implications and Recommendations

1. Because diabetes appears to impact the day to day social functioning of most diabetics it is recommended that a psychosocial component be added to diabetic educational programs. This recommendation has also been made by other researchers. Furthermore, studies have shown that patient education can contribute to the development of more positive attitudes (eg. Anderson, Nowacek, & Richards, 1988). The finding of Davis et al. (1988) that the adverse social impacts of diabetes correlate with mortality gives a sense of urgency to this issue.

2. Continue to promote good metabolic control. Thus far, this is the only way of minimizing the secondary complications which cause many of the physical limitations of diabetes.

3. The lack of evidence for any relationship between any quality of life variables and glycemic control suggests that increasing quality of life and promoting metabolic control may have to be treated as two separate goals. This conclusion was also reached by Holstein et al. (1986).

4. The remarkable amount of variation noted in objective, subjective, and anecdotal data points to a need to treat people as individuals.

5. If diabetes affects daily functioning with respect to alertness behavior, it may be important to include techniques for compensation in diabetes educational programs so that these deficits do not adversely affect an individual's ability to implement treatment regimens. In reviewing the implications of the growing evidence of cognitive deficits among diabetics, Holmes (1987) suggests teaching diabetics to use mneumonics and written cues.

G. Directions for Further Research

The following might be useful:

1. a longitudinal study of the cognitive sequelae of type II diabetes as measured by both neuropshycholgical battery and self-report.

2. the efficacy of using different treatment approaches for different subgroups of diabetics.

3. the development of programs which include measures to address the social needs of the diabetic.

4. the continued development of more sensitive ways of measuring psychosocial variables and of measuring their association with metabolic control (qualitative studies might be useful in identifying pertinent variables).

5. further study of the relationship between objective and subjective quality of life.

6. a comparison of the program at this hospital with other educational programs. It is possible that the low blood sugar levels achieved by this particular population are due to some component of their educational program.

H. Concluding Remarks

For me, personally, this study is a testimony to the remarkable capacity of the human being to adapt. The final message is one of hope: The physical limitations of a chronic disease need not pervade one's psychological well-being. I spoke to many persons who live under circumstances many of us imagine to be dreadful. Yet most seemed to take it all in stride, focussing on aspects of their lives over which they had more control. Should I ever find myself in their position, I can only hope to do the same.

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Appendix A

The following are the criteria that were used by the nurses in coding the obesity and secondary complications of the subjects in this experiment:

Obesity:
0 = ideal weight range
1 = 10 to 20% above ideal weight
2 = >20% above ideal weight

Vascular:
0 = post tibial, dorsal pedal pulses normal, feet warm, pink, toenails normal growth
1 = moderately impaired (weak) pedal pulses (any of four), toenails thickened, slow-growing. slow-healing trauma, lesions
2 = absent pedal pulses (any of four), dusky rubor (mottled) after dangling, ulceration, gangrene

Retinopathy:
0 = none by funduscopic exam
1 = simple retinopathy
2 = proliferative retinopathy

Neuropathies (peripheral):
0 = none evident
1 = weak reflexes, mild sensations
2 = absence of reflexes and sensations

Nephropathy:
0 = absence of proteinuria
1 = proteinuria (trace to 300 mgm)
2 = proteinuria > 300 mgm and/or creatinine > 1.4 mmol/litre

Note. From Diabetes, Yearly Assessment (p. II-B-12) Edmonton: General Hospital (Grey Nuns) of Edmonton.

Appendix B

Percentage of Persons Responding Affirmatively to Each Item of the Sickness Impact Profile

SR-0499
1) I spend much of the day lying down in order to rest. _12__(083)
2) I sit during much of the day. _33__(049)
3) I am sleeping or dozing most of the time - day and night. _09__(104)
4) I lie down more often during the day in order to rest. _24__(058)
5) I sit around half-asleep. _07__(084)
6) I sleep less at night, for example, wake up too early, don't fall asleep for a long time, awaken frequently. _45__(061)
7) I sleep or nap more during the day. _29__(060)

EB-0705
1) I say how bad or useless I am, for example, that I am a burden on others. _02__(087)
2) I laugh or cry suddenly. _17__(068)
3) I often moan and groan in pain and discomfort. _12__(069)
4) I have attempted suicide. _00__(132)
5) I act nervous or restless. _22__(046)
6) I keep rubbing or holding areas of my body that hurt or are uncomfortable. _24__(062)
7) I act irritable and impatient with myself, for example, talk badly about myself, swear at myself, blame myself for things that happen. _19__(078)
8) I talk about the future in a hopeless way. _03__(089)
9) I get sudden frights. _10__(074)

BCM-2003
1) I make difficult moves with help, for example, getting into or out of cars, bathtubs. _12__(084)
2) I do not move into or out of bed or chair by myself but am moved by a person or mechanical aid. _00__(121)
3) I stand only for short periods of time. _33__(072)
4) I do not maintain balance. _09__(098)
5) I move my hands or fingers with some limitation or difficulty. _07__(064)
6) I stand up only with someone's help. _02__(100)
7) I kneel, stoop, or bend down only by holding on to something. _28__(064)
8) I am in a restricted position all the time. _03__(125)
9) I am very clumsy in body movements. _12__(058)
10) I get in and out of bed or chairs by grasping something for support or using a cane or walker. _12__(082)
11) I stay lying down most of the time. _00__(113)
12) I change position frequently. _19__(030)

13) I hold on to something to move myself around in bed. _03__(086)
14) I do not bathe myself completely, for example, require assistance with bathing. _00__(089)
15) I do not bathe myself at all, but am bathed by someone else. _00__(115)
16) I use the bedpan with assistance. _00__(114)
17) I have trouble getting shoes, socks, or stockings on. _19__(057)
18) I do not have control of my bladder. _09__(124)
19) I do not fasten my clothing, for example, require assistance with buttons, zippers, shoelaces. _00__(074)
20) I spend most of the time partly undressed or in pajamas. _02__(074)
21) I do not have control of my bowels. _02__(128)
22) I dress myself, but do so slowly. _09__(043)
23) I get dressed only with someone's help. _00__(088)

HM-0668
1) I do work around the house only for short periods of time or rest often. _36__(054)
2) I am doing <u>less</u> of the regular daily work around the house than I would usually do. _43__(044)
3) I am not doing <u>any</u> of the regular daily work around the house that I would usually do. _03__(086)
4) I am not doing <u>any</u> of the maintenance or repair work that I would usually do in my home or yard. _12__(062)
5) I am not doing <u>any</u> of the shopping that I would usually do. _00__(071)
6) I am not doing <u>any</u> of the house cleaning that I would usually do. _12__(077)
7) I have difficulty doing handwork, for example, turning faucets, using kitchen gadgets, sewing, carpentry. _05__(069)
8) I am not doing <u>any</u> of the clothes washing that I would usually do. _05__(077)
9) I am not doing heavy work around the house. _36__(044)
10) I have given up taking care of personal or household business affairs, for example, paying bills, banking, working on budget. _05__(084)

M-0719
1) I am getting around only within one building. _03__(086)
2) I stay within one room. _00__(106)
3) I am staying in bed more. _05__(081)
4) I am staying in bed most of the time. _00__(109)
5) I am not now using public transportation. _14__(041)
6) I stay home most of the time. _16__(066)
7) I am only going to places with restrooms nearby. _12__(056)
8) I am not going into town. _09__(048)
9) I stay away from home only for brief periods of time. _17__(054)
10) I do not get around in the dark or in unlit places without someone's help. _05__(072)

SI-1450

1) I am going out less to visit people. _30__(044)
2) I am not going out to visit people at all. _05__(101)
3) I show less interest in other people's problems, for example, don't listen when they tell me about their problems, don't offer to help. _03__(067)
4) I often act irritable toward those around me, for example, snap at people, give sharp answers, criticize easily. _31__(084)
5) I show less affection. _09__(052)
6) I am doing fewer social activities with groups of people. _24__(036)
7) I am cutting down the length of visits with friends. _12__(043)
8) I am avoiding social visits from others. _03__(080)
9) My sexual activity is decreased. _33__(051)
10) I often express concern over what might be happening to my health. _19__(052)
11) I talk less with those around me. _09__(056)
12) I make may demands, for example, insist that people do things for me, tell them how to do things. _03__(088)
13) I stay alone much of the time. _10__(086)
14) I act disagreeable to family members, for example, I act spiteful, I am stubborn. _09__(088)
15) I have frequent outbursts of anger at family members, for example, strike at them, scream, throw things at them. _05__(119)
16) I isolate myself as much as I can from the rest of the family. _05__(102)
17) I am paying less attention to the children. _02__(064)
18) I refuse contact with family members, for example, turn away from them. _00__(115)
19) I am not doing the things I usually do to take care of my children or family. _03__(079)
20) I am not joking with family members as I usually do. _05__(043)

A-0842

1) I walk shorter distances or stop to rest often. _36__(048)
2) I do not walk up or down hills. _22__(056)
3) I use stairs only with mechanical support, for example, handrail, cane, crutches. _22__(067)
4) I walk up or down stairs only with assistance from someone else. _02__(076)
5) I get around in a wheelchair. _05__(096)
6) I do not walk at all. _00__(105)
7) I walk by myself but with some difficulty, for example, limp, wobble, stumble, have stiff legs. _14__(055)
8) I walk only with help from someone. _00__(088)
9) I go up and down stairs more slowly, for example, one step at a time, stop often. _31__(054)
10) I do not use stairs at all. _02__(083)
11) I get around only by using a walker, crutches,

cane, walls, or furniture. _05__(079)
12) I walk more slowly. _45__(035)

AB-0777
1) I am confused and start several actions at a time. _05__(090)
2) I have more minor accidents, for example, drop things, trip and fall, bump into things. _22__(075)
3) I react slowly to things that are said and done. _10__(059)
4) I do not finish things that I start. _09__(067)
5) I have difficulty reasoning and solving problems, for example, making plans, making decisions, learning new things. _09__(084)
6) I sometimes behave as if I were confused or disoriented in place or time, for example, where I am, who is around, directions, what day it is. _12__(113)
7) I forget a lot, for example, things that happened recently, where I put things, appointments. _50__(078)
8) I do not keep my attention on any activity for long. _12__(067)
9) I make more mistakes that usual. _12__(064)
10) I have difficulty doing activities involving concentration and thinking. _19__(080)

C-0725
1) I am having trouble writing or typing. _14__(070)
2) I communicate mostly by gestures, for example, moving my head, pointing, sign language. _00__(102)
3) My speech is understood only by a few people who know me well. _00__(093)
4) I often lose control of my voice when I talk, for example, my voice gets louder or softer, trembles, changes unexpectedly. _02__(083)
5) I don't write except to sign my name. _05__(083)
6) I carry on a conversation only when very close to the person or looking at him. _10__(067)
7) I have difficulty speaking, for example, get stuck, stutter, stammer, slur my words. _05__(076)
8) I am understood with difficulty. _00__(087)
9) I do not speak clearly when I am under stress. _12__(064)

The next group of statements has to do with any work you usually do other than managing your home. By this we mean anything that you regard as work that you do on a regular basis.

Do you usually do work other than managing your home? ___ yes ___ no

If you answered yes, go on to the next page.

If you answered no:

Are you retired? _47 yes ___ no

If you are retired, was your retirement related to your health? _09 yes ___ no

If you are <u>not</u> retired, but are not working, is this related to your health? _03 yes ___ no

W-0515

1) I am not working at all. _____(361)

IF YOU CHECKED THIS STATEMENT, SKIP TO THE NEXT PAGE.

2) I am doing part of my job at home. _10__(037)

3) I am not accomplishing as much as usual at work. _07__(055)

4) I often act irritable toward my work associates, for example, snap at them, give sharp answers, criticize easily. _07__(080)

5) I am working shorter hours. _10__(043)

6) I am doing only light work. _00__(050)

7) I work only for short periods of time or take frequent rests. _10__(061)

8) I am working at my usual job but with some changes, for example, using different tools or special aids, trading some tasks with other workers. _00__(034)

9) I do not do my job as carefully and accurately as usual. _03__(062)

RP-0422

1) I do my hobbies and recreation for shorter periods of time. _28__(039)

2) I am going out for entertainment less often. _33__(036)

3) I am cutting down on some of my usual inactive recreation and pastimes, for example, watching TV, playing cards, reading. _19__(059)

4) I am not doing any of my usual inactive recreation and pastimes, for example, watching TV, playing cards, reading. _03__(084)

5) I am doing more inactive pastimes in place of my other usual activities. _28__(051)

6) I am doing fewer community activities. _22__(033)

7) I am cutting down on some of my usual physical recreation or activities. _21__(043)

8) I am not doing any of my usual physical recreation or activities. _19__(077)

E-0705

1) I am eating much less than usual. _33__(037)

2) I feed myself but only by using specially prepared food or utensils. _07__(077)

3) I am eating special or different food, for example, soft food, bland diet, low-salt, low-fat, low-sugar. _40__(043)

4) I eat no food at all but am taking fluids. _03__(104)

5) I just pick or nibble at my food. _00__(059)

6) I am drinking less fluids. _03__(036)

7) I feed myself with help from someone else. _00__(099)

8) I do not feed myself at all, but must be fed. _00__(117)

9) I am eating no food at all, nutrition is taken through tubes or intravenous fluids. _00__(133)

Appendix C

Study on the Impact of Diabetes Mellitus: Consent Form

A research team from the Edmonton General Hospital (Grey Nuns) and the University of Alberta are conducting a study on the impact of diabetes. Your cooperation will play an important part in helping us determine how diabetes affects day to day living. This information will be used in planning educational/support programs and in evaluating future treatment alternatives.

This study requires about one hour of your time. You will be asked to answer a variety of paper and pencil questions. Most require only a true or false response and you may decide to withdraw at any time without penalty. In addition, all of your answers will be held in strictest confidence and only researchers directly involved in the project will have access to your file.

A letter describing the findings of this study will be made available to you at a later date. Should you have any questions or concerns please do not hesitate to phone Clinical Services at the University of Alberta (432-3746).

Thank you very much.

MJ Wiersema,
research assistant

Dr. Carl Blashko

I hereby consent to participate in the aforementioned study. I am aware that I may withdraw at any time without penalty. I also agree to allow the researchers access to the medical and demographic information in my file.

Signature and address of participant	Witness
______________________________	________________
______________________________	Date
______________________________	________________

Appendix D

September 1, 1989

Dear participant,

Thank you for participating in the study of the impact of diabetes which was conducted in the summer and fall of 1988. This letter is to inform you of some of the preliminary results. We apologize for the delay in analyzing the data. Thus far, only the results of the long-standing, type II diabetics are available. These are as follows:

1. Long-standing, type II diabetes appears to affect both physical and social functioning. With respect to physical limitations many persons reported experiencing difficulty with standing, walking distances, climbing stairs, and bending down. Many individuals also indicated that because of their diabetes they tend to stay at home more often and when they do go out they look for places with rest-rooms nearby. With respect to limitations in social functioning many persons reported that their diabetes makes them irritable, and that they go out visiting less often. In addition, most reported some difficulty with memory, concentration and/or reaction times. Finally, about one-third of the sample reported a decrease in sexual activity.

2. Despite these limitations, scores on measures of psychological well-being and overall satisfaction with life are similar to that of the rest of the population. This may be interpreted to mean that many persons with diabetes adapt to the limitation of their disease.

3. There was a great deal of variation in how diabetes affects different individuals. Some persons experienced very little effect while others described themselves as devastated.

4. There was some indication that persons who are severely depressed may have higher blood sugar levels than other diabetics.

5. Several persons mentioned that they were very impressed with the staff and program at this particular hospital. Some expressed a desire for some kind of followup to the educational program.

Please remember that these are the findings of only one small study. Much more research is needed before any firm conclusions can be drawn.

Should you have any further questions or comments please do not hesitate to leave a message for me at the Psychological Testing Centre of the University of Alberta (492-3746). I will return all calls.

Thanks again for taking the time to participate in this study.

Sincerely yours,

MJ Wiersema