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Individuals who do and do not perceive difficulties adhering to a diet for diabetes mellitus, their quality of life and glycaemic control

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INDIVIDUALS WHO DO AND DO NOT PERCEIVE DIFFICULTIES ADHERING TO A DIET FOR DIABETES MELLITUS, THEIR QUALITY OF LIFE AND GLYCAEMIC CONTROL.

BY

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ABSTRACT:

Opinion regarding the successful management of insulin dependent diabetes mellitus (IDDM) has identified nutrition as a key player. Whilst important, diet has also been highlighted as one of the most difficult aspects of the regimen, by both individuals with IDDM and health workers. Current dietetic recommendations for the nutritional management of individuals with IDDM include, the normalisation of plasma glucose and the promotion of patient well being.

This study aimed to determine if any significant difference in quality of life (QOL) and glycaemic control existed between groups of individuals with IDDM, who perceive their diet difficult to adhere to and those who perceive adherence easy.

Nineteen individuals, all clients of a diabetes education centre and aged 18–30 years, volunteered to participate. The Diabetes Control and Complications Trial QOL questionnaire and the SF–36 were used to assess QOL. Glycaemic control was assessed via a non fasting blood sample to determine HbA1c. Finally a question was used to divide the nineteen subjects into three groups, based on their perception of adherence difficulties. The three groups were those that found adherence difficult (A), neither difficult or easy (B) and easy (C). QOL and glycaemic control

comparisons were then made for the two most polarised groups (A and C).

Of the nineteen subjects, ten perceived no difficulty, seven perceived neither difficulty or ease, and only two subjects perceived any difficulty with adherence to their diet. The ages of the subjects, duration of IDDM and the sample selection process was believed to contribute to the afore mentioned distribution. Statistical analysis comparing glycaemic control and QOL results between the groups was restricted by the small size of group A. The two subjects in group A displayed incompatible results for glycaemic control and QOL, both compared to one another and to the mean of group C. The QOL tools were practical and simple to work with and it is recommended to continue the study utilising the current method, with modifications to the sample selection process.

CHAPTER 1: INTRODUCTION.

Diabetes mellitus is characterised by an abnormality of glucose metabolism, resulting in hyperglycaemia (Coulston 1994). There are two major types of diabetes mellitus; insulin dependent (IDDM) or Type I and non insulin dependent (NIDDM) or Type II. Normal glucose metabolism is facilitated by the action of the pancreatic hormone insulin. In individuals with IDDM there is a relative or absolute lack of this hormone. Whilst in NIDDM there is a decreased ability to secrete the insulin and a decreased effectiveness of the insulin available (Zeman 1991).

In 1993 the New England Journal of Medicine published the results of the Diabetes Control and Complications Trial (DCCT). This trial was able to strengthen the link between hyperglycaemia and an increased risk of development and progression of diabetic complications in the IDDM patient (DCCT Research Group 1993a). Although not the first study to determine this, the study design and response rate cemented the significance of the findings.

The existence of chronic illness, including IDDM, has been associated with a reduced quality of life (Stewart 1989). The demands and concerns of IDDM may result in a feeling of great impact of the disease on daily life

and thus a reduced satisfaction or functional ability (Hanestad and Albrektsen 1991a).

Current recommendations for the nutritional management of individuals with IDDM are to;

> "normalise plasma glucose and lipid levels thus reducing the risk of short and long term complications, to maintain optimal body weight in adults and normal growth in children and adolescents and to promote optimal patient well being." (Dietitians Association of Australia 1995:1)

It would appear that the successful management of the individual with IDDM can be based on a satisfactory balance between their glycaemic control and their quality of life. "Satisfactory" being determined by the individual with IDDM. But the relationship between glycaemic control and quality of life continues to be elusive, and the management of IDDM remains complex.

The association between glycaemic control and quality of life is unclear, although several differing relationships have been postulated (Mazze et al 1984; Hanestad et al 1991b; Nerenz et al 1992). These differing results put forward may have been influenced by variations in the methodologies and

an inconclusive relationship remains.

Diet, exercise and medication are all part of the regimen that constitutes the treatment for IDDM (Bantle 1992). The co ordination and integration of various pieces of the regimen can make it difficult (McCaul et al 1987). The management of IDDM relies heavily on nutrition, and this is recognised as one of the most difficult aspects of the treatment (Coulston 1994; Schlundt et al 1994; American Diabetes Association Position Statement 1994; Nuttal et al 1993). The beliefs of the individual, situational factors and the complexity of the diet contribute to difficulties with adherence to the dietary regimen (Rosenstock 1985; Schulndt et al 1994; Holli and Calabrese 1991).

Current investigations have suggested that if the difficulties faced by the individual are reduced adherence will increase (Rosenstock 1985; Ary et al 1986; Schlundt et al 1994). Furthermore research to date has investigated relationships between the level of adherence to diet and glycaemic control, with several differing conclusions proposed (Glasgow et al 1987; Rubin et al 1989 and 1991; Delahanty and Halford 1993).

The relationship between dietary adherence and quality of life has not been explored, although adherence to the regimen as a whole, has been investigated (Hanestad and Albrektsen 1991a).

Considering the difficulty recognised with the dietary aspect of the regimen, investigation of any difficulty with dietary adherence perceived by the person with IDDM, and its effect on the two measures of the successful management of IDDM, glycaemic control and quality of life, would broaden the base of information available to assist the individual with IDDM.

The number of tools with which to measure quality of life is near endless (Bowling 1991). In this research quality of life will be measured using two instruments, the Medical Outcome Study Health Survey 36 Item Short Form (SF–36) (Ware et al 1992), and the diabetes quality of life measure developed for the DCCT (DQOL) (DCCT Research Group 1988).

The SF–36 (Ware et al 1992) was selected because of its generic nature and emerging widespread use (Stevenson 1995). Whilst the DQOL (DCCT Research Group 1988) was chosen because of its ability to reflect illness specific problems and the fact that it is more sensitive to lifestyle issues such as diet and insulin (Jacobson et al 1994). The complementary nature of these questionnaires supports their collective use (Jacobson et al 1994). Both the SF–36 and the DQOL are self administered, brief and validity and reliability (McHorney et al 1992;1994; DCCT Research Group 1988), characteristics which secure their use for this research.

1.1 RESEARCH AIM:

To compare the quality of life and glycaemic control of a group of individuals with IDDM who perceive difficulty adhering to their diet, with a group of individuals with IDDM who perceive that it is easy to adhere to their diet.

1.2 RESEARCH OBJECTIVES:

1. To develop, from a central pool of volunteers with IDDM, three groups, those that perceive difficulty (group A), those that perceive ease (group C) and those that perceive neither ease nor difficulty (group B) with adherence to a diet for diabetes.

2. To determine the level of glycaemic control, as measured by glycosylated haemoglobin (HbA1c), in each of these individuals and to test for significant difference between these values for groups A and C.

3. To determine the self perceived quality of life of each individual and to test for significant difference between the quality of life scores of groups A and C.

1.3 RESEARCH HYPOTHESIS:

1. The mean HbA1c value of people who perceive difficulty adhering to their diet is significantly different from the mean HbA1c value of people who perceive adherence easy.

   Ho: uA=uC

   H1: uA=uC

2. The mean quality of life scores of people who perceive difficulty adhering to their diet is significantly different from the mean quality of life scores of people who perceive adherence easy.

   Ho: uA=uC

   H1: uA=uC

   uA denotes mean of group A

   uC denotes mean of group C

1.4 DEFINITION OF TERMS

Diabetes Control and Complications Trial:

This was a nine year multicentre, prospective, randomised clinical trial, conducted in the United States. The study involved 1441 subjects with insulin dependent diabetes mellitus. It was designed to evaluate the effects of two different diabetes treatments on the development, progression or amelioration of early microvascular complications in persons with IDDM. Results of the study were published in the New England Journal of Medicine 1993;329(14):977–86.

Glycaemia:

Glyc– a prefix denoting sugar. (Oxford Reference Concise Medical Dictionary 4th edition, 1994:12)

aemia– a suffix denoting a specific biochemical condition of the blood. (Oxford Reference Concise Medical Dictionary 4th edition, 1994:278)

Glycaemia– sugar in the blood.

Glycosylated Haemoglobin (HbA1c):

A type of red blood cell that has bonded with glucose. The quantity of this cell present in the blood indicates how well blood glucose has been controlled over the previous six to eight weeks. (Eschelman 1991:386)

Hyperglycaemia:

An excess of glucose in the bloodstream. (Oxford Reference Concise Medical Dictionary 4th edition, 1994:319)

Hypoglycaemia:

A deficiency of glucose in the bloodstream, causing muscular weakness and incoordination, mental confusion and sweating. (Oxford Reference Concise Medical Dictionary 4th edition, 1994:323)

Insulin:

A protein hormone, produced in the pancreas by the beta cells of the islets of Langerhans, that is important for regulating the amount of sugar (glucose) in the blood. (Oxford Reference Concise Medical Dictionary 4th edition, 1994:339)

Ischaemic:

Interference with the blood supply. (Zeman 1991:10)

Ketoacidosis:

Raised levels of ketone bodies in the body tissues. (Eschelman 1991:390)

Ketone bodies:

Normal products of fat metabolism which can be oxidised to produce energy. Elevated levels arise when there is an imbalance in fat metabolism, as is the case with prolonged hyperglycaemia. (Oxford Reference Concise Medical Dictionary 4th edition, 1994:356)

Nephropathy:

Disease of the kidney. (Oxford Reference Concise Medical Dictionary 4th edition, 1994:440)

Neuropathy:

Any disease of the peripheral nerves, usually causing weakness and numbness. (Oxford Reference Concise Medical Dictionary 4th edition, 1994:445)

Polydipsia:

Abnormally intense thirst, leading to the drinking of large quantities of fluid. (Oxford Reference Concise Medical Dictionary 4th edition, 1994:522)

Polyphagia:

Gluttonous excessive eating. (Oxford Reference Concise Medical Dictionary 4th edition, 1994:523)

Polyuria:

The production of large volumes of urine, which is dilute and of a pale colour. (Oxford Reference Concise Medical Dictionary 4th edition, 1994:524)

Retinopathy:

Any of the various disorders of the retina resulting in impairment or loss of vision. It is usually due to damage to the blood vessels of the retina. (Oxford Reference Concise Medical Dictionary 4th edition, 1994:573)

CHAPTER 2: LITERATURE REVIEW.

2.1 DEFINITION AND PREVALENCE OF DIABETES MELLITUS:

Diabetes Mellitus consists of a group of disorders which are characterised by hyperglycaemia. Insulin dependent diabetes mellitus (IDDM) exists within this group and is often referred to as type I or juvenile onset diabetes because those with IDDM are usually children or young adults at onset (Zeman 1991). For those people with IDDM the hyperglycaemia is due to an absolute or relative lack of insulin, a hormone produced by the pancreas (Coulston 1994). IDDM leaves the individual dependent on regular exogenous insulin doses, diet and exercise to control the hyperglycaemia (McDonald & Roberts 1990; DCCT Research Group 1993b; Coulston 1994).

The other major form of diabetes is non insulin dependent diabetes (NIDDM), type II or mature onset. In NIDDM the pancreas's ability to secrete insulin is decreased or delayed, there is also a decreased effectiveness of the insulin available (Zeman 1991). Primarily diet and exercise control the hyperglycaemia of NIDDM, oral medications may also be required for some people (McDonald and Roberts 1990). Both of these forms of diabetes are life long diseases.

Acute complications of uncontrolled hyperglycaemia include; dehydration, weight loss, fatigue, polyuria, polydipsia, polyphagia and ketoacidosis (Zeman 1991). Chronic complications of poor glucose regulation include both macrovascular and microvascular disease, which may result in; ischaemic heart disease, peripheral vascular disease, retinopathy, nephropathy, and neuropathy (Brownlee and Cerami 1981; Hartog 1987; McDonald and Roberts 1990; Zeman 1991).

According to Diabetes Australia (1994) all types of diabetes mellitus combine to be the fifth major cause of death by disease in Australia and collectively they are a major health issue in this country. The Australian Bureau of Statistics reveals that from 1985–1989, 10,059 deaths were due to diabetes mellitus (ABS 1991). This classification does not include those deaths due to heart, kidney and other diseases primarily caused by diabetes mellitus. Diabetes mellitus is also an independent risk factor for cardiovascular disease, which is a major cause of morbidity in Australia and in other developed countries (Lester 1994).

Current trends indicate that in the next fifteen years the number of people with diabetes mellitus will double (Diabetes Australia 1994). Current available data reveal that IDDM accounts for ten to fifteen per cent of the diabetic population (Diabetes Australia 1994). This means an estimated

50,000 – 75,000 people in this country have IDDM.

In the Illawarra region the exact prevalence of IDDM is unknown. The records of the Diabetes Education and Information Centre (DEIC) provide the most accurate estimation, as it is routine for the local endocrinologists to refer all individuals with IDDM to this centre for ongoing treatment and care.

2.2 GLYCAEMIC CONTROL AND IDDM:

The Diabetes Control and Complications Trial (DCCT) was a landmark study which aimed to determine if "complications of diabetes mellitus are related to elevation of the plasma glucose concentration" (American Diabetes Association 1993). The DCCT did succeed in finding a direct relationship between blood glucose control and the diabetic complications of retinopathy, nephropathy and neuropathy (DCCT Research Group 1993a).

Due to the DCCT results a position statement from the Australian Diabetes Association has been issued, it includes the following;

> "The DCCT has unequivocally shown that when compared with poorer metabolic control, maintenance of near normoglycaemia over an average period of six and one–half years can reduce by 35–76 per

cent the development and progression of retinopathy, nephropathy and neuropathy in people with IDDM." (Yue et al 1993:803)

The DCCT was not the first study to investigate the link between glycaemia and diabetic complications. Several studies of an epidemiological, clinical and statistical nature have concluded that long–term intensive blood glucose control reduces the development and progression of complications (Orchard et al 1990; Reichard et al 1993; Wang et al 1993). These studies arrived at analogous findings, but the DCCT with its; multidisciplinary team, long term follow up (average 6.5 years), large number of participants (1441) and low attrition rate (99% of participants completed the study) was able to provide extraordinary weight to these conclusions (DCCT Research Group 1993a).

These findings reveal the significance of better glycaemic control and the benefits of intervention to reduce hyperglycaemia in the individual with IDDM.

Glycosylated haemoglobin (HbA1c) has become a routine assay for glycaemic control. This blood test measures the percentage of red blood cells that have bonded with plasma glucose (Eschelman 1991). A high concentration of plasma glucose will result in more bonding (Karam et al

1991). Since the bonding is for the life of the haemoglobin molecule and non reversible, an objective assessment of glycaemic control for the preceding six to eight weeks can be obtained (Goldstein et al 1986).

Portable blood glucose monitors enable ease of testing for the individual and provide near instant glycaemia levels (Eschelman 1991). The self monitored blood glucose records kept by some people with IDDM can be useful to determine glycaemic control, but the objective nature of the HbA1c assay make it superior for research purposes. Glycosylated haemoglobin has been used reliably in studies into the effect of intensive insulin treatment and the development of diabetic complications (Orchard et al 1990; Reichard et al 1993; Wang et al 1993 and DCCT Research Group 1993a).

2.3 QUALITY OF LIFE: CONCEPT AND ASSESSMENT:

Quality of life is a multidimensional concept that researchers and clinicians use to provide information on populations or an individuals' physical, social and emotional health (Weinberger et al 1994). It is used particularly in chronic illnesses where benefits or drawbacks of the care are unclear (Fitzpatrick et al 1992). People with IDDM constitute part of this group. The quality of their life may depend on "the severity of the disease and the intensity of the treatment." (Parkerson et al 1993:630)

Quality of life can be described as,

> "the value assigned to duration of life as modified by impairments, functional states, perceptions and social opportunities that are influenced by disease, injury, treatment or policy" (Donald and Erickson 1993:22)

The concept of quality of life is by its very nature a subjective interpretation. Avis and Smith (1994) suggest that the way in which quality of life is interpreted will influence how and what it is measured with. Donald and Ericksons' aforementioned definition highlights both a functional and perceptual nature of quality of life. The functional approach regards quality of life as the effect an illness and its associated therapy has on a person's ability to function eg climbing stairs, carrying shopping or bathing and dressing. Whilst the psychological or perceptual approach views quality of life as the gap between the individual's expectations and their achievements, that is, general satisfaction with life and their well being (Avis and Smith 1994). Both the functional and perceptual approaches reflect real situations for the person with IDDM.

There are a plethora of quality of life measures available, The Sickness Impact Profile and The Quality of Well Being Scale are among them. For a comprehensive review of the measurement tools refer to Bowling (1991).

In quality of life assessment a distinction is often made, that of generic versus condition specific measures (Andrews et al 1995). The condition specific measures assess particular aspects of quality of life that may be affected by disease or treatment of that disease, this makes them more sensitive to changes in the disease (Andrews et al 1995). Alternatively the generic measures can be used across all populations regardless of the presence, absence or type of disease (Parkerson et al 1993). This makes them more useful for comparison across differing disease states. The choice of assessment tool will depend on the needs of the user (Parkerson et al 1993).

The SF–36 (Ware et al 1992) is a generic, self administered, multiple choice questionnaire. It is suitable for use in people fourteen years and older and takes five to ten minutes to complete. It assesses eight predominant health concepts; physical functioning, role limitation due to physical health problems, bodily pain, general health, vitality, social functioning, role limitations due to emotional problems and mental health. The SF–36 yields a profile of scores reflecting the eight separate domains. Appendix 1 contains a detailed description of high and low scores for each of the eight domains.

The SF–36 scores can be interpreted by comparing specific domains. Alternatively the profile of the scores can be used, with domains on the left side of the profile reflecting physical health status and domains on the right side reflecting mental health status (Ware et al 1993).

The DQOL (DCCT Research Group 1988) is a condition specific, self administered multiple choice questionnaire, which can be completed in approximately ten minutes. It is suitable for use with both adults and adolescents. Subjects are asked to rate their current status from the perspective of; satisfaction with themselves, overall health status, impact of diabetes and worry about the future. A five point Likert scale is used with forty–six core items and sixteen addition items for those subjects that live with parents. The DQOL differs from the SF–36 in that it produces a total score rather than a profile of scores.

The SF–36 is rapidly becoming a standard tool for quality of life measurement, and has been included in the Australian Bureau of Statistics 1995–96 National Health Survey, results of which will be available for use late 1996 (Stevenson 1995). The SF–36's generic nature and emerging widespread use, particularly in Australia, will enable comparison of results across other studies and different illness populations (Jacobson et al 1994). The SF–36 has been shown to be both reliable and valid across diverse

population groups (McHorney et al 1992;1994).

The DQOL (DCCT Research Group 1988) is more sensitive than the SF–36 to lifestyle issues such as diet and insulin (Jacobson et al 1994). It is both valid and reliable in the IDDM population and this has been reviewed elsewhere (DCCT Research Group 1988).

Jacobson and colleagues (1994) have evaluated the SF–36 and the DQOL and established the complementary nature of each questionnaire's perspective. The SF–36 was found to assess the functional issues whilst the DQOL evaluated the perceptual factors that contribute to a particular level of quality of life.

Fitzpatrick et al (1992) and McHorney et al (1992) suggest there are several basic requirements for quality of life measurements. The instrument must be: valid and reliable for the population chosen, show a sensitivity to change, be appropriate to the target group and finally be practical in administration. In addition Avis and Smith (1994) highlight as essential, adequate representation of the health related factors: physical state, mental health and social interaction. These factors are all "indicators that are presumed or known to contribute to a relatively positive or negative life experience" (Lerner and Levine 1994 p45). The SF–36 and the DQOL include all of

these factors and enable a comprehensive picture of quality of life to be determined.

2.4 QUALITY OF LIFE AND GLYCAEMIC CONTROL IN IDDM:

The Medical Outcomes Study (Stewart et al 1989) has revealed that those people living with diabetes mellitus, IDDM or NIDDM, have a significantly lower quality of life than the general population or those without chronic illness. Nerenz et al (1992), in a separate diabetic population, has found comparable results, that is, self perceived quality of life scores which are similar to those reported in the Medical Outcomes Study (Stewart et al 1989). Hanestad (1989:123) through a theoretical analysis concluded that "IDDM has every chance of decreasing quality of life but that good quality of life and diabetes are not necessarily incompatible." Whilst in contrast Mazze and colleagues (1984) submitted that there was no difference between the quality of life of diabetic and non diabetic populations. Although Mazze et al (1984) reported on the characteristics of the diabetic population no information was available regarding the non diabetic population to which he referred, causing the conclusions to be queried.

The Stewart et al (1989) and Nerenz et al (1992) studies, assessed diabetic populations which included both insulin dependent and non insulin

dependent subjects, comparing quality of life scores with non diabetic populations. Stewart and colleagues' (1989) research does not reveal information about what factors affect quality of life within the IDDM population nor the existence or nature of any possible relationship between quality of life and glycaemic control.

The relationship between quality of life and glycaemic control is unclear. Mazze et al (1984) in a sample of 115 IDDM subjects, concluded that good glycaemic control was associated with a higher quality of life than either poor or average control. Quality of life in this study was measured using the Mooney Problems Check List. Mazze and colleagues (1984) did highlight that based on this research a directional relationship could not be concluded. Confounding these results is the classification of good and poor glycaemic control, which as Mazze and the team (1984) acknowledges, are not identical to diagnostic ranges.

In contrast to this Hanestad et al (1991b) could find no relationship between any level of glycaemic control and overall quality of life. He did however find poorly regulated IDDM subjects scored lower on the somatic dimensions of the quality of life assessment whilst better regulated IDDM subjects reported being more lonely and less sociable. In this research Hanestad and colleagues (1991b) measured quality of life with a tool

developed by Hornquist, a member of the research team.

Slightly later Nerenz et al (1992) discovered an inverted U relationship between glycaemic control and quality of life in IDDM subjects. Those people with very good or very poor glycaemic control reported lower quality of life scores using the SF–36 tool, than people with moderate glycaemic control. This relationship was attributed not to the complex diabetic regimen but rather a combination of age, education and number of daily injections.

The conflicting results presented here are not surprising when different techniques for collecting the data were employed. These three studies used three different quality of life measurement tools. Three differing classifications of the levels of poor and good glycaemic control, (which was measured using HbA1c and HbA1), were evident. Whilst the age representation across the studies ranged from sixteen to seventy–four, with no two studies representing exactly the same age sample.

In addition, although the quality of life instruments employed were able to measure the individual health domains of, emotional, physical, social etc, when these scores were computed to a total score the influence of each domain may not have been captured, leaving relationships that are incomplete. By employing frequently used, standardised quality of life tools,

the values obtained may be compared across studies and a more complete picture of IDDM and quality of life can be developed.

Apart from glycaemic control the level of diabetic complications, duration of IDDM and various demographic factors have been examined in relation to quality of life.

Rodin (1990) found that when IDDM was complicated by end stage renal disease the level of quality of life, as assessed by the Sickness Impact Profile, decreased. Measuring the quality of life using the DQOL tool, Lloyd et al (1992) was able to determine that the quality of subjects' lives was significantly related to the presence of diabetic complications, and the presence of more than one complication further decreased their quality of life.

Jacobson et al (1994), in the course of evaluating the DQOL and SF-36 questionnaires, was able to establish that the presence and number of complications was related to an individual's quality of life. With a lower quality of life being experienced by people who have one or more complications.

Interestingly, both Jacobson et al (1994) and Hanestad (1993) came to separate coinciding conclusions; that the length of time each subject had IDDM failed to have any consistent effect on quality of life.

The work of Hanestad (1993) and Jacobson et al (1994) determined that of the demographic factors no relationship could be found between quality of life and sex or education. Jacobson and colleagues (1994) found only a very limited relationship existed for age and quality of life, that of older individuals with IDDM reporting worse physical functioning, a result which was unsupported by the work of Hanestad (1993).

However marital status did play a role; with separated or divorced individuals reporting a reduced quality of life compared to single or married individuals. Due to the multifactorial nature of quality of life all of these factors need to be considered in quality of life assesment (Jacobson et al 1994).

2.5 DIETARY ADHERENCE:

The fundamental treatment for diabetes mellitus continues to be diet, exercise and medication (Bantle 1992). This treatment can be considered difficult for the person with diabetes mellitus. The difficulty is not only

following a guideline but coordinating and balancing the diet, exercise and medication for the rest of their life (McCaul et al 1987).

Compliance and adherence are words that are often used interchangeably. Compliance can be defined as "the extent to which the individual's food and dietary behaviour coincides with the dietary recommendations and prescriptions" (Holli and Calabrese 1991:10). This definition tends to emphasise an authoritive relationship, and de–emphasise the role played by the client. Alternatively, Holli and Calabrese (1991) suggest that the word adherence implies greater participation by the client in decision making and problem solving.

Adherence to the dietary regimen is frequently referred to as the most difficult part of the regimen by both people with diabetes mellitus and health workers (Lockwood et al 1986; Bantle 1992; Delahanty and Halford 1993; Nuttal 1993; American Diabetes Association Position Statement 1994; Schlundt et al 1994). House and colleagues (1986) found that people with diabetes ranked diet as the most difficult aspect of the diabetic regimen. These people cited environmental issues such as family, job and economic conditions, as the primary reason for the difficulty with adherence. The type of diet related difficulties reported by people with diabetes mellitus are similar regardless of whether they have IDDM or NIDDM (Ary et al 1986).

Researchers have investigated the reasons behind this difficulty, and attempted to measure the adherence level of the person living with IDDM. Rosenstock (1985:615) hypothesised that adherence to a diabetic regimen, including diet, depends on:

"1. a motive or incentive to comply,

2. the belief that one has diabetes and is susceptible to the consequences of it,

3. the belief that adherence would be beneficial,

4. the belief that one has the ability to comply with the recommendations,

5. the belief that the benefits outweigh the costs and

6. the knowledge and skills to adhere."

These are all internal factors. Adopting this approach implies that modification of the person's beliefs and skills will alter adherence.

Research by Ary et al (1986) found situational obstacles such as eating at restaurants and refusing offers of food from others created the greatest difficulty with adherence. Schlundt et al (1994) took this a step further and developed a taxonomy of situational obstacles to dietary adherence as perceived by the person with diabetes, they are as follows:

"1. Negative emotions
2. Resisting temptation
3. Eating out
4. Feeling deprived
5. Time pressure
6. Temptation to relapse
7. Planning
8. Competing priorities
9. Social events
10. Family support
11. Food refusal
12. Friends support"

(Schulndt et al 1994:876)

These elements emphasise the external nature of factors that influence adherence. Schlundt et al (1994) proposes that by being aware of the possible obstacles, improvements can be made to patient education and intervention, thus possibly increasing dietary adherence.

Apart from the internal and external factors outlined above, the characteristics of the diet can influence adherence (Holli and Calabrese 1991). The complexity of the diet is one such factor, as the level of complexity increases the level of adherence is found to decrease (Meichenbaum and Turk 1987 cited in DCCT 1993b).

From the research above, a reduction in the difficulties, be they internal, external or characteristics of the diet, should lead to an increase in adherence. Nagasawa et al (1989), through a meta-analysis, found that as

patients perceived more barriers to following a regimen, compliance decreased. The research of Nagasawa and colleagues (1989) was examining the diabetic regimen and not diet alone.

Glasgow et al (1987) found no relationship between dietary adherence and glycaemic control. Whilst Rubin et al (1989;1991) associated higher rates of dietary adherence with better glycaemic control. In the intensively treated population of the DCCT, those people that displayed dietary adherence rates of greater than 90% had a lower HbA1c than those with adherence rates of less than 45% (Delahanty and Halford 1993).

Measurement of adherence is fraught with difficulties and the frequent use of subjective measures of adherence in preference to standardised objective measures (Eckerling and Kohrs 1984), can create variability in the result obtained. Glasgow et al (1987) attempted to control for this by using multiple measures of adherence for each subject. Rubin et al (1989;1991) did not control for this and measured adherence by pre and post intervention questionnaires. The DCCT results should be interpreted with caution as the study population differed from the general population in the level and nature of the support provided by the health care team, one factor identified as likely to increase adherence (Rosenstock 1985; Holli and Calabrese 1991). The HbA1c levels in the DCCT were also being influenced by specific

instructions for hypoglycaemic episodes and any changes can not be attributed solely to dietary adherence.

The theory behind the research into adherence proposes that, if the difficulties associated with the diet are reduced, adherence will increase (Rosenstock 1985; Ary et al 1986; DCCT Research Group 1993b; Schulndt et al 1994). Better adherence is then suggested to contribute to near normoglycaemia which will result in fewer diabetic complications (Delahanty and Halford 1993; DCCT Research Group 1993a).

Hanestad and Albrektsen (1991a) explored the relationship between perceived difficulty in adherence to the diabetic regimen and quality of life. The sample of 247 IDDM subjects displayed that a higher quality of life was associated with perceived ease of adherence to the regimen. Hanestad and Albrektsens' (1991a) diabetic regimen included injection treatment, monitoring of blood or urine glucose, foot care, diet, weight regulation, exercise, regimen adjustments due to illness etc and finally smoking and alcohol habits. Whilst establishing that perceived ease of adherence to this regimen and quality of life were associated, it was the total regimen that was assessed. A gap remains in the research as to the effect difficulties with individual aspects of the regimen, particularly diet, have on quality of life and glycaemic control.

CHAPTER 3:
METHODS AND MATERIALS.

3.1 ETHICS APPROVAL:

The study was approved by the Human Research Ethics Committee at the University of Wollongong, as part of a PhD study undertaken by Ms Farideh Tabhaz. Informed consent was obtained from all participants prior to commencing the study (Appendix 2).

3.2 STUDY POPULATION:

The study population consisted of people with IDDM who were aged between eighteen and thirty years inclusive, residents of the Illawarra area and registered at the Wollongong Diabetes Education and Information Centre (DEIC). To be registered at the centre subjects had to have contacted the DEIC at least once. Although they did not necessarily receive initial education for diabetes from this centre.

3.3 SAMPLE SELECTION:

Subjects were selected from the records of the DEIC. Seventy one subjects, the total IDDM population in this age range registered at the DEIC for the

period January 1984–December 1994, were contacted by letter and invited to participate in the study (Appendix 3).

Question three of the 'practical aspects of IDDM' questionnaire (Appendix 4), was used to divide the twenty one diabetic subjects into tertials based on whether they found their diet difficult, easy or neither difficult nor easy to adhere to. The groups that found adherence difficult or easy were then compared for any differences in glycaemic control and quality of life.

3.4 DATA COLLECTION:

Subjects were interviewed individually at a hospital premises in Wollongong. The data collection protocol was a pooling of resources to collect data for several areas of investigation as well as a PhD study. Only those parts of the data collection relevant to this project are outlined here. The total procedure (to collect information for all areas of research) took approximately 1 1/2 hours per subject.

3.4.1. Demographic Data and Practical Aspects of IDDM Questionnaire:

Subjects were asked to provide demographic, socioeconomic, diabetic history and dietary adherence information (Appendices 4 and 5).

3.4.2. Quality of Life Measurement:

The Medical Outcomes Health Survey Short Form (Ware et al 1992) and the DCCT quality of life measure (DCCT Research Group 1988) were used to determine the subjects' current quality of life (Appendices 6 and 7).

3.4.3. Biochemical Assay:

Venous blood was taken from non fasting subjects and glycosylated haemoglobin (HbA1c) was determined utilising an in house method of high performance liquid chromatography (Biochemistry Department, Illawarra Regional Hospital, Wollongong Campus). Normal, non diabetic ranges were 4.2%–5.9%.

3.5 DATA ANALYSIS:

The data collected was coded and analysed using Version 3 JMP statistical software package (SAS Institute Inc 1994).

3.5.1. Dietary adherence data:

Subjects were classified based on their response to question three of the practical aspects of IDDM questionnaire (Appendix 5):

Subject response	Group
very difficult or moderately difficult	A
neither difficult nor easy	B
moderately easy or very easy	C

3.5.2. Quality of life data:

This analysis required three stages; item recoding, computation of raw scores and transformation of raw scores.

The SF–36 questionnaire required recoding of ten items and this method is outlined by Ware et al (1993). The DQOL required all items to be recoded (Jacobson et al 1994). This process ensures that the highest score represents the best quality of life.

The final codes were computed by summing scores for each domain in the case of the SF–36 and in total for the DQOL to produce raw scores.

The DQOL scores were analysed in their raw form; whilst the raw scores of the SF–36 were arithmetically transformed to a 100 point scale, this method has been outlined by Ware et al (1993). In both situations a high score represented a better quality of life than a low score.

3.5.3. Statistical analysis:

Due to the small sample size and only two people finding the diet difficult to adhere to, many of the basic assumptions that provide power to statistical tests were unable to be met. In addition the small sample size directly affects the amount of confidence to be had in any assumptions made (Oyster et al 1987). The following analysis was made in light of this information.

Descriptive statistics (mean±standard deviation) were calculated for group C, whilst individual scores for each of the two subjects in group A were presented for the following variables; HbA1c, total DQOL score, and each of the eight SF-36 domains as well as age, duration of IDDM and occurrence of diabetes complications. Raw data on sex, marital status and level of education was presented in table form.

Separate results were shown for each subject in group A because the mean was distorted when N=2 especially in situations when variability was great (Munro et al 1986).

CHAPTER 4: RESULTS.

Of the seventy one people contacted twenty one individuals volunteered to participate in the study. Of the remaining fifty people, thirteen were not eligible to participate; three did not have IDDM, and ten people had moved away from the area. A further seventeen people declined to participate due to personal reasons, and an additional fourteen could not be contacted, finally six people could not be seen in the time available for data collection. In total twenty one subjects with IDDM completed the questionnaires.

After data collection a further two subjects were found to be ineligible as a parent and not themselves completed the questionnaire. Questions asking for the degree of satisfaction with various aspects of diabetes treatment, care and long term outcomes were unable to be answered by the parent and are thus absent from the raw data. The final sample included nineteen subjects with IDDM. Appendix 8 contains a summary of the raw data collected for this study.

4.1. DISTRIBUTION OF SUBJECTS:

Table 4.1 Distribution of subjects according to self perceived difficulty or ease with adherence to their diet.

VARIABLE	GROUP A*	GROUP B**	GROUP C***	TOTAL
N	2	7	10	19

*difficulty adhering to diet
** neither difficult or easy adhering to the diet
*** ease adhering to diet

Table 4.1 illustrates that this sample contained two people who perceived any difficulty with adherence to their diet, seven people who found neither difficulty or ease with the diet and ten people who perceived the diet easy to adhere to.

4.2. DESCRIPTION OF STUDY GROUPS:

Table 4.2a Characteristics of the study groups; sex, marital status and education level.

VARIABLE	GROUP A*	GROUP C**
SEX (N)		
MALE	1	7
FEMALE	1	3
MARITAL STATUS (N)		
SINGLE	2	6
MARRIED	0	4
SEPARATED/DIVORCED	0	0
WIDOWED	0	0
EDUCATION (N)		
COMMENCED PRIMARY	0	0
FINISHED PRIMARY	0	0
COMMENCED SECONDARY	0	1
FINISHED SECONDARY	1	1
COMMENCED TERTIARY	1	2
FINISHED TERTIARY	0	6

* difficulty adhering to diet
** ease adhering to diet

Table 4.2a provides information on groups A and C for sex, marital status and education level. Both males and females were represented in each of groups A and C. No subjects were separated/divorced or widowed, the population was predominantly single, whilst all married subjects reported the diet to be easy to adhere to. The education level of subjects conveys that more people in group C have finished tertiary level education. The whole sample has commenced at least a secondary education. Group C represents the most highly educated subjects, but also the least educated subject.

Table 4.2b Characteristics of the study groups; age, duration of IDDM and complications.

VARIABLE	GROUP A*		GROUP C**
	SUBJECT 16 (RAW SCORE)	SUBJECT 4 (RAW SCORE)	(MEAN±SD)
AGE	24	22	24.7±3.2
DURATION IDDM (MONTHS)	45	37	115±20.1
COMPLICATIONS	0	0	0

* difficulty adhering to diet
** ease adhering to diet

Table 4.2b provides details of the mean age, duration of IDDM and level of complications for groups A and C. The age of the two groups is similar, whilst the duration that each has had IDDM reveals that those subjects that perceive adherence difficult have had IDDM for a shorter period of time. Neither group A or C reported the presence of any of the following diabetic complications; eye, kidney, heart, blood vessel or circulation problems.

4.3 Quality of life and glycaemic control

Table 4.3 Summary of glycaemic control and quality of life values for groups A and C.

VARIABLE	GROUP A*		GROUP C*
	SUBJECT 16 (RAW SCORE)	SUBJECT 4 (RAW SCORE)	(MEAN±S.D)
HbA1c	11.2	8.3	9.5±1.3
DQOL** (TOTAL)	189	170	181.5±15
SF-36 PHYSICAL FUNCTIONING	100	100	95.5±6.4
ROLE-PHYSICAL	100	100	100.0±0
BODILY PAIN	100	74	88.2±14.8
GENERAL HEALTH	32	87	74.8±15.9
VITALITY	100	35	67.0±13.3
SOCIAL FUNCTIONING	100	87.5	76.3±30.8
ROLE-EMOTIONS	100	33.3	86.7±32.2
MENTAL HEALTH	84	68	78.0±11.5

* difficulty adhering to diet
** ease adhering to diet
*** diabetes quality of life measure.

Table 4.3 illustrates the glycaemic control and quality of life variables for the two individuals in group A who perceived their diet difficult to adhere to and the mean value of group C (N=10) who perceive the diet easy to adhere to.

One subject in group A had a higher HbA1c than the mean of group B whilst the other had a lower HbA1c value. All HbA1c values were higher than the normal non diabetic range of 4.2–5.9%.

The DQOL values appear similar, with subject 16 displaying a slightly higher score, and thus a higher quality of life and subject 4 displaying a slightly lower score, and thus a lower quality of life, than group C.

The SF–36 domains exhibit the following characteristics as shown in table 4.3;

* physical functioning – reveals the two subjects from group A have obtained the highest score possible, whilst group C has a slightly lower score.

* The role–physical domain reveals that all subjects have attained the highest score possible.

* Bodily pain, vitality, role–emotional and mental health domains– subject 16 from group A received a higher score and subject 4 a lower score than the mean of group C.

* The general health domain shows that subject 4 has a higher score than the mean of group C whilst subject 16 has a lower score.

* For the social functioning domain both subjects from group A received higher scores than the mean of group C.

The large standard deviations of the group C values indicates that within this group there is a large amount of variation in scores, especially for the social functioning and role–emotional domains.

Figure 4.1 The SF–36 profile of scores.

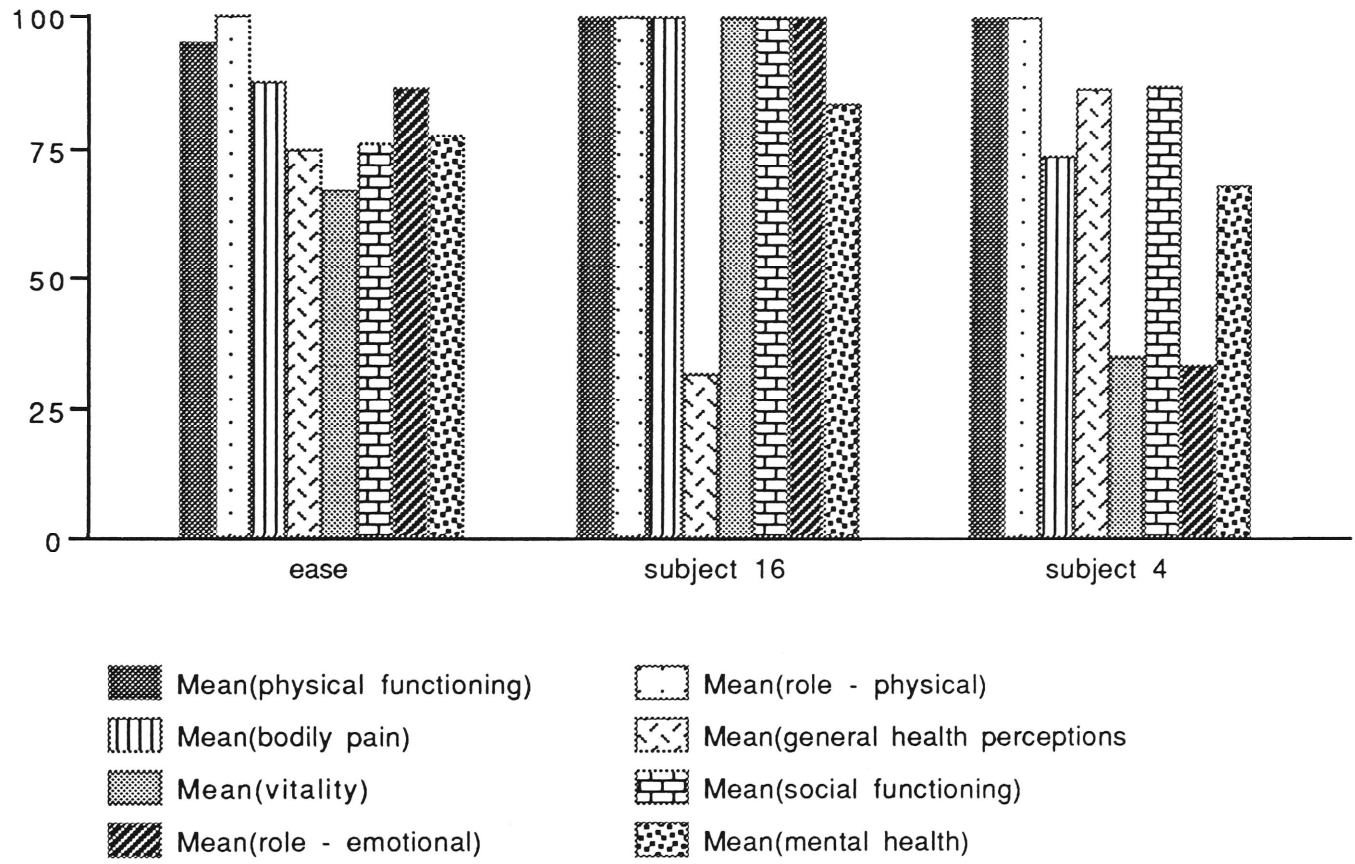

Figure 4.1 graphically presents the SF–36 profile of scores for those subjects that perceive ease adhering to their diet and the two subjects that perceive difficulty adhering to their diet (subjects 16 and 4). Examination of the results for the group that perceives ease with the diet shows the left side of the profile, representing the physical aspects of quality of life, are ranked highly whilst the mental aspects represented by the right side of the profile

are lower. Subjects 16 and 4 showing dissimilar profiles, display that although both perceived difficulty with adherence to their diet, the factors that contribute to their quality of life vary.

CHAPTER 5: DISCUSSION.

5.1 DISTRIBUTION OF SUBJECTS:

Individuals eligible for this study were unevenly distributed between the three groups available. The majority of subjects were classified into group C (N=10), representing the group that found least difficulty with adhering to the diet. Whilst group B (N=7), represented those people who perceive neither difficulty or ease with adherence. Group A (N=2) contained those people who perceived the most difficulty with adherence to the diet.

No previous research has estimated the number of people with IDDM who *perceive* adherence to the diet difficult. Although diet is recognised as being difficult and specific factors which contribute to such difficulty have been identified (Coulston 1994, Schulndt et al 1994, ADA 1994, Nuttal 1993 and Rosenstock 1985), it would appear that a large proportion of the individuals in this study did not perceive great difficulties.

Possible explanations for this are;

(1) time limitations prevented a larger representation of the Illawarra IDDM population being included in the study. Twenty nine per cent of the individuals eligible to participate declined to be involved, these people cited

personal reasons for their decision, one individual who declined said he did not wish to be involved because he had poor glycaemic control. In addition an unknown number of people with IDDM in the Illawarra are not registered with the DEIC and therefore were not contacted. These groups of people may represent individuals who have a different perception of difficulty with adherence to their diet than the sample that were included in this study. By attaining a population based sample a different distribution amongst the groups may have been evident.

(2) Alternatively, studies that have investigated the issue of difficulty with diet have surveyed populations with age ranges broader than this population, who had a mean age of 24±3 years (Schulndt et al 1994, Ary et al 1986). The research into dietary difficulties faced by people with diabetes is often limited to identifying the types of difficulties faced (Rosenstock 1985; Schulndt et al 1994). It could be possible that this populations' perception of difficulty differs from that of the broader age ranged population, not in the *type* of difficulties faced but the *degree* of each difficulties' impact upon the individual with IDDM, this area has yet to be investigated.

(3) Finally, all subjects were selected from the records of the DEIC. The dietary support and assistance available from the centre may be very

effective, thus reducing the difficulties perceived by the individuals who participated.

5.2 DESCRIPTION OF STUDY GROUPS:

An examination of Tables 4.2a and 4.2b provides information on the characteristics of the study groups. The comparison of the characteristics of these groups was designed to highlight any variables that may confound the quality of life results. A comparison of data between groups A and C is restricted by the existence of only two individuals in group A, and any statistical tests of significant difference would lack adequate power.

The mean ages of the two groups is similar. This is to be expected as the total age range was 18–30 years. Both male and female subjects are represented in both groups, but no trend can be distinguished due to the small sample size.

The influence of marital status on quality of life is unlikely to be a confounding variable in this study. Neither separated nor divorced subjects, the two marital statuses that have been reported to influence quality of life, are represented in either group A or C (Jacobson et al 1994).

Trends are unable to be established from the education level of the subjects due to the small sample size of group A. The education level has been recognised to not influence the quality of life of the subjects (Hanestad 1993; Jacobson et al 1994).

The existence of diabetic complications has been associated with a decreased quality of life (Rodin 1990; Lloyd et al 1992; Jacobson et al 1994). All subjects in this study group reported an absence of complications, this is expected considering the age and the duration of IDDM for the subjects (Brownlee and Cerami 1981; Hartog 1987). In this study, the issue of diabetic complications would not confound the quality of life results.

The length of time that each group had IDDM varied considerably, 41 months for group A and 115 months for group C. Although reported to have no affect on the quality of life score (Hanestad 1993; Jacobson et al 1994), the duration of IDDM may have influenced why each subject perceived a certain level of difficulty with adhering to the diet. A consideration is that those people who have had IDDM for a longer period of time (group C), may have overcome some of the difficulty associated with the diet. Through experience, contact with health professionals and acceptance of the diagnosis, all of which come with time, they may perceive less difficulty. This type of issue has not been addressed in the literature to date.

Of the characteristics of the subjects none of the above factors are likely to confound this study. Although the duration of IDDM for each subject may have influenced the level of difficulty perceived by each subject.

5.3 PERCEIVED DIFFICULTIES WITH ADHERENCE TO THE DIET AND GLYCAEMIC CONTROL.

The issue of perceived difficulties with the diet and glycaemic control has not been directly examined in the past. The results of this pilot study suggest that subjects who perceive the diet difficult to follow present with two extremes of glycaemic control; whilst those that perceive adherence easy have a level of glycaemic control in between this. Interpreting this data in light of the research into dietary adherence (Rosenstock 1985; Ary et al 1986; DCCT Research Group 1993b; Schulndt et al 1994; Delahanty and Halford 1993; DCCT Research Group 1993a), reveals that individuals who perceive difficulty could be expected to have a lower level of adherence to their diet and therefore possibly a poorer level of glycaemic control than those who perceive no difficulty; the results of this research differ from this interpretation.

Caution should be exercised when adopting these results as;

(1) the small number of subjects representing group A may not be truly representative of those people who perceive difficulty with adherence.

(2) All mean values of glycaemic control were above the ideal level of 8%, but below 12%, the level classified as being poor (Dietitians' Pocket Book 1992).

(3) The dietary adherence of an individual is not the only thing that can impact on the level of glycaemic control. As Bantle (1992) and McCaul et al (1987) have pointed out, the balancing of diet, exercise and insulin treatment contribute to the treatment for IDDM, which aims to attain normoglycaemia. Furthermore Glasgow et al (1987) advises that stress, individual metabolic factors and appropriateness of regimen prescriptions should be considered as part of the variety of factors which contribute to a level of glycaemic control.

5.4 PERCEIVED DIFFICULTIES WITH ADHERENCE TO THE DIET AND QUALITY OF LIFE.

The literature examining quality of life and diabetes has dealt with the diabetic population as a whole and how it compares with the non diabetic population (Stewart et al 1989). In addition some researchers, Mazze et al (1984) and Hanestad et al (1991b), have examined links between glycaemic control and quality of life. No research to date has examined the quality of life of those people with IDDM who have difficulties with the dietary aspect

of their regimen, although Hanestad and Albrektsen (1991a) have looked at quality of life and difficulties with total regimen adherence, not solely diet.

The DQOL scores presented in table 4.3 reveal that the scores of subjects 16 and 4 lie either side of the mean for group C. This infers that those individuals who perceive the diet difficult to adhere to display either a relatively high or low quality of life. Whilst those who perceive little difficulty have a quality of life in between subjects 16 and 4. These results differ from Hanestad and Albrektsens' (1991a), which have shown that a greater perceived ease of adherence to the (total) regimen was associated with a higher quality of life.

As is the case with the glycaemic control results presented earlier, these results must be used with caution.

The profiles evident in figure 4.1 reveal that group C reports higher physical rather than mental aspects of quality of life. Subjects 16 and 4 have dissimilar profiles, both between themselves and in comparison to group C. Although visually recognised as dissimilar, without a greater sample size for what was group A, caution must be exercised when interpreting this difference.

Due to the dissimilarity of the profiles for subjects 16 and 4, a collective summation regarding the quality of life for people who perceive difficulty adhering to their diet would be inappropriate. Whilst the quality of life data is limited by the small sample size, the SF-36 results reveal the areas in which quality of life could be enhanced for each subject. An examination of the raw data (appendix 8), emphasises this fact.

Fitzpatrick et al (1992) identifies that quality of life assessment may be useful in monitoring individual patients. Although a particular quality of life tool may be considered accurate and useful in individual subjects, the extrapolation of that one (or in this case two) subject's response to represent a specific portion of the population would be inappropriate.

Considering the SF-36 questionnaire has been shown to be reliable and accurate for the following applications; (1) monitoring the general populations' quality of life, (2) estimating burden of differing conditions, (3) the effects of different treatments for similar conditions and (4) monitoring outcomes in individual patients over time (Ware et al 1993). The data collected can be deemed an accurate representation of each individual's quality of life.

5.5 RECOMMENDATIONS

Firstly, the attainment of an adequate sample size is essential for any statistical analysis, this study did not achieve this. Reasons contributing to this are the use of only one method of contacting the potential subjects, (DEIC registration lists), and the short time frame available for completion of the study. It is recommended to continue the study utilising a variety of methods to obtain an adequate sample. These methods should include:

* DEIC registration lists,
* contact with local general practitioners and endocrinologists,
* contact with dietitians in private practice,
* use of advertisements in local press and Diabetes Australia newsletters,
* notices/posters in local pharmacies,
* flyers to be sent with Diabetes Australia mail outs.

Secondly, with regard to the study design, the questionnaire subjects were asked to complete was a lengthy one, due to the inclusion of other researchers questions, subjects may have become tired and haphazard with responses toward the end of the questionnaire. In addition the issue of adherence to a recommended diet is a multifactorial one. By asking only one question to ascertain difficulty or ease with adherence, a broad brushed approach was taken. By asking a compilation of questions on all aspects of

adherence a more accurate picture may have been obtained. In light of the above issues the study design could be strengthened by ensuring the questionnaire contained only the essential information without compromising accuracy of responses.

Finally, the SF–36 and DQOL questionnaires are simple to administer and computation of scores is uncomplicated. The information obtained from questionnaires such as the DQOL or SF–36 should be collected in routine assessments of patient care. The information can be used on an individual basis to benefit the patient directly, whilst collectively being used to provide a picture of quality of life of people with diabetes in the Illawarra.

CHAPTER 6: CONCLUSIONS.

The conclusions of this study are as follows:

(1) Three groups A, B and C were able to be developed from a central pool of volunteers. However, the number of subjects in group A was so disproportionate that it suggested questioning the adequacy of the selection process.

(2) The level of glycaemic control was determined for each subject. Nevertheless any comparisons of glycaemic control between groups A and C was rendered powerless by the small size of group A.

(3) The quality of life was determined for each subject using the SF–36 and the DQOL questionnaires. Regardless, any comparisons of quality of life between groups A and C was rendered powerless by the small size of group A.

CHAPTER 7: LIMITATIONS OF THE STUDY.

(1) The selection of subjects relied on records which were up to ten years old. Some information on these records proved to be out of date, which resulted in;

i) a number of individuals on the list being ineligible to participate, eg not living in the Illawarra or not having IDDM 13/71 (18%) and,

ii) a proportion of the population not being able to be contacted 14/57 (25%).

(2) A large proportion of the subjects eligible to volunteer, declined to participate 17/57 (29%), these individuals may have represented a group with different characteristics to those who participated in the study.

(3) The sample size used in the study was small, nineteen individuals, 19/57 (33%). A larger sample size may have given more statistical power to the recommendations and conclusions made.

(4) The records from which the sample was chosen only included those people with IDDM who have attended the DEIC. Any people in the Illawarra who have IDDM and have not attended the DEIC (an unknown number of people) were not included in the sample. Time constraints

prevented these people from being contacted. The individuals who have attended the DEIC may represent a group of people who have had a different level of support and assistance in managing their IDDM.

(5) Response bias, the people that volunteered to participate may have differed from the general IDDM population. The lengthy process of the study may have prevented all but those people who were very motivated to volunteer.

CHAPTER 8: AREAS FOR FURTHER RESEARCH.

(1) To continue this study and expand it to a larger proportion of the 18–30 year old Illawarra IDDM population by using avenues other than DEIC records to contact subjects.

(2) The level of perceived difficulties with adhering to a diet for diabetes may vary for other diabetes populations. To examine the relationship between any difficulty and glycaemic control and quality of life in the older, younger or NIDDM population may provide valuable information for these populations.

(3) This study did not look at the actual diet of each individual. To examine the perception of difficulty or ease and the actual diet, may provide insight into whether those that perceive difficulty or those that perceive ease actually achieve a recommended diet.

(4) The measurement and comparison of the quality of life of different diabetic population groups such as age and sex, using standardised quality of life tools, would improve the calibre of the information on diabetes and quality of life that is available.

(5) The area of patient perception of adherence to therapeutic diets and quality of life is fascinating. The investigation of patient perception of the difficulty with a dietary recommendation and their quality of life over other dietetic fields could be explored.

(6) Since the exact prevalence of IDDM in the Illawarra is not known, research to determine the prevalence of this and other diabetic populations would provide a standard against which to measure adequacy of sample size for local diabetes research.

(7) To examine the degree of difficulties faced by various diabetes populations, and to determine if the same difficulties are faced by the same sub populations. For example do older or younger people have the most difficulty with eating out, feeling deprived or family support. The coping information held by one group may benefit the other.

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APPENDIX 1: Interpretation of SF-36 domains

CONTENT BASED DESCRIPTION OF SF-36 DOMAINS

	Meaning of scores	
Concept	**Lowest score**	**Highest score**
Physical Functioning	Limited a lot in performing all physical activities including bathing or dressing due to health	Performs all types of physical activities including the most vigorous without limitations due to health
Role- Physical	Problems with work or other daily activities as a result of physical health	No problems with work or other daily activities as a result of physical health
Bodily Pain	Very severe & extremely limiting pain	No pain or limitations due to pain
General Health	Evaluates personal health as poor & believes it is likely to get worse	Evaluates personal health as excellent
Vitality	Feels tired & worn out all the time	Feels full of pep & energy all the time

Table continued over page

Table continued.

	Meaning of scores	
Concept	**Lowest score**	**Highest score**
Social Functioning	Extreme & frequent interference with normal social activities due to physical or emotional problems	Performs normal social activities without interference due to physical or emotional problems
Role–Emotional	No problems with work or other daily activities as a result of emotional problems	Problems with work or other daily activities as a result of emotional problems
Mental Health	Feelings of nervousness & depression all of the time	Feels peaceful happy & calm all of the time

(Ware et al 1993. p9.2)

APPENDIX 2: Information Form and Consent Form

UNIVERSITY OF WOLLONGONG

ILLAWARRA AREA HEALTH SERVICE

INFORMATION SHEET

ASSESSMENT OF INSULIN-DEPENDENT DIABETES MANAGEMENT

We plan to carry out an evaluation of the way in which people with insulin-dependent diabetes mellitus manage the diabetes. We hope as a result of this evaluation to be able to recommend ways in which management guidelines or services may be improved to provide the best possible outcomes for people with diabetes.

We have explained to you how we obtained your name, and we have reassured you that this information, and indeed any information we discover about you, is confidential and will not be released to anybody, unless you give us specific consent to pass information to your doctor. Any other information about this study that is published or passed to other bodies (for instance, the NSW Health Department) will be in such a form that no individuals can be identified. We shall, of course, send you a copy of your results, and (if you wish) the group results when they are available.

We will ask if we can interview you. Interviews will be conducted by Ms Farideh Tahbaz, who is a nutritionist with a Masters degree in nutrition or a graduate in nutrition who is studying for a Masters Degree. Ms Tahbaz, or a colleague will give you a standard questionnaire to fill out, which contains information on your own circumstances, on the way you manage your diabetes, on the way in which insulin is prescribed, and on the way you feel you manage your diabetes and your reactions to diabetes.

You will be asked if you can give a blood and urine specimen, to check the degree to which your diabetes is controlled, and have your height and weight and degree of fatness estimated. Blood would normally be taken from a vein in the arm. You will be asked for further information on the details of your usual diet.

It should be clear that there are no right or wrong answers on diet or diabetes management; we wish to obtain an accurate picture of current management, in its diversity, in the Illawarra.

Please feel free to ask Ms Tahbaz any questions that occur to you. We will ask you if we can write to your doctor and let him/her know the results of your blood test and if you wish, the dietary analysis.

If there are any outstanding questions, please ring Professor Dennis Calvert, phone (042) 266 594. If you have any queries regarding the conduct of the research, please contact the Secretary of the Human Research Ethics Committee on (042) 214 457.

UNIVERSITY OF WOLLONGONG

ILLAWARRA AREA HEALTH SERVICE

CONSENT FORM

FOR PARTICIPANTS WITH DIABETES

ASSESSMENT OF INSULIN-DEPENDENT DIABETES MANAGEMENT

This research on the current management of diabetes in the Illawarra is being conducted by a group of clinicians and scientists supported by a steering committee with representatives from the Illawarra Area Health Service, the NSW Health Department, and the medical profession. Professor Dennis Calvert in the Medical Research Unit (Illawarra Area Health Service/University of Wollongong) heads the group, and Ms Farideh Tahbaz is coordinating

Information relating to this study is detailed in the attached information sheet.

You are free to withdraw from all or part of this research program at any time without penalty, and without compromising in any way your treatment or access to services.

The ethical aspects of this study have been approved by the University of Wollongong Human Research Ethics Committee, which is responsible for the ethical aspects of research involving people in the Illawarra. If you have any enquiries regarding the conduct of the research please contact the Secretary of the University of Wollongong Human Research Ethics Committee on (042) 21 3079.

****

I understand that the information collected in this research will be used for the assessment of insulin-dependent diabetes management and I consent for the data to be used in that manner.

If you wish to take part in this research please sign below

.....	.....	...../...../.....
Name	*Signature*	*Date*

APPENDIX 3: Contact Letter

GDC:EK

«name»
«address1»
«address2»

Dear «name2»

As part of the effort to improve the management of diabetes mellitus, we are about to conduct a study on the way people with insulin-dependent diabetes in the Illawarra manage their diabetes. We hope to contact all younger adults (aged 18-30 initially) with this type of diabetes in the Illawarra. I obtained your name from the Diabetes Education Centre, to which you were referred. This letter is written to ask if you would take part in this study, which will be important in helping us plan diabetes care services and which will give you information on your diabetes management.

The study involves an interview, in which one of our interviewers asks questions about diabetes, a questionnaire to be filled in (at home, if you wish) and, if you agree, a blood test. We want to find out about diet (what does the person with diabetes normally eat?), insulin, the degree to which diabetes is controlled (for which a blood test is needed) and factors influencing "quality of life". All this is confidential information, and no identifying information will be given to anyone without your specific consent. (We shall ask whether you would like us to send your results to a GP or medical specialist.) Neither you nor your doctor will be identified in any report arising from this study. The study is not primarily aimed at being an assessment of your diabetic control. Rather, we will use the group results to assess current management strategies throughout the Illawarra area. Your results will of course be passed on to you, as will the group results if you wish.

We are working in collaboration with a steering committee with representatives from the Illawarra Area Health Service, the IAHS Diabetes Education Centre, the NSW Health Department, the Illawarra Division of General Practice, and a local endocrinologist.

If you do not want to be part of this study I would be very pleased if you could let us know as early as possible. Please write to, or phone, my secretary, Mrs Elaine Knight, at the above address (phone 266 594). If you are happy to continue, you will be contacted by a nutritionist, Ms Farideh Tahbaz, or by an assistant, Ms Cate Kelly, and they will forward further information and/or make an appointment to have these aspects of your diabetes management checked by one of our team. In order to have a good picture of current diabetic management, it is important to have input from as many people as possible, whether or not they have good diabetes control.

I believe that this is an important step in working to improve diabetes management in Australia. I hope you will be able to help.

Yours sincerely

Dennis Calvert
Professor of Medicine and Public Health

Farideh Tahbaz
PhD Student

APPENDIX 4: Practical Aspects Of IDDM

Questionnaire

Practical Aspects of IDDM - Questionnaire

For the following questions please tick the response that best applies to yourself

DIETARY ADHERENCE

In Questions 1 - 3, we want to find out about your adherence to a diabetic diet, and the difficulties that you may experience keeping to a diabetic diet.

Office use only

1. In general, how often do you routinely follow a carbohydrate portion plan on a typical day ? For example do you have a pattern of carbohydrate "portions" you follow over the day, such as 3 portions for breakfast, 2 portions for morning tea, 4 for lunch, etc.

287 ☐

I follow my carbohydrate portion plan:

Always	(7 days a week)	☐
Usually	(5-6 days a week)	☐
Sometimes	(3-4 days a week)	☐
Not very often	(1-2 days a week)	☐
No	(0 days a week)	☐
Don't Know		☐

2. We would like to know what specific factors prevent you from routinely following a carbohydrate "portion" meal plan or from following it as often as you might otherwise. You may tick more than one response or write your own down on the space provided.

If don't follow a set carbohydrate controlled meal plan it is because

288 ☐

It didn't give me good blood sugar control when I tried it before	☐
I am tired of following a set plan	☐
My work is too hectic	☐
My family life makes it difficult	☐
Family/friends are not supportive enough	☐
I crave food I shouldn't eat	☐
Other. Please Specify:	☐

_____

_____

3. I generally find it....

289 ☐

Very difficult	☐
Moderately difficult	☐
Neither difficult or easy	☐
Moderately easy	☐
Very easy	☐

to adhere to my diabetic diet

WEIGHT CONTROL

In Questions 4 - 7 we want to find out about your weight maintenance

Office use only

4. Are you currently trying to reduce your weight (please indicate)
   No ☐
   Yes ☐

   If yes what measures are you taking?

   _____

   _____

290 ☐

5. Are you trying to maintain your current weight? (please indicate)
   No ☐
   Yes ☐

   If yes what measures are you taking?

   _____

   _____

291 ☐

6. Are you currently trying to increase your weight? (please indicate)
   No ☐
   Yes ☐

   If yes what measures are you taking?

   _____

   _____

292 ☐

7. Please indicate what you think is your ideal goal weight: _____kg

293 ☐

ALCOHOL INTAKE

In Questions 8-9 we want to find out about the amount of alcohol you drink

Office use only

8. How often do you usually drink alcohol?

294 ☐

- I don't drink alcohol ☐
- Less than once a week ☐
- On 1 or 2 days a week ☐
- On 3 or 4 days a week ☐
- On 5 or 6 days a week ☐
- Every day ☐

9. On a day when you drink alcohol, how many drinks do you usually have?

295 ☐

- 1 or 2 drinks ☐
- 3 or 4 drinks ☐
- 5 to 8 drinks ☐
- 9 to 12 drinks ☐
- 13 to 20 drinks ☐
- more than 20 drinks ☐

EXERCISE

In questions 9-12, we want to find out about the exercise you had during the PAST 2 WEEKS
* For recreation, sport or health-fitness purposes
* As part of your tasks at work and around the house

Please distinguish between vigorous and exercise which made you breathe harder or puff and pant, and less vigorous exercise

Office use only

_____

RECREATION, SPORT OR HEALTH-FITNESS

9. In the PAST 2 WEEKS, did you engage in vigorous exercise - exercise which makes you breathe harder or puff or pant? (eg vigorous sports such as football, netball, tennis, squash, athletics: jogging or running: keep fit exercises: vigorous swimming: etc.) 296 ☐

No ☐ 297 ☐
Yes ☐ 298 ☐

If yes, how many sessions of vigorous exercise did you have over the 2 week period? _____

Please estimate the TOTAL TIME spent exercising vigorously during the PAST 2 WEEKS. 299 ☐

_____ hours _____minutes

10. In the PAST 2 WEEKS, did you engage in less vigorous exercise for recreation, sport or health-fitness purposes which did not make you breathe harder or puff and pant? 300 ☐

No ☐ 301 ☐
Yes ☐

If yes, how many sessions of less vigorous exercise did you have over the 2 week period? _____

Please estimate the TOTAL TIME spent exercising less vigorously each week. 302 ☐

_____ hours _____minutes 303 ☐

11. In the PAST 2 WEEKS, did you walk for recreation or exercise for periods of 20 minutes or longer?

No ☐
Yes ☐

If yes, how many times?_____

VIGOROUS TASKS AT WORK AND AROUND THE HOUSE (paid or unpaid work)

Office use only

12. In the PAST 2 WEEKS, did you engage in vigorous activity, apart from exercise, which makes you breathe harder or puff and pant? (eg carrying loads, heavy gardening, chopping wood, labouring - at home, during employment or anywhere else).

No	☐	304 ☐
Yes	☐	305 ☐

If yes, how many sessions of these types of vigorous activity did you have over the 2 week period?_____ 306 ☐

Please estimate the TOTAL TIME spent in these types of vigorous activity during the past 2 weeks: _____ hours_____minutes

Thank you for taking time to complete these questions ☺

APPENDIX 5: Subject Characteristic Questionnaire

UNIVERSITY OF WOLLONGONG

MEDICAL RESEARCH UNIT

INSULIN DEPENDENT DIABETES STUDY

Date:

Please indicate your answer by ticking the appropriate box ❑ or by writing your answer in the space provided. If you are uncertain about the answer to any of the questions leave them blank and ask the receptionist to help you.

Office use only

Characteristics of the subject:

1. Sex: Female ❑ — ❑ 1
   Male ❑

2. Marital Status:

   Single ❑ — ❑ 2
   Married ❑
   Separated/Divorced ❑
   Widowed ❑

3. Date of Birth: Day: ❑❑ Month: ❑❑ Year: 19❑❑ — ❑ 3

4. Country of Birth: Australia ❑ — ❑ 4
   Not Australia ❑

   If not Australia, what is your country of birth? ----------

5. How long have you been resident in Australia? Months ❑ Years ❑ — ❑ 5

6. Where were members of your family born?

   - Your father ---------- ❑ 6
   - Your father's father (paternal grandfather) ---------- ❑ 7
   - Your father's mother (paternal grandmother) ---------- ❑ 8
   - Your mother ---------- ❑ 9
   - Your mother's father (maternal grandfather) ❑ 10
   - Your mother's mother (maternal grandmother) ❑ 11

7. Are you of Aboriginal or Torres Strait Islander origin?
   (If of mixed origin indicate the one to which you belong)

   No ❑ — ❑ 12
   Yes, Aboriginal ❑
   Yes, Torres Strait Islander ❑

DIABETES HISTORY:

Office use only

1.What date was diabetes diagnosed? Mo❑/Yr❑❑ ❑ 13

2. What is the name and address of your doctor who normally treats your diabetes? ❑ 14

---

3. Do you want us to send any results to your doctor (eg. diet and blood test results)?

No ❑
Yes ❑ ❑ 15

4. Have you ever taken oral drugs (tablets) for diabetes?

No ❑
Yes ❑ ❑ 16

a. If yes, are you currently taking oral drugs (tablets)?

No ❑
Yes ❑ ❑ 17

b. If no, how long ago did you stop taking oral drugs (tablets)?

Mo ❑ Yr ❑❑ ❑ 18
Unknown ❑

5. Are you currently taking insulin?

No ❑
Yes ❑ ❑ 19

6. When did you begin permanent use of insulin?

Mo ❑ Yr ❑❑ ❑ 20
Unknown ❑

7. What is your current total daily dose of insulin: ----- ------ units ❑ 21

8. Are you currently taking oral drugs and insulin?

No ❑
Yes ❑ ❑ 22

If yes to #5 or #8, what is your current insulin regimen? (answer one)

one injection daily ❑ pump ❑ ❑ 23
two injections daily ❑ other ❑
three or more injections daily ❑ Specify:----------

Office use only

9. Have you ever been hospitalized for diabetes ketoacidosis?

No ☐
Yes ☐
Unknown ☐

☐ 24

MEDICAL HISTORY:

A. Eye problems:

Have you ever been told by a health care professional that you have or had:

1. Any diabetes related eye problems?

No ☐
Yes ☐
Unknown ☐

☐ 25

If yes please specify: ----------

2. Laser treatment?

No ☐
Yes ☐
unknown ☐

☐ 26

3. Impairment of vision?

No ☐
Yes ☐
Unknown ☐

☐ 27

4. Cataracts?

No ☐
Yes ☐
Unknown ☐

☐ 28

5. Detached retina?

No ☐
Yes ☐
Unknown ☐

☐ 29

B. Kidney problems:

Have you ever been told by a health care professional that you have or had:

1. Diabetic kidney problem?

No ☐
Yes ☐
Unknown ☐

☐ 30

2. Protein or albumin in the urine?

No ☐
Yes ☐
Unknown ☐

☐ 31

Office use only

Have you ever had:

3. Kidney transplant?

No ☐
Yes ☐
Unknown ☐

☐ 32

4. Kidney dialysis?

No ☐
Yes ☐
Unknown ☐

☐ 33

C. Cardiovascular (heart or circulation) problems:

Have you ever been told by a health care professional that you have or had:

1. Any problems with heart or blood vessels?

No ☐
Yes ☐
Unknown ☐

☐ 34

If yes, please specify: ----------

2. Abnormal Electrocardiogram?

No ☐
Yes ☐
Unknown ☐

☐ 35

Have you ever had:

3. Heart pains or angina?

No ☐
Yes ☐
Unknown ☐

☐ 36

4. Heart attack?

No ☐
Yes ☐
Unknown ☐

☐ 37

5. Coronary bypass surgery?

No ☐
Yes ☐
Unknown ☐

☐ 38

Office use only

6. Stroke?

No ☐
Yes ☐
Unknown ☐

☐ 39

7. High blood pressure?

No ☐
Yes ☐
Unknown ☐

☐ 40

8. Drug treatment for high blood pressure?

No ☐
Yes ☐
Unknown ☐

☐ 41

If yes, are you currently receiving drug treatment?

No ☐
Yes ☐
Unknown ☐

☐ 42

D. Peripheral vascular complications:

Have you ever been told by a health care professional that you have or had:

1. Any trouble with circulation in legs?

No ☐
Yes ☐
Unknown ☐

☐ 43

2. Foot ulcers?

No ☐
Yes ☐
Unknown ☐

☐ 44

3.Gangrene?

No ☐
Yes ☐
Unknown ☐

☐ 45

Have you ever had:

4. Non-traumatic amputation?

No ☐
Yes ☐
Unknown ☐

☐ 46

Office use only

E. Other major medical disease?

1. Do you have any serious medical problems not mentioned yet?

No ☐
Yes ☐
Unknown ☐

☐
47

Specify: ----------

F. Are there any people with diabetes in your family?

☐
48

No ☐
Yes ☐

If yes what is his/her relation with you? ----------

Information on your background:

Office use only

1. Education

What is the highest level of your education?
(Please tick and complete level if appropriate)

commenced primary school	❑	☐
finished primary school	❑	49
commenced high school	❑	
finished high school	❑ level ----	
university or other tertiary schooling (eg. TAFE) started	❑	
university or other tertiary schooling (eg. TAFE) finished	❑ level ----	

2. Economic data:

2.1 What is the total estimated family income before taxes?

less than $12000	❑	☐
$12000 -$15000	❑	50
$15001 -$18000	❑	
$18001 -$22000	❑	
$22001 -$26000	❑	
$26001 -$32000	❑	
$32001 -$40000	❑	
$40001 -$50000	❑	
$50001 and over	❑	

2.2 Occupation

What is your current occupation (if applicable)? ---------- ☐ 51

Do you want a summary of the study results when available ?

No ❑ ☐
Yes ❑ 52

Contact address (to send you a summary of the results if you wish, and for future follow up): ☐ 53

Tel:----------

APPENDIX 6: Medical Outcomes Study Health Survey 36 Item Short Form

SF-36 HEALTH SURVEY

INSTRUCTIONS: This questionnaire asks for your views about your health, how you feel and how well you are able to do your usual activities.

Answer every question by marking the answer as indicated. If you are unsure about how to answer a question, please give the best answer you can.

1. In general, would you say your health is:

(circle one)

Excellent 1

Very good 2

Good 3

Fair 4

Poor 5

2. Compared to one year ago, how would you rate your health in general now?

(circle one)

Much better now than one year ago 1

Somewhat better now than one year ago 2

About the same as one year ago 3

Somewhat worse now than one year ago 4

Much worse now than one year ago 5

1 (For further information, write to: Medical Outcomes Trust, PO Box 1917, Boston MA 02205-8516, USA.)

3. The following questions are about activities you might do during a typical day. Does your health now limit you in these activities? If so, how much?

(circle one number on each line)

ACTIVITIES	Yes, Limited A Lot	Yes, Limited A Little	No, Not Limited At All
a. **Vigorous activities**, such as running, lifting heavy objects, participating in strenuous sports	1	2	3
b. **Moderate activities**, such as moving a table, pushing a vacuum cleaner, bowling, or playing golf	1	2	3
c. Lifting or carrying groceries	1	2	3
d. Climbing **several** flights of stairs	1	2	3
e. Climbing **one** flight of stairs	1	2	3
f. Bending, kneeling or stooping	1	2	3
g. Walking **more than one kilometre**	1	2	3
h. Walking **half a kilometre**	1	2	3
i. Walking **100 metres**	1	2	3
j. Bathing or dressing yourself	1	2	3

4. During the past 4 weeks, have you had any of the following problems with your work or other regular daily activities as a result of your physical health?

(circle one number on each line)

	YES	NO
a. Cut down on the **amount of time** you spent on work or other activities	1	2
b. **Accomplished less** than you would like	1	2
c. Were limited in the **kind** of work or other activities	1	2
d. Had **difficulty** performing the work or other activities (for example, it took extra effort)	1	2

(For further information, write to: Medical Outcomes Trust, PO Box 1917, Boston MA 02205-8516, USA.)

5. During the past 4 weeks, have you had any of the following problems with your work or other regular daily activities as a result of any emotional problems (such as feeling depressed or anxious)?

(circle one number on each line)

	YES	NO
a. Cut down on the **amount of time** you spent on work or other activities	1	2
b. **Accomplished less** than you would like	1	2
c. Didn't do work or other activities as **carefully** as usual	1	2

6. During the past 4 weeks, to what extent has your physical health or emotional problems interfered with your normal social activities with family, friends, neighbours, or groups?

(circle one)

Not at all 1

Slightly 2

Moderately 3

Quite a bit 4

Extremely 5

7. How much bodily pain have you had during the past 4 weeks?

(circle one)

No bodily pain 1

Very mild 2

Mild 3

Moderate 4

Severe 5

Very severe 6

(For further information, write to: Medical Outcomes Trust, PO Box 1917, Boston MA 02205-8516, USA.)

8. During the past 4 weeks, how much did pain interfere with your normal work (including both work outside the home and housework)?

(circle one)

Not at all 1

A little bit 2

Moderately 3

Quite a bit 4

Extremely 5

9. These questions are about how you feel and how things have been with you during the past 4 weeks. For each question, please give the one answer that comes closest to the way you have been feeling. How much of the time during the past 4 weeks -

(circle one number on each line)

	All of the Time	Most of the Time	A Good Bit of the Time	Some of the Time	A Little of the Time	None of the Time
a. Did you feel full of life?	1	2	3	4	5	6
b. Have you been a very nervous person?	1	2	3	4	5	6
c. Have you felt so down in the dumps that nothing could cheer you up?	1	2	3	4	5	6
d. Have you felt calm and peaceful?	1	2	3	4	5	6
e. Did you have a lot of energy?	1	2	3	4	5	6
f. Have you felt down?	1	2	3	4	5	6
g. Did you feel worn out?	1	2	3	4	5	6
h. Have you been a happy person?	1	2	3	4	5	6
i. Did you feel tired?	1	2	3	4	5	6

10. During the past 4 weeks, how much of the time has your physical health or emotional problems interfered with your social activities (like visiting with friends, relatives, etc.)?

(circle one)

All of the time 1

Most of the time 2

Some of the time 3

A little of the time 4

None of the time 5

11. How TRUE or FALSE is each of the following statements for you?

(circle one number on each line)

	Definitely True	Mostly True	Don't Know	Mostly False	Definitely False
a. I seem to get sick a little easier than other people	1	2	3	4	5
b. I am as healthy as anybody I know	1	2	3	4	5
c. I expect my health to get worse	1	2	3	4	5
d. My health is excellent	1	2	3	4	5

(For further information, write to: Medical Outcomes Trust, PO Box 1917, Boston MA 02205-8516, USA.)

APPENDIX 7: Diabetes Quality of Life Measure

Diabetes Quality of Life Measure

Please read each statement carefully. Please indicate how satisfied or dissatisfied you currently are with the aspect of your life described in the statement. Circle the number that best describes how you feel. There are no right or wrong answers to these questions. We are interested in your opinion.

	Very Satisfied	Moderately Satisfied	Neither	Moderately Dissatisfied	Very Dissatisfied
A1. How satisfied are you with the amount of time it takes to manage your diabetes?	1	2	3	4	5
A2. How satisfied are you with the amount of time you spend getting checkups?	1	2	3	4	5
A3. How satisfied are you with the time it takes to determine your sugar level?	1	2	3	4	5
A4. How satisfied are you with your current treatment?	1	2	3	4	5
A5. How satisfied are you with the flexibility you have in your diet?	1	2	3	4	5
A6. How satisfied are you with the burden your diabetes is placing on your family?	1	2	3	4	5
A7. How satisfied are you with your knowledge about your diabetes?	1	2	3	4	5
A8. How satisfied are you with your sleep?	1	2	3	4	5
A9.How satisfied are you with your social relationships and friendships?	1	2	3	4	5
A10. How satisfied are you with your sex life?	1	2	3	4	5

	Very Satisfied	Moderately Satisfied	Neither	Moderately Dissatisfied	Very Dissatisfied
A11. How satisfied are you with your work, school, and household activities?	1	2	3	4	5
A12. How satisfied are you with the appearance of your body?	1	2	3	4	5
A13. How satisfied are you with the time you spend exercising?	1	2	3	4	5
A14. How satisfied are you with your leisure time?	1	2	3	4	5
A15. How satisfied are you with with life in general?	1	2	3	4	5

Please indicate how often the following events happen to you. Circle the appropriate number.

	Never	Very Seldom	Sometimes	Often	All the Time
B1. How often do you feel pain associated with the treatment for your diabetes?	1	2	3	4	5
B2. How often are you embarrassed by having to deal with your diabetes in public?	1	2	3	4	5
B3. How often do you have low blood sugar?	1	2	3	4	5
B4. How often do you feel physically ill?	1	2	3	4	5
B5. How often does your diabetes interfere with your family life?	1	2	3	4	5

	Never	Very Seldom	Sometimes	Often	All the Time
B6. How often do you have a bad night's sleep?	1	2	3	4	5
B7. How often do you find your diabetes limiting your social relationships and friendships?	1	2	3	4	5
B8. How often do you feel good about yourself?	1	2	3	4	5
B9. How often do you feel restricted by your diet?	1	2	3	4	5
B10. How often does your diabetes interfere with your sex life?	1	2	3	4	5
B11. How often does your diabetes keep you from driving a car or using a machine (e.g. a typewriter)?	1	2	3	4	5
B12. How often does your diabetes interfere with your exercising?	1	2	3	4	5
B13. How often do you miss work, school, or household duties because of your diabetes?	1	2	3	4	5
B14. How often do you find yourself explaining what it means to have diabetes?	1	2	3	4	5
B15. How often do you find that your diabetes interrupts your leisure-time activities?	1	2	3	4	5
B16. How often do you tell others about your diabetes?	1	2	3	4	5

	Never	Very Seldom	Sometimes	Often	All the Time
B17. How often are you teased because you have diabetes?	1	2	3	4	5
B18. How often do you feel that because of your diabetes you go to the bathroom more than others?	1	2	3	4	5
B19. How often do you find that you eat something you shouldn't rather than tell someone that you have diabetes?	1	2	3	4	5
B20. How often do you hide from others the fact that you are having an insulin reaction?	1	2	3	4	5

Please indicate how often the following events happen to you. Please circle the number that best describes your feelings. If the question is not relevant to you, circle non-applicable.

	Never	Very Seldom	Sometimes	Often	All the Time	Does not Apply
C1. How often do you worry about whether you will get married?	1	2	3	4	5	0
C2. How often do you worry about whether you will have children?	1	2	3	4	5	0
C3. How often do you worry about whether you will not get a job you want?	1	2	3	4	5	0
C4. How often do you worry about whether you will be denied insurance?	1	2	3	4	5	0

	Never	Very Seldom	Sometimes	Often	All the Time	Does not Apply
C5. How often do you worry about whether you will be able to complete your education?	1	2	3	4	5	0
C6. How often do you worry about whether you will miss work?	1	2	3	4	5	0
C7. How often do you worry about whether you will be able to take a vacation or a trip?	1	2	3	4	5	0
D1. How often do you worry about whether you will pass out?	1	2	3	4	5	0
D2. How often do you worry that your body looks differently because you have diabetes?	1	2	3	4	5	0
D3. How often do you worry that you will get complications from your diabetes?	1	2	3	4	5	0
D4. How often do you worry about whether someone will not go out with you because you have diabetes?	1	2	3	4	5	0

E1. Compared to other people your age, would you say your health is: (Circle One)

1. Excellent
2. Good
3. Fair
4. Poor

APPENDIX 8: Raw data

stats iddm

Rows	pt code1	Column 289	diet diff/ease	HbA1c	DQOL	physical functioning	role - physical	bodily pain
1	4	2	difficulty	8.3	170	100	100	74
2	8	2	difficulty	8	.	.	.	.
3	9	2	difficulty	8.9	.	.	.	.
4	16	2	difficulty	11.2	189	100	100	100
5	2	3	neither	9	149	80	25	22
6	3	3	neither	7.6	181	100	100	84
7	10	3	neither	8	153	85	0	62
8	11	3	neither	11.5	179	95	100	90
9	13	3	neither	8.6	193	100	100	100
10	14	3	neither	8.1	162	95	75	84
11	18	3	neither	11.4	151	100	25	51
12	1	5	ease	8.2	204	100	100	100
13	5	4	ease	10	159	90	100	84
14	6	5	ease	7.2	191	100	100	84
15	7	4	ease	9.6	176	95	100	52
16	12	5	ease	.	169	95	100	100
17	15	4	ease	10.1	189	100	100	84
18	17	4	ease	10.1	162	95	100	84
19	21	5	ease	11.7	199	80	100	100
20	19	4	ease	8.9	182	100	100	100
21	20	5	ease	10.1	184	100	100	94

stats iddm

Rows	general health perceptions	vitality	social functioning	role - emotional	mental health	comp 100	age
1	87	35	87.5	33.3333333	68	0	22
2	.	.	.	.	.	0	24
3	.	.	.	.	.	0	24
4	32	100	100	100	84	0	24
5	10	20	75	100	44	0	27
6	52	65	100	100	76	25	26
7	52	55	37.5	0	52	0	21
8	55	55	50	100	92	25	25
9	87	95	100	100	96	0	18
10	52	50	87.5	66.6666667	64	0	31
11	57	65	75	33.3333333	72	0	29
12	97	90	100	100	96	0	29
13	57	70	100	100	76	0	28
14	97	55	50	100	68	0	27
15	80	40	12.5	0	60	0	22
16	57	75	87.5	100	80	0	21
17	77	70	100	100	88	0	27
18	57	60	62.5	66.6666667	64	0	22
19	87	65	100	100	76	0	20
20	77	70	50	100	88	0	26
21	62	75	100	100	84	0	25

stats iddm

Rows	sex	marital sta	education	duration of IDDM	Column 13	Column 25	Column 30	Column 34
1	1	1	5	45	187	1	1	1
2	2	1	5	57	91	1	1	1
3	2	1	5	129	85	1	1	1
4	2	1	4	37	992	1	1	1
5	1	1	4	186	483	1	1	1
6	1	2	6	66	490	1	1	2
7	2	2	6	17	594	1	1	1
8	2	2	3	17	594	1	1	1
9	2	1	5	127	385	1	1	1
10	2	2	5	35	1192	1	1	1
11	2	2	5	12	1094	1	1	1
12	2	1	4	.	1195	1	1	1
13	1	2	6	136	684	1	1	1
14	2	1	6	69	190	1	1	1
15	1	1	5	110	886	1	1	1
16	2	1	5	123	785	1	1	1
17	2	2	6	138	484	1	1	1
18	1	1	6	113	586	1	1	1
19	2	1	3	120	85	1	1	1
20	2	2	6	120	1085	1	1	1
21	2	2	6	113	687	1	1	1

stats iddm

Rows	Column 43	complication total	204 dqol	Column 205	Column 206	Column 207	Column 208	Column 209
1	1	4	4	4	2	5	4	5
2	1	4	.	.	.	.	.	.
3	1	4	.	.	.	.	.	.
4	1	4	1	4	4	1	2	2
5	1	4	3	3	3	1	4	3
6	1	5	4	4	4	4	4	4
7	1	4	3	3	4	3	2	2
8	2	5	4	2	4	4	4	4
9	1	4	3	4	4	5	3	4
10	1	4	4	4	4	5	2	4
11	1	4	1	1	4	1	1	1
12	1	4	5	5	5	5	5	3
13	1	4	4	4	5	4	4	4
14	1	4	5	5	4	5	5	5
15	1	4	4	4	5	5	5	4
16	1	4	3	3	4	4	4	3
17	1	4	2	2	5	2	4	4
18	1	4	4	3	5	3	5	4
19	1	4	5	4	5	5	5	5
20	1	4	4	4	4	4	3	3
21	1	4	4	4	3	4	5	5

stats iddm

Rows	Column 210	Column 211	Column 212	Column 213	Column 214	Column 215	Column 216	Column 217
1	5	4	5	5	4	4	2	4
2	.	.	.	.	.	.	.	.
3	.	.	.	.	.	.	.	.
4	4	5	5	5	5	5	5	5
5	5	4	5	5	5	2	3	4
6	5	5	5	5	4	4	4	4
7	3	5	2	2	2	3	2	2
8	5	5	5	5	5	4	2	4
9	5	5	5	3	5	4	3	5
10	4	5	4	5	4	5	4	5
11	4	4	4	4	4	4	2	4
12	5	5	5	5	5	5	4	5
13	4	4	5	5	4	2	2	4
14	5	4	4	3	4	4	4	5
15	4	5	5	3	4	2	4	4
16	5	4	5	4	4	3	4	2
17	5	4	5	5	4	4	3	4
18	4	2	4	4	4	2	3	2
19	5	2	4	5	5	4	5	4
20	4	4	5	5	5	4	3	3
21	4	5	5	5	5	4	4	4

stats iddm

Rows	Column 218	Column 219	Column 220	Column 221	Column 222	Column 223	Column 224	Column 225
1	5	4	5	3	4	4	3	5
2	.	.	.	.	.	.	.	.
3	.	.	.	.	.	.	.	.
4	5	5	5	5	5	5	5	5
5	3	3	1	2	3	5	3	4
6	5	3	4	3	3	5	3	4
7	3	5	3	3	4	4	4	3
8	4	4	4	3	3	5	3	5
9	5	5	3	3	5	4	5	5
10	4	4	3	3	3	3	4	3
11	4	5	2	4	3	4	3	2
12	5	4	5	4	4	5	5	5
13	4	4	5	2	4	4	4	4
14	4	2	5	3	4	4	4	3
15	4	4	3	4	3	5	4	5
16	4	4	5	3	4	4	4	4
17	4	4	5	4	4	5	3	4
18	3	4	5	2	3	3	2	4
19	5	5	5	4	5	5	3	5
20	4	4	4	3	4	4	4	4
21	5	2	2	3	4	4	5	5

stats iddm

Rows	Column 226	Column 227	Column 228	Column 229	Column 230	Column 231	Column 232	Column 233
1	2	3	3	5	4	5	3	4
2	.	.	.	.	.	.	.	.
3	.	.	.	.	.	.	.	.
4	1	3	5	5	5	5	3	5
5	3	2	4	5	3	4	1	3
6	2	3	4	5	5	4	2	3
7	3	4	4	5	4	4	2	4
8	2	5	5	5	4	4	3	4
9	1	2	5	5	5	5	4	5
10	2	2	5	5	3	4	2	2
11	4	2	4	5	4	3	2	4
12	1	4	5	5	5	5	3	5
13	2	1	3	4	4	4	2	4
14	3	3	5	5	5	5	2	4
15	3	4	5	5	5	5	5	5
16	2	4	3	4	3	4	3	4
17	2	5	5	4	4	5	5	5
18	2	3	5	4	3	4	2	3
19	3	5	5	5	5	4	3	5
20	2	4	4	5	4	4	3	4
21	1	3	5	5	4	3	2	5

stats iddm

Rows	Column 234	Column 235	Column 236	Column 237	Column 238	Column 239	Column 240	Column 241
1	3	5	3	4	3	2	2	2
2	.	.	.	.	.	.	.	.
3	.	.	.	.	.	.	.	.
4	3	5	3	4	4	4	4	4
5	1	5	1	2	1	2	5	2
6	3	5	4	3	4	5	5	5
7	3	5	2	4	5	5	1	3
8	2	5	4	3	5	4	1	4
9	3	5	5	5	5	4	4	3
10	3	4	3	4	3	5	5	2
11	3	5	2	4	5	3	5	5
12	2	5	5	3	5	4	4	4
13	3	5	3	4	3	4	4	0
14	2	5	5	5	5	3	4	4
15	4	5	4	3	4	1	1	3
16	3	5	5	5	5	4	4	1
17	4	5	5	4	5	3	5	5
18	3	5	5	4	4	4	4	4
19	3	5	5	5	5	2	4	2
20	4	5	4	4	4	3	5	5
21	3	5	3	3	4	3	5	5

stats iddm

Rows	Column 242	Column 243	Column 244	Column 245	Column 246	Column 247	Column 248	Column 249
1	2	3	4	2	3	4	2	4
2	.	.	.	.	.	.	.	.
3	.	.	.	.	.	.	.	.
4	4	2	4	4	4	4	4	4
5	5	5	2	4	2	5	1	5
6	2	5	3	3	3	3	2	5
7	2	5	3	3	3	4	2	3
8	4	4	4	4	3	3	3	4
9	4	4	4	4	4	4	2	4
10	0	1	3	3	2	4	1	5
11	3	4	1	3	1	4	1	5
12	4	4	4	4	4	4	4	4
13	2	4	2	4	0	4	0	4
14	4	4	4	4	4	4	3	4
15	3	4	2	2	3	1	1	4
16	1	4	3	4	2	4	1	4
17	3	5	4	4	3	3	2	5
18	1	4	4	4	4	3	1	4
19	4	4	4	4	3	4	2	4
20	3	4	4	4	4	3	2	5
21	5	5	3	3	3	4	2	5

stats iddm

Rows	Column 250	251 sf36	Column 252	Column 253	Column 254	Column 255	Column 256	Column 257
1	3	4.4	3	3	3	3	3	3
2	.	.	.	.	.	.	.	.
3	.	.	.	.	.	.	.	.
4	3	4.4	3	3	3	3	3	3
5	2	2	3	1	3	3	2	3
6	3	3.4	3	3	3	3	3	3
7	3	3.4	4	2	3	3	2	3
8	2	2	2	3	3	3	3	3
9	4	4.4	3	3	3	3	3	3
10	3	4.4	3	2	3	3	3	3
11	3	4.4	2	3	3	3	3	3
12	3	4.4	2	3	3	3	3	3
13	3	4.4	2	2	3	3	2	3
14	4	4.4	3	3	3	3	3	3
15	4	5	2	2	3	3	3	3
16	3	3.4	3	2	3	3	3	3
17	3	4.4	3	3	3	3	3	3
18	3	3.4	1	2	3	3	3	3
19	4	4.4	3	3	3	3	3	3
20	3	4.4	3	3	3	3	3	3
21	4	3.4	1	3	3	3	3	3

stats iddm

Rows	Column 258	Column 259	colom 260	Column 261	Column 262	Column 263	Column 264	Column 265
1	3	3	3	3	3	2	2	2
2	.	.	.	.	.	.	.	.
3	.	.	.	.	.	.	.	.
4	3	3	3	3	3	2	2	2
5	3	2	3	3	3	1	1	2
6	3	3	3	3	3	2	2	2
7	2	3	3	3	3	1	1	1
8	3	2	3	3	3	2	2	2
9	3	3	3	3	3	2	2	2
10	3	3	3	3	3	2	1	2
11	3	3	3	3	3	1	1	1
12	3	3	3	3	3	2	2	2
13	3	3	3	3	3	2	2	2
14	3	3	3	3	3	2	2	2
15	3	3	3	3	3	2	2	2
16	3	3	3	3	3	2	2	2
17	3	3	3	3	3	2	2	2
18	3	3	3	3	3	2	2	2
19	1	1	3	3	3	2	2	2
20	3	3	3	3	3	2	2	2
21	3	3	3	3	3	2	2	2

stats iddm

Rows	Column 266	Column 267	Column 268	Column 269	Column 270	Column 271	Column 272	Column 273
1	2	2	1	1	4	5.4	4	3
2	.	.	.	.	.	.	.	.
3	.	.	.	.	.	.	.	.
4	2	2	2	2	5	6	6	6
5	1	2	2	2	5	2.2	2	4
6	2	2	2	2	5	5.4	5	5
7	1	1	1	1	2	4.2	4	3
8	2	2	2	2	5	6	5	5
9	2	2	2	2	5	6	6	6
10	2	2	2	1	4	5.4	5	4
11	2	1	1	2	4	3.1	4	5
12	2	2	2	2	5	6	6	5
13	2	2	2	2	5	5.4	5	5
14	2	2	2	2	5	5.4	5	3
15	2	1	1	1	2	4.2	3	3
16	2	2	2	2	4	6	6	5
17	2	2	2	2	5	5.4	5	4
18	2	2	1	2	3	5.4	5	4
19	2	2	2	2	5	6	6	5
20	2	2	2	2	5	6	6	5
21	2	2	2	2	5	5.4	6	5

stats iddm

Rows	Column 274	Column 275	Column 276	Column 277	Column 278	Column 279	Column 280	Column 281
1	5	6	3	2	4	3	4	3
2	.	.	.	.	.	.	.	.
3	.	.	.	.	.	.	.	.
4	4	6	4	6	6	6	6	6
5	2	4	2	2	4	1	4	1
6	5	6	4	4	4	4	5	4
7	5	4	3	2	3	5	3	5
8	5	6	6	5	6	1	5	4
9	6	6	5	6	6	5	6	6
10	4	5	4	4	4	3	4	3
11	5	5	5	4	5	4	3	4
12	6	6	6	5	6	6	5	6
13	4	5	5	4	5	5	5	4
14	6	6	3	4	4	4	3	4
15	4	5	3	2	5	5	3	2
16	5	6	4	4	5	5	5	5
17	6	6	5	4	5	5	5	5
18	4	5	3	2	5	5	4	5
19	6	5	3	4	5	4	5	4
20	6	6	5	5	5	4	5	4
21	5	6	5	5	5	5	5	4

stats iddm

Rows	Column 282	Column 283	Column 284	Column 285	286	physical functioning total	role physical total
1	5	5	5	4	4	30	8
2	.	.	.	.	.	.	.
3	.	.	.	.	.	.	.
4	5	1	2	2	2	30	8
5	3	1	1	2	1	26	5
6	5	2	4	2	4	30	8
7	3	3	4	1	4	27	4
8	1	4	4	4	2	29	8
9	5	5	5	4	4	30	8
10	5	1	4	2	4	29	7
11	4	1	4	3	4	30	5
12	5	5	5	5	5	30	8
13	5	3	4	1	4	28	8
14	1	5	5	5	5	30	8
15	1	4	5	3	4	29	8
16	5	3	4	2	4	29	8
17	5	4	4	4	4	30	8
18	4	4	4	3	2	29	8
19	5	3	5	5	5	26	8
20	1	4	4	4	4	30	8
21	5	3	4	3	4	30	8

stats iddm

Rows	bodily pain tota	general health perception tota	vitality tota	social functioning tota	role emotional tota
1	9.4	22.4	11	9	4
2	.	.	.	.	.
3	.	.	.	.	.
4	12	11.4	24	10	6
5	4.2	7	8	8	6
6	10.4	15.4	17	10	6
7	8.2	15.4	15	5	3
8	11	16	15	6	6
9	12	22.4	23	10	6
10	10.4	15.4	14	9	5
11	7.1	16.4	17	8	4
12	12	24.4	22	10	6
13	10.4	16.4	18	10	6
14	10.4	24.4	15	6	6
15	7.2	21	12	3	3
16	12	16.4	19	9	6
17	10.4	20.4	18	10	6
18	10.4	16.4	16	7	5
19	12	22.4	17	10	6
20	12	20.4	18	6	6
21	11.4	17.4	19	10	6

stats iddm

Rows	mental health tota
1	22
2	.
3	.
4	26
5	16
6	24
7	18
8	28
9	29
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