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**THE ROLE OF SELF-EFFICACY IN PERCEIVED
QUALITY OF LIFE IN PEOPLE WITH BOTH
INSULIN-DEPENDENT AND NON-INSULIN
DEPENDENT DIABETES.**

A thesis presented in fulfilment of the requirements

for the degree of

Master of Arts in Psychology

at Massey University

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1995

ABSTRACT

Diabetes Mellitus is an illness that affects more than 100,000 people in New Zealand. This study examined the variables which were thought to be most likely to impact on the quality of life of people with either Insulin Dependent Diabetes Mellitus (IDDM) or Non-Insulin Dependent Diabetes Mellitus (NIDDM).

Diabetes requires a high degree of self-management on a daily basis. The challenges for people with diabetes are to maintain a healthy level of blood glucose by carrying out adequate self-care behaviours. It was thought these may represent barriers to unrestricted quality of life, and the study investigated the degree to which cognitive-affective processes were diverted into self-care and illness appraisal. The two groups were studied to investigate which psychological factors would influence perceptions of wellbeing, and whether or not the psychological areas of significance were correlated with blood glucose levels (HbA_{1C}), depicting good metabolic control.

Using a questionnaire survey method, this study examined the psychological processes of 99 people with diabetes (36 IDDMs and 63 NIDDMs), assessing in particular, their self-efficacy, perception of risk, and psychological control, all considered to be factors that would be likely to affect their quality of life. Measures used included illness appraisal, wellbeing and self-efficacy scales, as well as a small qualitative section eliciting personal comments.

The findings indicated a moderate level of self-efficacy and wellbeing across the sample which was adversely affected when they were compelled to take barriers to effective self-care into account. Risk perception was considered to be inadequate, especially when correlated with other factors, suggesting that self-efficacy was maintained by sidelining the risks or threats of diabetes. On the whole, the sample were particularly effective at maintaining adequate weight through diet, and a significant proportion were not taking any medication at all. Severe hypoglycaemic episodes were rare. Perception of control was another issue which appeared to be adequate for the sample, but it was found that people's perceived control was a more cogent variable than actual metabolic control (as measured by HbA_{1c} assay).

It was possible to infer stages of self-efficacy according to the manner in which people responded. Drawing on self-efficacy measures found to be effective in assessing populations with chronic conditions, it was found that there was some support for the notion that resistance self-efficacy and coping self-efficacy were the mechanisms at work for these people.

Comments from respondents showed a desire for more information and better public awareness of diabetes, and offered some insight into the mechanisms by which people maintain an adequate quality of life despite chronic illness.

DEDICATION

This thesis is dedicated to my children, Richard, Erin and Jonathan, who continue to believe in me.

ACKNOWLEDGEMENTS

I am indebted to a number of people for their help throughout this project. First, my warmest appreciation is due my supervisor, Kerry Chamberlain, who thought of the project in the first place, who collaborated in the research design and methodology, and who maintained an active and inquiring interest into every facet of the task.

I am grateful also to Julie Bunnell, my friend and departmental mentor, for her unflappable and practical support when I got bogged down.

Dr Paul Dixon, and Dr David Scott, Diabeticians, and Marian Moore and Helen Snell, Nurse Manager and Diabetes Nurse Specialist, respectively, at the Palmerston North Diabetes Lifestyle Centre were helpful in making real for me the difficulties faced by people with diabetes, as well as the challenges for the care providers. They also took on the task of selecting the sample and record-keeping, both necessary but tedious tasks. Dr Scott's seminal work on the life of the diabetic in New Zealand was a valuable handbook for my research.

No research of this kind is ever possible without the contributions of the participants. My thanks go to the 99

anonymous people who went to the trouble of completing and returning the questionnaires.

I am very much indebted to Professor Ralf Schwarzer, of the Freie Universitat Berlin, whose Visiting Fellowship at Massey University coincided with the early stages of my thesis. He generously assisted me in devising the appropriate self-efficacy format for use with diabetics and very greatly increased my understanding of the self-efficacy construct.

My son Richard Parry, of Lingo Computer Systems, Wellington, was a patient, reliable and unfailingly courteous consultant to me on all matters to do with computer technology. Without his technical know-how and never-say-die sense of humour, I would never have mastered the machine.

My friends Marie and Gloria, and my clinical supervisor, Mary Lane Dodd, were there to support me in the myriad ways friends do - thank you all.

Finally, thanks to my family for bearing up through it all. My daughter, Erin, cooked meals and made me cups of tea when I was totally immersed, and demonstrated a maturity beyond her years in understanding why this was so important to me. Jonathan's contribution was to play for hours on his own so I could work. Jonathan, here is Mummy's "book".

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Introduction

Diabetes Mellitus, is an illness caused by defective carbohydrate metabolism and characterised by abnormally large amounts of sugar in the blood and urine. It affects more than 100,000 people in New Zealand. Additionally, there is estimated to be up to 40,000 people who are at risk from developing diabetes or who have mild- but undiagnosed - diabetes.

People with diabetes either lack insulin - Type I, Insulin Dependent Diabetes Mellitus (IDDM), or their insulin does not work effectively - Type II, Non-Insulin Dependent Diabetes Mellitus (NIDDM). Symptoms of diabetes include excessive appetite and thirst, frequency of urination, weight loss, fatigue and blurred vision. IDDM, formerly called juvenile-onset diabetes, which occurs mainly in children and young adults, is thought to stem from defects in both genetic and autoimmune function. Rapid in onset and progress, it accounts for between 10 and 15% of all cases. NIDDM, formerly called adult-onset diabetes, also has hereditary origins, is usually found in people over 40 years old, and progresses slowly. (Cox & Gonder-Frederick, 1992). Not all people diagnosed with diabetes experience symptoms to the same degree (Scott & Palasti Brown, 1989). Diabetes is not able to be cured, but it can be treated (by insulin injections or pills), and managed, by diet and exercise.

Inconsistent adherence to a daily regimen of appropriate diet and exercise, or inconsistency with prescribed medication, can lead to severe and even fatal results. These include blindness, kidney failure, male impotence, poor circulation (leading to limb amputation), heart attack and stroke, and can endanger pregnancy (Scott & Palasti Brown, 1989, Cox & Gonder-Frederick, 1992). These complications may take years to develop in most diabetics, but are cumulative, and the tissue damage may be irreversible.

Aetiology

Diabetes is considered a group of disorders with multiple causes, rather than a single disorder. The human pancreas secretes a hormone called insulin that facilitates the entry of the sugar glucose into all tissues of the body, providing energy for bodily activities.

In the NIDDM diabetic, the pancreas often makes a considerable quantity of insulin, but the hormone is unable to promote the entry of glucose into the tissues. This resistance is often due to prolonged obesity, because a high level of blood sugar inactivates the tissue components, which, in turn, act as a target for insulin (Scott & Palasti Brown, 1989).

In IDDM sufferers, there is a severe or total reduction in insulin production. Untreated, the disease can rapidly be fatal. Because the body lacks sufficient energy from tissue glucose, it begins to break

down stored fat. This produces increasing amounts of compounds called ketone bodies in the blood, making blood acidic and interfering with respiration. This causes failure of vital bodily systems by a process called ketoacidosis. Another, far more common short-term complication is hypoglycaemia (low blood sugar), known as a “hypo”, which is caused by an imbalance between insulin, food, and physical activity. Severe episodes can cause loss of consciousness or seizures, progressing to coma, and even death (Cox & Gonder-Frederick, 1992).

Treatment & Management

[Diabetes] does dominate my life. You cannot get away from it. Everything you do, you have to think, Is it O.K. to do this? Or is my blood glucose too high or too low? When do I need my next shot of insulin? (Scott & Palasti Brown, 1989, p. 100).

For IDDMs and some NIDDMs, therapy involves insulin injections and crucial changes in diet. This requires distributing meals and snacks throughout the day so that the insulin supply is not overwhelmed and also eating foods that contain slow-release carbohydrates. If blood glucose is still unacceptably high, the patient may have to administer insulin injections. An oral sugar-lowering agent may be prescribed in tablet form for people who have difficulties managing insulin therapy, or whose diabetes is not controlled by the addition of insulin.

For NIDDMs, most of whom are at least moderately overweight, the basics of therapy are diet control, weight reduction and exercise. Weight reduction appears to partially reverse the condition of insulin resistance in the tissues (Cox & Gonder-Frederick, 1992).

It appears that chronic hyperglycaemia (high blood glucose) is the predominant cause of tissue and organ damage. Accordingly, diabetes care providers are concerned to monitor as closely as possible the levels of glycosylated haemoglobin (HbA_{1C}). This is done by blood assay which yields a marker of blood glucose over the previous 2 to 3 month period. Additionally, a fructosamine assay monitors blood glucose levels over the preceding 3 weeks, and a urinalysis yields results from the previous 2 hours (Moore & Snell, 1995). Treatment goals from the clinician's point of view are to normalise blood glucose levels and prevent long-term complications. Therefore, they recommend the diabetic self-monitor blood glucose by a "finger-prick" test carried out 3 to 5 times daily.

Hypoglycaemic episodes can occur at any time. While mild episodes are manageable by the diabetic (by consuming fast-acting glucose) severe episodes often require the care of others. Behaviour change (irritability, aggression, irrationality) is a common "marker" to the people around diabetics - who know the person is diabetic - although often the diabetics are unaware of this themselves (Scott & Palasti Brown, 1989).

What is clear from Scott and Palasti-Brown's (1989) case-studies is that diabetes is an illness which causes both physical and psychological suffering. Given the complexities of the course of the diabetic illness, the social implications of special dietary needs, obesity, fluctuating levels of physical strength and fatigue, sudden frightening episodes of hypoglycaemia, and the "no-win" nature of a chronic illness, the psychological adjustments are considerable.

Diabetes can be considered both a disease, in biomedical terms, and an illness with significant psychosocial ramifications. Eisenberg's distinction is helpful:

illnesses {are} experiences of disvalued changes in states of being and in social function...diseases are abnormalities in the structure and function of body organs and systems. (Eisenberg, 1977, p. 9).

Thus, from the patient's perspective, what they experience is likely to be illness, whereas their medical helpers are likely to see their function as treating a disease. This may have significant ramifications for patient-perceived quality-of-life, as we shall see later in this paper.

Pamphlets abound in diabetes care which emphasise the treatable or manageable nature of the illness, but whether they reduce or add to the confusion of the patient and his or her supporters is arguable. One noticeboard seen at a city hospital trumpeted that "DIABETES

IS NOT A DISEASE", which is neither technically correct, nor likely to be reassuring to a person who feels unwell and under threat a lot of the time.

While it is doubtless helpful for diabetics to feel as if they have some control over the course of their illness (through diet, exercise, self-monitoring of blood glucose and a conscientious attention to their medication regimen) it is a great deal of responsibility to carry on their shoulders, and their psychosocial difficulties are problematic. What is clear is that diabetes is fraught with ambiguities, and requires constant self-reference, that is, diabetic people are compelled to think about their health all the time. Schwarzer (1994) points out that these are both high-risk factors in generating stress and affecting mood. These are psychological "givens" for both IDDMs and NIDDMs and will impact directly on their quality of life. How they do so, and to what degree, are the considerations of this study.

Quality of Life

The persons with whom we [researchers] are concerned... are best viewed as lives lived with some degree of coherence: a human person is a life lived according to a human plan. (Cohen, 1982, p. III-30).

Quality of life is an abstraction of the human condition. While it is not the purpose of this study to join the keen and wide-ranging debate on its meaning, value and function in the health psychology

field, it is important to provide some background and overview of the construct in order to provide a context for the psychosocial nuances of the diabetic experience. This is necessary because social research has revealed that it is not possible to extract a person from his or her cultural milieu, or to treat their psychological makeup in isolation from their day-to-day lived experience. Thus, the following discussion will highlight the origin of the expression *quality of life*, and will attempt to show the reason for the inclusion of quality of life parameters in health research. Because perspectives are culture-bound, the studies used in this paper will reflect a 'white, western and modern' viewpoint.

Edlund & Tancredi (1985) call quality of life an ideology and join others in decrying its elusiveness of definition (McCauley & Bremer, 1991, Romney et al., 1992). Most people would recognise the phrase as having implicit meaning but would probably differ in their views of what ought to be included in its categorisation. However, most people would probably agree that "having a life" implies social and psychological connectedness, the ability to work, to engage in relationships, and to make a contribution to, and derive some benefit from, society in however small a way.

Siri Naess (1987) has explicated the factors which she believes directly and indirectly affects people's quality of life. She says:

A person enjoys a high quality of life (or well-being) to the degree that that person is active, relates well to others, has

self-esteem and a basic mood of happiness (Naess, 1987, p. 14).

She concludes that the loss or diminution of the balance of these four fundamental conditions destabilises a sense of quality of life. Naess offers a thoughtful discussion of how to define “needs”: fundamental, social and desired, which contribute to a person’s welfare. She points to Maslow’s (1970) seminal work on the hierarchy of needs as providing a useful list of priorities for the organism, beginning with the fundamental physiological needs: food, potable water, oxygen, warmth, and rest. The satisfaction of these basic needs is the organism’s primary objective, and an end in itself. However one may argue the organisation of secondary needs, humans share with lower-order species the physiological needs, and the need for security (freedom from harm), and it is axiomatic that one cannot search for “growth needs” unless survival needs are met. Threats to survival in diabetes are considered later in this paper.

Cohen (1982) points out that quality of life is by its own nature, subjective, and that the person of whom to inquire about such a construct is the individual. He cites great thinkers such as Aristotle, St. Thomas Aquinas, Immanuel Kant and John Dewey in arguing, like Naess, that although people may disagree as to the extensiveness or rank ordering of any list about qualities, “*being free from external interference, having a sense of our own worth and integrity, and enjoying satisfactory organic function*” (p. III-

30), are not really in dispute. It would appear that the third condition would equate with Naess's fundamental need; the second Naess deals with as social needs. She argues that self-esteem is vital to the maintenance of satisfactory social relationships, and vice versa, and does not separate the social from the psychological. Certainly, studies about the impact of psychological dysfunction on the people in the sufferer's social and familial network bear this out (Laing, 1988). This prefigures one of the foci of this study, in that the psychosocial factors are considered important considerations in quality of life, and treated as an inclusive unit.

In Cohen's context, the first condition (freedom from external interference) appears to mean the absence of enslavement, coercion, to have control over one's own destiny and the sanctity of one's own thoughts and emotions, roughly analagous to Naess's desired need state. Later in this paper we will look at the notion of control more closely.

Quality of life emerged from the biomedical debates about sanctity of life. This notion underpins Edlund and Tancredi's critique on quality of life. The health field, in their view, has in the past been dedicated to keeping people alive, at any cost, even if their social utility is nil, as can be seen in the dramatic stories of braindead people being kept "alive" on respirators, and so on. The term "quality of life" appears to have arisen from these and similar medical dilemmas. Medical providers are concerned to maximise

people's social and economic utility and the emphasis in medicine in the last 20 years has seen funds directed to education, rehabilitation and retraining, and away from chronic care provision (Edlund & Tancredi, 1985). These authors argue pungently that quality of life, like sanctity of life, is culturally-driven by moral and social imperatives, is subject to politically-derived notions of "rationality", and changes over time.

The quality of life debate has extended to include chronic illness, whether terminal or not. Studies of chronic illness yield information about the way people perceive their life in that illness context which may have some bearing on quality of life in diabetes. Therefore an attempt will be made to draw together those studies whose focus appears to say something about quality of life, even if that particular phrase is not always employed.

Many people, if not all, would include **good health** as fundamental to quality of life, but would probably differ in their definition of that sub-category. A robustly healthy person may believe that a continuation of the robustness was essential to their quality of life: a person suffering from a chronic condition may have to seek other qualities and values to find satisfaction and contentment. However wellness may not be essential for a sense of wellbeing (Naess, 1987).

Different researchers bring their own perspectives into their studies, for instance, Caplan (1987) who mentions “toxicity” from cancer and cancer treatments as being a crucial dimension in quality of life. He also mentions both spirituality and culturality as important factors for consideration in quality of life studies, and argues - as many do - for the subjectiveness of the construct (see also Hollandsworth, 1988, McCauley & Bremner, 1991, Romney et al, 1992, and Kreitler et al., 1993).

Ware and Sherbourne (1992) while avoiding the use of the term quality of life, nonetheless offer eight key areas of health functioning and the degree to which their limitations or impairment affect “medical outcome”. These are:

- 1) *limitations in physical activities because of health problems*
- 2) *limitations in social activities because of physical or emotional health problems*
- 3) *limitations in usual role activities because of physical health problems*
- 4) *bodily pain*
- 5) *general mental health (psychological distress and wellbeing)*
- 6) *limitations in usual role activities because of emotional problems*
- 7) *vitality (energy and fatigue)*
- 8) *general health perceptions* (p. 473).

It is difficult to avoid the inference that disabilities in functioning affect quality of life, and their study offers useful insights into the

way in which medical outcomes are affected by a person's level of functioning, which in turn, impacts on their ability to enjoy life.

Chronic illness impacts on quality of life via adverse affects on relationships. Human beings are social animals, and function best when in social relationship and there is evidence to suggest that there are health-enhancing effects of committed relationships, especially for men (Morgan, 1975, Carroll et al., 1993a, Carroll et al., 1994b) . Difficulties in familial relationships create stress, which is detrimental to immune functioning and psychological wellbeing (Helz & Templeton, 1990, Goldston et al., 1995). Chronic illness can be especially hard for people to adjust to in relationship terms: treatment for the patient is often supportive rather than palliative. That is, visits to medical specialists occur routinely, often with no discernible outcome, and can therefore aggravate rather than relieve stress. Difficult as it undoubtedly is for the patient, it may be just as bad affectively for those in the person's social and familial network. They do not have the benefit of medical consultations, cannot tell from surface appearance whether the patient is having a "good" day or a "bad" day, and their supportive efforts may perhaps be misdirected and therefore unappreciated. Therefore, the quality of life of those in the person's network will also be affected.

Carroll et al., (1993) provide a useful outline of the factors which impact on both morbidity and mortality. They argue that there is an irresistible and consistent negative correlation between low socio-

economic conditions and high health risks, across cultures and across illness conditions. They also confirm that stressful day-to-day life, major crises, and vocational stress contribute to poor health, as well as *"the relative absence of positive events"* (p. 306). In other words, living a life without pleasure, however non-aversive it may otherwise be, is detrimental to wellbeing.

One can imagine therefore, that people with chronic illness would need to develop different strategies from the normatively well to maximise their quality of life, and this may include sidelining a number of issues which others may consider necessary, such as reliable functioning, control over environmental factors, and perception of risk.

The Impact of Diabetes on Quality of Life

...in reality do staff and doctors really appreciate what it is like to be a diabetic? You physically don't have to live with this condition - how can you relate to what a diabetic constantly has to go through? I suppose you will never actually know". (Appendix A, No. 123).

Diabetes is a chronic illness. Onset can be as young as 3 years, in IDDMs, or as late as 60 years for NIDDMs (Scott & Palasti Brown, 1989). It can change over time in its impact on day-to-day functioning, from no effect, to tiredness, to major health crisis, finally causing irrevocable tissue damage. Psychologically, it is characterised by ambiguity and inconsistency. Nevertheless, it is not

medically considered a sinister illness, and is popularised in brochures and pamphlets as a “condition”. Its commonness is emphasised, as is its treatableness. Most pamphlets offer matter-of-fact and useful information on diet, exercise and medication needs. Stern warnings are conveyed about the consequences of poor control, with the emphasis being on self-care. Diabetic experts (nurses, doctors and dieticians) are to be consulted initially for advice about their treatment objectives, but otherwise the diabetic is left to manage largely alone, unless things go badly wrong (see, for example, Auckland Area Health Board booklet, 1991). Thus, illness management becomes the domain of the patient, not the care provider.

In contrast, the research literature on diabetes chronicles the pervasive damage diabetes can cause to the human organism, and emphasises the difficulties of both adequate treatment and satisfactory metabolic control (Scott & Palasti Brown, 1989, Cox & Gonder-Frederick, 1992, Bradley, 1994c, Goldston et al., 1995). While it is characterised as a “disorder”, it is treated as an illness, with all the biomedical terminology which attaches itself to the disease model of illness.

There are significant social costs of diabetes. Friends and family may fail to understand the implications that, while their loved one may be unlikely to die, he or she is not going to get better, and may react in insensitive and unsympathetic ways, or may avoid the

sufferer altogether. Employers and co-workers may resent the loss of productive work time, or of having to cover for absences. In this country, prospective employees often must make a declaration of health status when applying for a position in a state organisation, and failure to disclose carries heavy penalties. Thus, private suffering becomes public property, and others decide whether or not the illness “unfits” the person for the position.

Finally, the diabetic’s attempts to maintain optimism, to remain mobile, to conceal the less salubrious aspects of their condition, and to appear to be coping well may have the effect of confusing those around them, misleading them into thinking all is well. This lack of understanding of people in a sufferer’s social network may leave the sufferer feeling unheard, unsupported, and perhaps even disbelieved.

Against this background, a review of the research literature on diabetes as it relates to quality of life, is presented. Perspectives from both biomedical and psychological studies will be discussed, and some tentative conclusions and ‘working hypotheses’ outlined.

Diabetes has been a popular illness condition for research since the mid-1980’s, when the Diabetes Complications and Control Trial (DCCT) was initiated, reporting in 1988. While the major purpose of the study was to assess the variables that related to reducing the development of diabetes-related complications, the research team prudently included instruments to investigate the patients’ perceptions of the impact on their lives of tight control and

invigilation. Among these instruments was a quality of life measure. The DCCT study was designed to run over 10 years, but was terminated after 5 years because the conclusions relating to complications were irrefutable: tight metabolic control reduced complications. Moreover, the research team concluded that diabetes did not significantly affect quality of life. However, they did acknowledge the likelihood of treatment being affected by:

complex shifts in patterns of morbidity, asymptomatic changes in physiologic measures, treatment side effects, and differential burdens on patient and family lifestyles (1988, p. 725, emphasis added).

There have been a number of other studies which have attempted to replicate the DCCT findings. Due to the elusiveness of definition, researchers have attempted to isolate the factors which they believe impact on quality of life. Most studies of this kind are located within the disease context of health. That is, they link whatever findings may emerge back into the biomedical functioning of the persons studied. In this respect, efforts have been made to describe well-being and control (Kavanagh, Gooley & Wilson, 1992), social support (Kvam & Lyons, 1991, Cox & Gonder-Frederick, 1992), hardiness (Rapley, 1991) psychosocial adjustment and control (Helz & Templeton, 1990, Wrigley & Mayou, 1991), coping style (Sensky & Petty, 1989, Toobert & Glasgow, 1991) and self-efficacy (Kavanagh, Gooley & Wilson, 1993). Mayou, Bryant & Turner (1990) assessed social difficulty and mental state in day-to-day life. In a review of the literature, Rapley (1991) found the variables

which impact most on quality of life were psychosocial adjustment to chronic illness, hardiness, self-efficacy and coping style. Lundman et. al. (1990) studied Swedish IDDM patients. They found a greater tolerance to the disease in older patients and hypothesised these people to have developed better coping abilities than younger people. They found that many patients felt diabetes to have had a **positive** effect on their lives, in that "*the family ate more nutritious food ... and that they themselves lived a healthier life* " (p. 258) . They found no correlation between well-being ("subjective health") and metabolic diabetic control ("objective health") and concluded, like Bradley (1994c) that an emphasis on strict control was detrimental to coping both intrapersonally and interpersonally.

These studies provides a useful springboard into the kinds of data sought in health psychology research, but may be limited by the emphasis on metabolic control. Psychological factors which both underlie and flow from the experience of diabetes have not yet been fully explored, and the reasons for patient choice in self-management are still poorly understood (Bradley, 1994c). Helz and Templeton (1990) provide a review of studies on the psychological, psychophysiological and psychosocial variables in diabetes. While maintaining a focus on metabolic control, they offer some evidence that the effects of functional disorders, lifestress and poor intrafamilial relationships are implicated in poor diabetes self-management. This theme is echoed by others (Scott & Palasti Brown, 1989, Wrigley & Mayou, 1991).

What is less clear is whether the dysfunction accompanying diabetes is primary or secondary to their diabetic illness, or whether assisting diabetic patients to address and improve self-management strategies would have a beneficial effect on (a) functional states and (b) diabetic control. Goldston et al. (1995) argue that it is the severity of the stress which occurs following life changes that is the crucial variable in poor metabolic control, rather than the number of life changes themselves, and that "serious noncompliance" is a result - rather than a cause - of stress. On the other hand, Bradley (1994c) informs us that there are many disturbances of mood and behaviour which may all be symptoms of elevated blood glucose levels.

Psychosexual difficulties recur as a theme in quality of life studies (Mayou, et al. 1990, Wrigley & Mayou, 1991, Bradley, 1994c) That is, they are assumed to flow from the effects of a chronic and debilitating illness, or from neuropathies. While this may be a reasonable assumption when there is evidence of neuropathy leading to impotence (in males) or - less compellingly - orgasmic dysfunction (in females) (Bradley, 1994c) it is not explicated in the research. Loss of libido is seldom univariate in its causality. In many cases there is surface evidence provided via the other instruments in the research panoply for unsatisfactory interpersonal relationships, or loneliness, or excessive worry, in diabetes sufferers. It is reasonable to assume that unsatisfactory relationships and mood states impact directly on sexual performance. It is not clear whether

either sexual dysfunction or relationship dysfunction are primary or secondary effects of inadequate metabolic control.

Diabetes causes diminution in the vitality that might assist people to feel buoyant about managing the challenges of diet and exercise, and they are - especially NIDDMs - often overweight (Bradley, 1994c). Thus the barriers that are present for the "normal" population are possibly much greater for the diabetic. Also, since obesity impacts, not only on self-esteem - especially for women (Kolotkin et al., 1995) - but on morbidity, and since diabetics struggle against other biomedical barriers to healthy bodies, the impact on this aspect of quality of life is considerable.

Helz and Templeton (1990) and Bradley (1994c) consider the psychological factors which are important to consider in diabetes, and suggest there is more to the management of diabetes than metabolic control, and more suffering among diabetics than may be immediately apparent. While careful to acknowledge the wisdom of good metabolic control, they treat psychological factors as important in their own right and provide a glimpse into the information which is elucidated in the few qualitative studies of diabetes (see Lang, 1989, Scott & Palasti Brown, 1989, and Roberson, 1992).

As has already been noted, the DCCT study established a benchmark for research in diabetes by running a study of IDDM

diabetics over several years, seeking to assess a number of variables thought to be significant in health behaviour. The sub-scales they developed assessed a range of psychological, behavioural, and emotional responses to diabetes, as well as its impact on the people's lives. They acknowledged the lack of a "gold standard" to assess the validity of the measures as denoting this elusive thing called quality of life, but concluded that on the whole the people in their sample were "*generally satisfied and not worried and that diabetes made only a modest impact on their lives*" (p. 728). Their research is significant, in that it established conclusively a link between "tight control" and subsequent avoidance of diabetic complications, and is cited as the standard for clinical practice in many papers on the subject.

However, in marked contrast to the DCCT study's findings about quality of life is that of Scott and Palasti Brown (1989). Their case studies of New Zealand diabetics reveal the degree to which diabetes haunts the lives of its' victims. Indeed, this research indicated with compelling detail that many diabetics soldier on against quite daunting odds and that even those who disregard treatment objectives are usually well-informed about the nature of the consequences. Lang's (1989) study of Dakota Indians afflicted with NIDDM echoes many of the findings of the Scott and Palasti-Brown study, showing that diabetics suffer considerable anxiety, and that their illness is a day-to-day source of irritation, obstruction and, often, despair. The people who were documented in these case

studies were aware of the agendas of their medical advisors, and chose to follow them, or not, in their own way.

What begins to become apparent from the research is that there are remarkable similarities in the perceptions of both IDDM and NIDDM patients, which is that good metabolic control (from a medical standpoint) is so difficult to achieve that it often becomes sidelined and that diabetics divert their anxieties about metabolic control via a range of cognitive-behavioural strategies which enable them to enhance their quality of life. Denied the possibility of cure, the diabetic is left with options about amelioration of 'necessary evils', of maximising pleasurable experiences, and of being as well as possible under the circumstances.

This paper will focus on three of the variables which are thought to influence quality of life in a direct and personal way: risk perception, control and self-efficacy: **risk perception**, because it yields information on people's ability to accurately gauge and adjust to risk factors in their life and is thought to be linked to the notion of self-efficacy (Schwarzer, 1995); **control**, because it is the most compelling clinical variable in treatment objectives, and may extend the notion of personal agency raised by self-efficacy research, and **self-efficacy**, because it relates to how people think, feel, make decisions about, and value themselves.

Risk Perceptions

Risk perception is the ability of the person to assess appropriately the degree to which their health/illness is likely to fall within the normative range, i.e. by comparing themselves to others of their own sex and age for a particular characteristic, and as a corollary, accepting the degree to which their illness predisposes them to risk or threat. Risks for the diabetic include the development of complications: disorders of the eye, circulation, kidneys; risks of stroke, heart attack, or early death. The ability to continue to carry out diet and exercise regimens against considerable barriers is a challenge for the diabetic, and is predicted to be enhanced by an accurate perception of risk, coupled with adequate perceived competence to overcome the barriers. People who hold a realistic view of their vulnerability to disease or illness, and who are prepared to take the necessary steps to avoid or mitigate against the likelihood, are more likely to be amenable to education and behavioural change (Kreuter & Strecher, 1995, Schiaffino & Revenson, 1995, Schwarzer, 1995, Weinstein & Klein, 1995).

Accuracy of risk perception requires considerable psychological adjustment (Bandura, 1992). People will, on the whole, view themselves optimistically, and are reluctant to perceive threat (Millar & Millar, 1995). For example, Brownlee (1991) looked at the notion of personal responsibility in general health behaviours in the American population, and found a staggering 93% of people nationally surveyed by Gallup Poll answered 'yes' to the question

“if I take the right actions I can stay healthy”. A corollary of Brownlee’s (1991) study into health responsibility was the implication that bad health was caused by irresponsible behaviour. People are anxious about maintaining the face of responsible behaviour by exercising and dieting, often to excess, and being intolerant of those who do not. Brownlee noted that the quest for the perfect physical body was a preoccupation for many, rather than a genuine desire for reducing risk of illness. She concluded that while good personal control could be beneficial to good health, it depended a good deal on how great a discrepancy there was between perceived control and reality. If perceived control lead to unrealistic beliefs, then the person could be locked into denial. This conception will be discussed in greater detail in the next section.

These unrealistic beliefs concord with Schwarzer’s defensive optimism (1995) where most people underestimate the actual barriers to achieving a goal, and thus do not - and are not really prepared to - undertake the necessary steps to secure the goal.

Millar and Millar (1995) found that people used cognitive appraisal strategies, in part, to avoid catastrophising about illness and to remain rational about suspected problems. The mechanism by which this occurs seems to be that negative affective responses occur when the risk is accurately perceived, and thoughts of illness or death loom. Accordingly, people employ cognitive-behavioural strategies to avoid depression. People who are mildly depressed tend to

exercise “depressive realism” (Schwarzer, 1994) wherein they more accurately assess their degree of control over positive and negative outcomes, than optimistically-biased people. Unfortunately, this ability to “see clearly” is usually accompanied by high anxiety, low self-esteem, poor self-efficacy and lack of motivation.

Weinstein and Klein (1995) investigated optimistic biases under several conditions and found two conditions under which people perceived risk accurately. The first was by being compelled to assess risk in item-by-item comparisons; the second was to have people rate themselves alongside attractive others who modelled precautionary actions or who demonstrated “risk-reducing characteristics”.

Accuracy of risk perception is thought to underlie genuine self-efficacy - the ability to perceive oneself as competent, despite barriers to action or self-regard. This is important, because self-efficacy may be fundamental to enhancing quality of life. Schwarzer’s (1994) overview of health-related cognitions outlines the precariousness of positive illusions which lead to defensive distortions, while demonstrating the utility of realistic appraisal of both risk and capability to handle that risk. On the whole, he argues, it is better for people to maintain moderately optimistic self-beliefs, because such a state of mind enhances motivation to adopt and retain adequate self-care behaviours. This will be discussed more fully in the section on self-efficacy.

There is a danger of excessive optimism interfering with perception of risk in relation to health. Kreuter and Strecher (1995) examined optimistic biases in patients with a range of illnesses, and found that people were less vigilant in denial, but were able to be taught health-enhancing behaviours by offering them modelling of the precautionary actions of others. Conversely, there may be a relationship between failure to accept the chronicity of a condition, and a tendency towards self-focus and rumination (“why me?”) in a helpless and dejected way. This can contribute towards ongoing depressed mood, helplessness, reduced coping efforts and feelings of loss of control (Schiaffino & Revenson, 1995).

Diabetics do not, in the main, appear to be guided directly by perception of risk. Scott and Palasti Brown (1989) document the case studies of several people living life in flamboyant disregard of the consequences. One can conjecture that human beings seek freedom from fear, and that illness precipitates fear. Diabetics lack of adherence to treatment objectives may represent in some as yet unknown way a choice to sideline the issues of the threat of diabetes, (perhaps by idiosyncratic definitions of acceptable metabolic control) so that they can get on with the business of living their lives to the fullest. After all, in ego defense terms, optimism is a desirable adaptive response of a healthy psyche (Schwarzer, 1994). It is easy to see how each interruption for testing, each assessment of what food they can or cannot put in their mouths, each exercise period for “the good of their health”, each refusal of social

behaviours (drinking alcohol, staying out late, dessert at dinner), could become not just a bore, but a burden, and even worse, serve to remind them of the threat that they have to live with. As Naess put it: *“most people would say that they expect more from life than merely avoiding illness”* (p. 34).

People are able to learn healthy behaviours through an educative process which first establishes a person's vulnerability to risk, next compels him or her to accept or believe the risk is real, and then promotes self-efficacy to enable that person to be competent in dealing with ongoing situations (Schwarzer 1995). The challenge for treatment providers is to understand the components sufficiently well for them to be conveyed to their patients (Martin et al., 1994).

In diabetic terms, people may often feel inadequate especially if they are unable to motivate themselves to follow the kind of programmes which would enhance good metabolic control. Support, if it is to enhance quality of life, would need to be targeted, first, at helping to facilitate realistic perception of risk or harm, second, to bolster the diabetic's self-efficacy, and third, to assist in practical ways to support those changes in behaviour which reduced the risk of later complications (i.e. diet, exercise, and a relatively stress-free environment).

There are important implications in this research for control, and the arguments that separate this notion into its component parts - metabolic control, psychological control and its subsets of *perceived control*, *behavioural control* and *vicarious control* - will be discussed next.

Control

"People who consider themselves to be wise are often indecisive when command is called for and rebellious when they are called upon to obey." (Coelho, 1992, p.188).

The concept of control has a respectable history in psychological research, and it is instructive to look at some of the literature which defines it. Control is also the word used by diabetes clinicians in defining treatment objectives, especially as it relates to adherence/compliance factors, and this section will set out some of the studies which have been helpful in elucidating what "control" might mean to the diabetic. Self-efficacy and optimistic self-belief concepts also consider control to be central to their operation, so some of the ideas and arguments are interchangeable.

Control is developmental, cognitive, behavioural and emotional in composition, self-referent, flexible, and subject to environmental influence. People can achieve control then lose it, can perceive control without needing to test it, and can modify it altogether. It

appears that, just as they can learn control through experience and trial and error, people can also unlearn it through aversive experience, often with devastating effects on their quality of life.

Heckhausen and Schulz (1995) provide an overview of control across the human lifespan, and draw out some important points about its changing nature. They posit an analysis of control into **primary control** - which is outer-directed and describes the individual's attempts to transform the external environment to suit his or her own needs and wants: and **secondary control**, which is an internally-directed strategy to both enhance primary control and protect it from diminution. The second-order response both helps the person cope with failure of the primary response, and helps channel motivation into goal-directed behaviour. Secondary control, then, is elicited in response to failure, especially in individuals who are failure-prone; that is, it is compensatory behaviour. The authors hypothesise that secondary control develops with experience and maturity, and buffers self-esteem and well-being by eliciting better selection of tasks, and improving problem-solving and coping. They propose that effective secondary control often develops after a failure of bodily systems following middle life, and that "*when effective coping is delayed, the risk of negative outcomes increases*" (p. 298). Jointly they provide the person with a perception of risk or vulnerability in a given situation, and provide the cognitive-behavioural tools to deal with the situation.

Control has long been studied in attributional research, and identified as a psychological “locus” which can be described along a number of dimensions, e.g. internal/external, stable/variable, global/specific (Weiner, 1986). People’s retrospective assessment of their beliefs in control over themselves or their situations are able to be assigned accordingly (e.g. external/stable/specific). Attribution theory shares many points in common with self-efficacy theory, especially as it relates to dispositional optimism and behavioural self-regulation.

Florian and his colleagues (1995) in describing hardiness as a personality construct argue that it operates as a “resistance resource” in stressful life events. In their health research, they adopt from Kobasa (1979) three characteristics of hardiness: commitment, control and challenge, which appear to combine to produce enhanced appraisal and coping in stressful situations, a situation roughly analogous to self-efficacy. Indeed, they found that there was a predisposition towards low perceptions of threat, risk or harm in people who view themselves as hardy, efficacious copers, along with a tendency to actively look for challenges, assured of their own abilities to handle whatever came their way. Coping capabilities appear synonymous with “functional optimism” in promoting preventive health behaviours and risk avoidance in Schwarzer’s self-efficacy model.

Reduced control is a fundamental difficulty for the chronically ill, because of the range of dysfunction that is thought to flow from it. Schwarzer (1995) reports on several studies which have related cognition, health and immune responding, drawing from them evidence for helplessness and hopelessness leading to reduced efficacy and compromised immune status. Skinner (1992) points out that a sense of personal control implies order and predictability, and increases both motivation and competence, which, she argues, is why helplessness is so distressing. Furthermore, if a person struggles ineffectively to achieve a goal, without success, the failure will initiate bursts of striving which weaken the person and further contribute to anger, exhaustion and finally, disengagement from the striving behaviour, passivity, and disinterest.

Control, then, is central to psychological management when things go wrong. The indications are that a person's control is shaped by their experiences in life, and that some people form more robust notions of their competence to handle crises than others. There is also, however, the implication that people's control can continue to be enhanced, and that belief in and reliance upon one's ability to learn and maintain competence in disagreeable circumstances can be learned.

Metabolic Control and Adherence in Diabetes

For diabetics, failure to achieve diabetic control may take them through the entire gamut of the control repertoire on an unpredictable roller-coaster. Thus, even highly self-efficacious people may 'learn helplessness' when it comes to diabetic control. This may modify, mute, or perhaps even extend, their previously-held notion of self-efficacy, depending on the degree to which their personal perception of control is validated by their experience of diabetes.

Control (the metabolic kind) is, invariably, the word most used by medical staff, investigators and patients alike in discussions of treatment and management regimes, and is considered the most cogent factor in treatment decisions (DCCT, 1988, Bradley, 1994c). Therefore, any study of diabetes necessitates an investigation into control factors. The psychological notions of control just discussed provide an useful springboard into diabetic notions of control, in that they are concerned with responses to threat, with the mobilisation of cognitive and behavioural strategies for management, and with action.

Diabetes threatens the existence of the organism - it can lead to severe illness, and even death. However, the threat of death is rarely imminent for the diabetic, and there is some anecdotal evidence (Scott & Palasti Brown, 1989) to suggest that the psychological

mechanisms of denial, repression, and minimalisation operate on a largely unconscious level for these people, enabling them to engage in risky behaviours. When, as a result, they become ill, they may be reminded forcefully of the nature of this life-threatening illness, renew attempts to achieve good control, and the cycle begins again.

Helz and Templeton (1990) discuss the relation between family systems and control and note the influence of dysfunctional interpersonal relationships on the cycles of poor control in some diabetics, and also that ketoacidosis may be induced by stress alone. They argue for the need for greater emphasis on stress-reduction techniques and on family therapy, to enable vulnerable diabetics to manage their illness more effectively. Support from social networks, thought to enhance good metabolic control, appears to be an important variable in perceived quality of life (Griffith et al., 1990, Kvam & Lyons, 1991, Carroll et al., 1993).

It is possible to speculate a mechanism for diabetics whereby chronic failure to achieve the sort of metabolic control desired by their medical advisors - especially if accompanied by 'bodily systems failure' (Heckhausen & Schulz, 1995) - could lead to a lessening in attempts to achieve that level of control. An additional factor is the high ambiguity, whereby a diabetic 'does everything right', then tests the blood glucose, only to find it at an unacceptable level, and is at a loss to explain the result. Medical personnel tend to believe that the explanation lies in circumstances not disclosed by

the patient (Moore & Snell, 1995), but as Helz and Templeton (1990) note, the patient may sometimes be no wiser about the causes of their swings in blood glucose than the doctors or nurses.

Di Nicola and DiMatteo (1984) have estimated that about 40% of patients in the general medical population will not comply with treatment regimens, even when fully informed about the consequences of non-adherence. While specific data on diabetics' compliance is not known, there is no reason to assume they would have a higher compliance rate. In fact, since, as Di Matteo et al. (1993) found, adherence is difficult to obtain in areas where the patient is required to make the primary prevention efforts in their own health, or where major lifestyle changes are required of them, diabetes would possibly tend towards higher non-adherence rates.

Studies which are assessing strategies for improving adequacy of self-care are rarely able to offer much insight into adherence. Studies of coronary heart disease patients found a tendency for adherence results to be higher in clinical trials of drugs than the rates observed in clinical practice (Horwitz & Horwitz, 1993). Some of the randomised clinical trials mentioned by them reported an adherence rate of 80% or better in trials, a result which is substantially better than overall adherence rates (DiMatteo, et al., 1993). The Horwitz's research documents the discovery in some studies of manipulation of trial materials by subjects (e.g. pill-dumping, or doubling-up of pill-taking prior to clinic visits), and also comments on the "non-specific

effects” of potential alteration in subjects’ behaviour concurrent with participation in clinical trials, such as improved general health behaviours. This is a similar effect to the “Hawthorne effect” (Gray & Starke, 1988) of being selected for research participation. People are usually both willing to please the researchers, and eager to be able to contribute to research outcomes in a positive and useful way, although this effect is not usually cited as a possible explanation for increased adherence-effects in health psychology studies. Since the consequences of non-adherence are often very severe - as with diabetes - health professionals have a well-founded interest in investigating what factors seem most influential in establishing adherence.

Diabetics differ substantially in their adherence to both treatment and management regimens. (DCCT, 1988, Cox & Gonder-Frederick, 1989, Bradley, 1994c). Knowledge about the consequences of non-adherence does not appear to carry much weight with the chronic low-adherer (Scott & Palasti Brown, 1989, Goldston et al., 1995) and there are difficulties in determining the “true” rate of adherence, because of differing expectations of what constitutes “good” adherence. Cox and Gonder-Frederick (1989) prefer the construct “*adequacy of diabetes self-care behaviours*” (p. 629). An emergent theme in the literature is that adherence declines with age and duration of diabetes, but that acceptance of the illness and its effects improves.

Diabetes physicians and Diabetes Nurse Specialists spend considerable amounts of their working life educating their patients about the benefits of good control, while acknowledging their efforts are often futile, that their patients “cheat” on their self-testing, their diet, and their exercise, and that even the most disciplined “adherer” will often have periods of time of very poor control, because of factors beyond anyone’s “control” e.g. family crises, physical illness, and so on.

In essence, the responsibility for maintaining treatment objectives in diabetes is in the patients’ hands, and it is their choice to accept or reject the advice and health education they receive. Since diabetes is a 24-hour-a-day going concern, and resources do not permit a 24-hour-a-day clinical attendant, the diabetic is the obvious candidate to select his or her own therapeutic regimens. Self-care is not, therefore, just a politically-correct option based on empowerment philosophies, but an imperative for achievable treatment and management goals, governed by concern over the rising cost of primary health care, and - arguably, to a lesser extent - by the advent of new technologies that make self-care feasible (Eitel et al., 1995). Nevertheless, if diabetics decline to adhere to treatment, it may be the clinical staff who feel left with the burden of care - managing the consequences - of inadequate control, especially as they equate adherence with good treatment outcomes (Moore & Snell, 1995).

Bradley (1994), in reminding us of the findings of the DCCT study showing incontrovertible evidence that tight control reduces long-term complications (e.g. retinopathy) of diabetes, offers the view that as a result of the impact of the DCCT study, emphasis is on treatment and management regimes which provide the kind of scrupulous adherence as was achieved in the study. Nevertheless, she warns against offering treatment to diabetics which is so seriously inconveniencing to their day-to-day lives that they refuse to pay the psychological costs of adherence. She sensibly points out that "*diabetes [metabolic] control is just one - and not the most important one - of several important outcomes*" (p. 13). Her views are compelling and clearly argued, and it is difficult to understand why more attention has not been paid to her findings.

Vital to the maintenance of adequate control is exercise and diet, if done systematically, yet adherence to these non-clinical health regimens appears to be difficult to predict and assess (Lundman, et al., 1990). Further, these self-management behaviours alone are seldom sufficient to control diabetes.

Stress factors have been implicated in reducing levels of control and good psychosocial adjustment for increasing them (Scott & Palasti Brown, 1989, Rapley, 1990). Rapley concluded:

Diabetics need to believe that metabolic control is necessary for their short and long-term wellbeing. Concomitant to this belief there needs to be a sense of control over the situation,

*willingness to change possibly long-standing habits in relation to food and/or exercise and **an efficacy expectation, that is, a belief in one's ability to implement the required treatment regimen.*** (Rapley, 1990, p. 45, emphasis added).

Of interest here is Mayou, Bryant and Turner's (1990) findings that poor control was significant in respect of physical factors for the person (i.e. lack of vigour and fatigue), but not overall to mood. This may give one explanation for the variable picture of control which emerges from the research - that is, it is not an emotionally significant factor for the diabetes sufferers **themselves**. Another explanation may link back to the notions of psychological control and the circumstances which change it, especially in respect of "secondary" control (Heckhausen & Schulz, 1995); that is, that having tried - perhaps repeatedly - to achieve satisfactory metabolic control, and failed, or succeeded only partially, the diabetic person sidelines metabolic control in favour of retaining their perceived self-efficacy levels. While highly speculative, this hypothesis may offer an explanation for the relative unimportance diabetics themselves place on diabetic control, compared with the agendas of their medical advisors.

Roberson's (1992) study into patients' own interpretation of the meaning of compliance reveals some useful insights. Her study showed that patients had their own, highly idiosyncratic, methods for managing their treatment regimens, which they thought were effective **for them**, and which they described as at least partially

compliant with their health professionals' advice. Lang's (1989) study of Dakota Indians concurs. The respondents in her sample gave rich and complex narratives of their understandings of diabetes; how and why they had got it, what worked and did not work to control it, and what they were prepared to do to manage it themselves. She says:

these beliefs and ideas are not 'static' realities, but ongoing deliberations that range over a different "ground" than the more familiar biomedical aspects of an illness. (p. 320).

Lundman, et al.'s (1990) sample of IDDMs, on the whole, were only marginally-adherent about self-monitoring (1-3 times a week) and felt that the constant and painstaking adjustments of insulin, diet and "regularity" were detrimental to psychological feelings of well-being, in that they produced feelings of dependence and lack of freedom. They appeared to prefer the vagaries of irregular control to the exacting disciplines of glucose monitoring, so long as they maintained a feeling of freedom and independence. This relates to the person's perception of quality of life, towards which this present study is directed.

Carey et al. (1991) found only a moderate correlation between their scale of diabetes appraisals, and adherence, (which is supposed to foster good control) but could not say whether poor diabetic control is responsible for negative appraisal or vice versa. (This is a common problem in multifactorial research, where correlation is

found between two or more sets of variables, but the direction of the effect is unclear). However, Goldston et al. (1995) examined the direction of effect in young IDDM patients and concluded that negativity caused poor control, not vice versa.

Di Matteo et al. (1993) carried out an investigation into the characteristics of physicians which impact on patient adherence, as part of a medical outcomes study. They found that communication style was especially important in engaging patients' attention to the advice and instructions they were given, in asking questions of their patients, and in being prepared to clarify areas of potential misunderstanding. They concluded there was still much work to be done in bridging the gap between health providers and patients in regard to treatment.

This last point may provide an insight into perhaps the greatest difficulty of all in discussing any notion of metabolic control - the lack of trust or confidence between the treatment providers and the patients in diabetes. After all, adherence (or compliance) is the extent to which people's behaviour is consistent with **medical or health advice**. The diabetics themselves are unlikely to generate either the notion or the terminology without input from the providers. Thus, metabolic control is a biomedical construct which is imposed on the diabetic, a new language which they are expected to learn, and in which they are expected to be immediately conversant. It

should not surprise anyone therefore, that there are failures in both communication and comprehension.

Horwitz and Horwitz (1993), noted:

If treatment were effective, we would expect patients who adhere to do better than those who do not adhere...one of the most startling observations of the past 10 years is how often this simple expectation does not occur" (Horwitz & Horwitz, 1993, P. 1).

From a medical viewpoint, therefore, it is clear that adherence and effective treatment are equated, whereas from the patients' viewpoint, it may be an alien construct which they understand imperfectly and - more importantly perhaps - do not agree with.

Taylor et. al (1991) argues the notion of *vicarious control* whereby sufferers from chronic illness may invest beliefs that powerful others (the medical staff) are able to intervene successfully in ameliorating illness effects. While it is easy to see how this might apply in medical situations where these powerful others are able to apply treatments which have a direct effect on feelings of wellness (via drug therapy, surgery, dialysis, and so on), it is unlikely to operate in the same way in diabetic management, because it is the diabetics themselves who handle most of their own treatment needs. Possibly the diabetic would prefer it to be otherwise, and Kaplan (1991) argues that patient preferences ought always to be considered in

treatment decisions, as a means of enhancing autonomy. He notes that patients will utilise a range of strategies for achieving this autonomy, even if it means disregarding prescribed medical regimens.

Eitel et al.'s (1995) study of chronically-ill persons argues that there is a vast difference between *perceived control* and "real" (behavioural) control. They found that notions of control changed with increasing severity of illness, and that severely ill persons were adversely affected in psychological terms if they were made responsible for their own treatment.

Eisenberg (1977) noted that as early as 1910, physicians in the United States were following the Cartesian duality model (proposing a mind/body split in operational terms), and developed:

working models of the disease process [which] determine the data that physicians gather, determine the ways in which 'facts' are integrated into a diagnosis, and circumscribe the boundaries of intervention designated as therapeutic (p. 10).

There is not a great deal of evidence that the 'medical model' has substantially changed, good intentions notwithstanding. In other words, as long as the authority for treatment decisions rests with medical staff, people are likely to feel disempowered whatever the decision. Having the technology to support self-care may be no better an argument for imposing it than the one about having the

technology for keeping braindead people alive being a sufficient rationale for doing so.

Even the DCCT study (1988) acknowledges the importance of *“increasing provider understanding of the patient’s perspective”* (p. 731), but so far, there appears no research into the methods or means of securing this co-operative stance. It would appear that the move needs to come from the medical and nursing professions, given that they are the “powerful others” - the holders of knowledge and gatekeepers of access into the treatment-arena of diabetes. The literature seems to suggest that diabetes health care providers acknowledge the need to share this power. The difficulty seems to be that they have simply attempted to transfer it to the patient, with mixed results.

Self-Efficacy

Self-efficacy is a ongoing psychological activity which is both pre-emptive AND mediating or moderating of activity. It concerns itself both with what one achieves, and also - and just as importantly - with what one **expects** to achieve. Thus a person may look at an anticipated choice or action and select whether and how to do it based on their self-knowledge, as well as their experience of their handling of similar past situations. Self-efficacy is able to operate on both intrapsychic and functional processes, apparently creating a climate in the person whereby they view life optimistically, have a

tendency to view difficulties as challenges, and most importantly of all, have confidence in their ability to deal with whatever comes their way.

Self-efficacy was outlined and described by Albert Bandura as early as 1977. He believed that a person's efficacy beliefs affected not only their choice of activities (behaviour), but also their expenditure of effort and the degree of persistence they were willing to exert in the activity. He noted that people's self-beliefs guided their selection of tasks, influenced the degree of specificity and difficulty they were willing to undertake to complete the task, and even influenced the person's expectations about task outcomes. He went on to describe how self-efficacy operates in aversive situations to reduce autonomic arousal, by providing the person with a sense of predictability and control, thereby eliminating or reducing a stress reaction (Bandura, 1982).

Bandura's theory seeks to explain why behaviour will take, or have taken, place. It is a predictive tool of both choice and perseverance behaviour.

There is an important distinction between this and cause-seeking, which is an end-point (retrospective) psychological activity, related to consequences, explanations, and the assignment of responsibility (Weiner, 1986). That is, it occurs after a choice-point has been

reached, or a behaviour completed. People are then able to look back at their behaviour and thoughts and say “I did this or that **because...**”. As we have seen in the section on Control, Weiner’s attribution model is based on these notions.

This expectation/anticipation basis of psychological coping has been shown to bolster resilience, increase endeavour, and facilitate repeated attempts at a goal (Toobert & Glasgow, 1991). Low expectations of success appear to mitigate against even making an attempt, and certainly, against repeat attempts following initial failure.

Self-efficacy can be seen as a mediator of the person’s achievement of healthy goals, and can operate in several different ways, and at several different stages of behaviour. For example, *Resistance Self-Efficacy* is the ability for a person to avoid risky behaviours from the beginning: *Harm-Reduction Self-Efficacy* enables a person to have the confidence to be self-regulating in tempting situations: *Action Self-Efficacy* denotes the person’s ability to take behavioural steps to resist, regulate or abstain from risky or tempting situations and activities: and *Coping Self-Efficacy* activates the person’s ability to deal with crises. Finally, *Recovery Self-Efficacy* is the person’s ability to incorporate stable and sustaining health behaviours into their day-to-day repertoire (Marlatt et al., 1995, Schwarzer, 1995).

Few clinical studies utilising self-efficacy provide a critical analysis of the typology, possibly because it provides a construct, or abstract “map” of strategies which are complex and often overlapping cognitions and behaviours, and may have been thought to not much matter in research terms at which self-efficacious point the person in locating themselves. This may be especially true when tested against other global trait measures in validity and reliability studies. The circumstances specific to the research context are probably more important than arguing particularity of stages. Schwarzer (1993) offers a useful context in providing an analysis of the measures against which his self-efficacy scales have been compared. For example, he has tested them against scales measuring anxiety, depression, optimism, curiosity, and so on, and has found good validation in most cases. This issue ought to be further explored in applied settings. Schwarzer (1992, 1993, 1995) cogently points out that understanding **which** particular strategy a person is utilising at a particular point in their self-management behaviours enables the provision of much more stream-lined assistance at that time.

Self-Efficacy in Health Research

Most people would believe they were able to handle one-off stressful events, even a chain of stressful events, or a period of stress which was necessary to endure in order to achieve some goal (training for a sports event, studying for exams, recovering from an operation). Human beings are “wired” for coping with shocking and

unexpected events, and there is a vast body of literature which addresses itself to how the physiology of the human body mobilises to deal with pain, infection, and so on. What seems less clear is how these mechanisms alter to deal with ongoing difficulties, and especially the interaction between mind and body that assesses and selects strategies for coping with chronic conditions. These may include adjusting to pain that will not go away, or needing to overcome instinctual barriers against self-infliction of pain (injecting the body with needles, exercising on painful limbs, pounding the body to discharge excess mucous, and so on). It could also mean pushing the body to exercise against overwhelming fatigue, or routinely swallowing unpalatable medicine. And these behaviours may still not “cure” the body, or worse, fail to stem the tide of encroaching morbidities or progressive deterioration.

Both coping and recovery self-efficacy would appear to be activated after a crisis or stress point has been reached. In this respect, they may be seen as qualitatively different from other forms of self-efficacy, and it is in this area that there is a need for clear analysis of both how people think, and what they actually do, and why.

Schwarzer examined people’s sense of competence in several settings, and found it related to “*better health, higher achievement, and more social integration*” (1993, p.1). He developed a scale of generalised self-efficacy, as well as several scales for situation-specific self-efficacy in relation to cigarette-smoking, physical exercise, safe-sex practices, cancer screening, helping (care-giving),

and healthy eating. Perusal of these categories will immediately highlight those areas which overlap with treatment objectives for diabetics: that is, healthy eating, exercise, and self-care practices.

Kavanagh, in conjunction with others, (Kavanagh & Wilson, 1989, Sitharthan & Kavanagh, 1990, Kavanagh et al., 1993) has also investigated self-efficacy in relation to substance abuse, and to depression, and people's ability to manage or control their behaviour, and found a general utility of application. Drawing on such research, Schwarzer (1995) mentions a range of applications manipulating self-efficacy in treatment facilities, relating to smoking cessation, and alcohol restriction. He has comprehensively studied research which details the way people think and feel about their health, for example, Scheier and Carver's Dispositional Optimism (1985), Becker and Rosenstock's Health Belief Model (1987), Ajzen's Theory of Reasoned Action (1988) and Maddux and Roger's Protection Motivation Theory (1983), among others. He argues that Bandura's "key construct" (i.e. self-efficacy) has become incorporated into all major models of health behaviour change.

Unpacking self-efficacy to see how it works in health psychology practice has led to studies of people suffering from hypertension, renal disease, rheumatoid arthritis, coronary heart disease and cancer. (Scheier & Carver, 1985, O'Leary et al., 1988, Ewart, C.K. 1992, Schwarzer, 1992, Thompson et al., 1993). Kaplan, et. al. (1994) studied survival rates of people suffering from chronic

obstructive pulmonary disease, and the factors that appeared to enhance survival. In these studies, people's own assessment and report of their efficacy "expectations" were a significant single predictor for survival, reduced pain, and generally enhanced quality of life.

In essence, a person must go through two basic stages to achieve effective behaviour change: a motivation stage, and a volition stage (see Schwarzer, 1992, 1994, 1995, for a comprehensive explanation). He argues that self-efficacy plays a major part in all stages, including the sub-stages of volition, which he further describes as planning, action, and maintenance. A person has to go through a process of contemplation early in the motivation stage, often prolonged, before they will move into action. During this stage the pros and cons, outcomes, and consequences will all be weighed. Once a decision to act has been reached, there is still a way to go before it actually happens. In the volition stage, people tend to have a ruminating phase between intention and action, during which plans are made. This is a crucial process, because if a person decides they are incapable of achieving the desired task, they will fail to adopt it, or - perhaps more importantly in diabetes - fail to maintain it.

The severity of the threat can - but does not always - promote risk perceptions that are sufficiently accurate to provide motivation to change. The person must not only perceive the risk, they must also perceive **themselves** to be vulnerable to the risk (that it is not just

something that happens to other people). This may precipitate the process of contemplation early in the motivational stage. If it does not, the person may need assistance in adopting realistic beliefs about harm - for example, utilising the approaches tested experimentally by Weinstein and Klein (1995). Other approaches in applied settings have presented people with gradated levels of a risky situation (e.g. alcohol-related settings) and asked them to self-select at which level they would be able to maintain their decision to abstain (Sitharthan & Kavanagh, 1990). This helps them assess their expectancies about outcome. As Schwarzer points out,

subsequent performance then represents a successful outcome of cognitive activities in the planning and preparation stage (1995, p. 30).

The motivation stage requires the person to make an informed choice about changing their behaviour. It requires decisions to be made. Schwarzer tells us that self-efficacy and outcome expectancies are the most reliable predictors of intention, and are correlated. Outcome expectancies are the mechanisms by which people will work towards a goal as long as they believe it is achievable and within their power to attain (Scheier & Carver, 1985). However, self-efficacy may be able to stand alone as a predictive tool of behaviour, even if a person has little idea about what to expect. Thus, even in situations with high ambiguity, a highly self-efficacious person is likely to perceive themselves as competent, is more likely to 'keep their options open' regarding the need for ongoing self-reflexive learning, and is less likely to sink

into despair, hostility or fatalism (Taylor et al., 1991, Kavanagh et al., 1993, Kaplan et al., 1994, Schwarzer, 1995). Just as importantly, they are able to employ coping self-efficacy and recovery self-efficacy during and after a crisis. This has important implications for diabetes self-management, which is fraught with ambiguities, and which can cause intermittent health crises.

In general, perceived self-efficacy is accepted as a robust and useful measure in health management. It can be assessed via test instruments, and is able to function as a predictive tool for both intention and action in initiating and maintaining adaptive health behaviours.

Self-Efficacy in Diabetes

As we have seen, diabetes affects the human organism in complex ways, altering the physiological functioning and requiring adjustments to strictly prescribed patterns of diet, exercise and medication. It can also produce sudden and unexpected shocks in the form of “hypos”, or simply via the unforeseen alteration in blood glucose which may throw the diabetic into disarray. It would be useful, then, for a person who develops diabetes to be armed with resilient psychological resources, or for them to be able to develop the resources.

Kavanagh et al., (1993) showed self-efficacy to be a significant predictor of adherence in diabetes. They discovered that previous levels of self-reported adherence in diabetic patients was not predictive of current levels of adherence but that self-efficacy was the most powerful single predictor in diet and exercise regimes over an 8-week period, even though the number of physical complications increased during the course of the study. This supports Bandura's (1982) work which suggests that high self-efficacy bolsters people's feelings of perceived control, and supports their view that they can handle the difficulties they are facing, like the development of physical complications. It lends support to the hypothesis that it is the **self-efficacy perception** that is important, rather than diabetic control. Kavanagh and his colleagues concluded:

Self-efficacy judgements allow the person to assess a wide range of information they consider relevant to their past adherence and to predict changes in the situation, in their skills, or in their effort that may be related to their adherence in the future. (p. 520)

Toobert & Glasgow (1991) studied diabetic patients using a problem-solving design. While the terminology differs, they appear to be describing an aspect of problem-solving that resembles self-efficacy in promoting a sense of competence. They found that patients who took insulin and who had diabetes for a longer period of time were more likely to utilise behavioural strategies. They found little predictive value for self-care strategies based on patient characteristics (personality factors, environmental factors, etc.), but noted that:

cognitive strategies were better predictors of exercise and glucose-testing, which may require a high level of motivating self-statements for long-term adherence (p. 82).

This reflects Lundman et al,'s (1990) study of IDDM patients, where long-term chronicity appeared to enhance acceptance of illness, coupled with optimism. Perhaps most people would be able to attain this matter-of-fact attitude and generate practical management strategies if they had sufficient time in which to do so. The problem with diabetes is that immediate or short-term behavioural regimens can allow the tissue deterioration which may give rise to later diabetic complications. In other words, diabetics may just not have enough time. The challenge for health workers is to persuade diabetics **early** in the onset of their illness about the risks, provide support during the transition to acceptance, and promote the adoption of adequate health management behaviours before tissue damage occurs.

Behavioural change is difficult even for the normatively well. On the whole, people will change only if the costs of changing are less than the costs of remaining the same. In early-stage NIDDM, a person may not have symptoms which disturb their equilibrium sufficiently to enable him or her to perceive risk. And IDDMs are likely to feel so much better after being put on insulin, that they are tempted to believe that the problem is solved. Furthermore, doing nothing is habit-forming. Adopting dietary change and exercise regimens - especially if one is accustomed to sweet and fatty foods, and a

minimal-exertion lifestyle - is problematic. Bradley (1994) has discussed the difficulty for NIDDMs to change eating habits and patterns, and argues for the development of modules for clinicians, which would enable the patient to self-select into the intervention programme most pertinent to their current needs. Schwarzer's (1993) measurements for assessing situation-specific self-efficacy would appear to be a useful clinical tool for adaptation to diabetes treatment, not only for dietary concerns, but also for the development of appropriate exercise regimens, and those management requirements with high nuisance-value, like finger-prick tests and insulin injections.

Carey et al. (1991) developed the appraisal of diabetes scale, a brief instrument designed to assess people's ability to self-appraise their diabetic illness. They were particularly interested in the relation between stress and glucose metabolism in diabetes, and were of the view that accurate self-appraisals were likely to influence both morale and psychological adjustment to the illness, as well as enhance adherence to the treatment regimens. They argued that it is difficult to find any relationship between blood glucose levels and self-appraisal, because of the complex factors which impact on blood glucose. Like Bradley (1994c), they perceived the need for adequate clinical tools for assessing the factors which are most likely to improve diabetic's management of their illness.

It appears there is general agreement that people who feel efficacious and are able to successfully utilise a blend of cognitive and behavioural strategies for managing their diabetes, are less likely to suffer psychosocial distress as a result of their illness, and more likely to attempt to comply either partially or fully with prescribed management and treatment regimens.

The Current Study

The clinical picture which emerges from the above summary of research material is less clear. The evidence seems to indicate that self-beliefs are not a consistent or reliable indicator of actual medical status, as revealed by blood assay, the worsening of the diabetic condition or of the development of complications. It may be that quality of life is so singular a construct that attempting to correlate biomedical variables with those variables that are thought to impact qualitatively, is at best clumsy, and at worst, mutually incompatible. Nevertheless, as long as the political imperatives which drive medical policy-making concentrate on biomedically-derived curative and ameliorative aspects of treatment objectives, rather than cognitive-affective or psychosocial aspects, researchers are virtually compelled to consider the two sets of variables side by side. The advantage of doing so is, of course, that the features of quality of life declare themselves more and more fully in analysis, and contribute to the growing body of knowledge about the construct. That is one of the purposes of this study.

Aims

This study seeks to determine the degree to which people with diabetes achieve a satisfactory quality of life. To do this, information will be sought about the degree to which illness impacts on their lives. An attempt will be made to discover their perception of their illness, the nature of control they perceive themselves to have, and whether they feel they are managing their illness adequately. The effect diabetes has on their wellbeing will also be looked at.

This study will be carried out as part of a continuing wider study. Specific items from the test instruments utilised in the collaborative study will be selected according to their pertinence to the aims of this portion of the research. The questionnaire in its entirety appears as Appendix B. The areas of interest for this study are as follows:

- (a) *demographics and biographics.*
- (b) *general self-efficacy* (Schwarzer, 1993): a 10-item scale designed to elicit people's perception of their ability to be competent in both planned and unplanned tasks, each presenting an imagined challenge or barrier;
- (c) *diabetes-specific self-efficacy*: a 6-item scale representing barriers common to the diabetic experience, which has been designed for this study;

- (d) *personal and metabolic control*: a 7-item diabetes illness appraisal scale designed by Carey et al. (1991);
- (e) *diabetes-specific risk perception*: a 6-item scale generated to assess diabetics' awareness of the complications (risks) specific to diabetes;
- (f) *diabetes awareness*: a 4-item scale to elicit perceived seriousness, severity, and cognitions about treatment and cure;
- (g) *illness acceptance and resolution*: a selection of items from Scheier et al.'s (1985) coping strategies scale, focusing on realistic acceptance of illness and the ability to look ahead;
- (h) *wellbeing and diabetes-specific wellbeing*: two scales created by Bradley (1994a) to assess general cognitive-affective wellbeing (22 items), and wellbeing within the experience of diabetes (6 items);
- (i) *aids to self-management*: a grouping of 5 items designed for this study to attempt to access information about desired treatment or resources, and to provide an avenue for qualitative input from the sample.

One aspect of this study will be to argue that metabolic control may be sidelined in order to enhance quality of life, so an attempt will be

made to compare respondents' perception of control with metabolic control, as assessed by blood glucose assay. Information will be sought from our medical collaborators on type and duration of diabetes, blood glucose levels, and diabetic complications.

The study will investigate both IDDMs and NIDDMs. It was thought important to include both groups because, while the onset of their diabetes is different, the impact it has on their lives would appear to be similar. Furthermore, many NIDDMs begin managing their illness with diet and exercise, progress to tablets, and finally become insulin-dependent. IDDMs are insulin-dependent from early on, but need to learn how to self-inject, and also have to watch their diet and exercise during their lifetime. Both groups have to self-monitor their blood glucose.

Method

The research measures chosen invite people to self-select their responses through a questionnaire. How people rate their own health is important to discover, because some people regard themselves as well, despite severe symptoms of illness, while others feel ill, without any or much discernable organic evidence (Ware & Sherbourne, 1992).

The study's medical collaborators were provided with 220 questionnaires, of which 99 were returned within the time allowed for this portion of the study. Thirty-five of these were from IDDM patients, and remaining 64 from NIDDMs (35.4 and 64.6% respectively).

Sample

Participants were selected from two groups of outpatients from the Diabetes Lifestyle Centre (DLSC) and the Diabetes Clinic at Palmerston North Hospital. To be eligible, patients had to be aged 18 years or older, have been diagnosed for one year or longer, have no existing comorbidity, and be self-monitoring of their blood glucose level. Selection was carried out by the DLSC and Diabetes Clinic staff from their records, and identities were known only to them at intake.

Procedure

All NIDDMs were first contacted by telephone by a Diabetic Nurse Specialist familiar with the patients, to determine willingness to participate, while emphasising the voluntary nature of the study. IDDMs were informed of the study when they attended the Clinic.

A package containing an information sheet, consent form and questionnaire was mailed to NIDDMs, and handed to IDDMs when they attended the Clinic for their check-ups. Medical staff also

sought current-status information about glycaemic control by asking those who agreed to take part to attend a laboratory for a blood test. Included in the study was information collected from patient files at DLSC and the Clinic relating to age at onset of diabetes, prescribed treatment regimen and history, presence and severity of complications. This information was elicited and number-coded by medical staff, and was not available to anyone outside the Clinic or the DLSC.

Demographics and Biographics

The demographic and biographic data gathered showed a skew towards an older age group, with low educational attainment; 34 (35.4%) indicated **no** educational attainment. Since the geographic area is not a socioeconomically-depressed area, the low educational level is perplexing. Most of the sample were born after 1925, which means they had access to the free education system promoted in New Zealand following the Second World War. Perhaps the missing data would provide an explanation.

The age range for the sample was 23 - 82 years, NIDDMs, $M = 64.9$; $SD = 9.57$ and IDDMs $M = 48.6$; $SD = 18.26$. The skew towards an older sample may be explained by the preponderance of NIDDMs, whose illness onset tends to be at middle-age or later.

There were 49 male respondents and 48 female (50.5% and 49.5%, respectively) The majority (79) were married, or widowed (81.4%), with only 6 (6.2%) divorced or separated (the remainder were unmarried). This indicates a stability in relationship greater than that found in the general population, and is perhaps surprising considering the research literature on relationship stress in diabetes. However, the overrepresentation of NIDDMs in the sample, whose diabetes onset is generally past middle-age may account in part for these findings, in that they had time prior to diabetes onset to establish a stable relationship, unaffected by diabetes.

Ninety percent were of European ethnicity. Maori are known to be overrepresented in the diabetic population, so we can only conclude that either Maori were not adequately selected, were not represented in the clinic populations, or failed to return the questionnaires.

Respondents did not appear overall to be obese, although there were some extreme outliers. Since it is commonplace for diabetics to struggle for weight control, these results were atypical. They may account, however, for the low incidence of "hypos" in the sample, as hypoglycaemic episodes are less likely to occur in people who are careful about their diet.

Medication

Of the sample, 50 (55.6%) were taking some form of oral medication, which leaves a substantial percentage who were not. The duration of time on tablets ranged from 6 months to 25 years. There were 36 (36.4%) claiming insulin use, indicating that one person who was identified by the DLSC as a NIDDM had in fact made the transition to insulin.

Overall, 78 (86.7%) claimed to be using diet as a treatment form, which may account for (a) the low dependence on medication and (b) the low incidence of “hypos”. This was especially interesting in its implications for metabolic control, because 78 people (82.1%) had not experienced a “hypo” in the past year, possibly demonstrating the effectiveness of diet in diabetes. However, since the question was framed specifically only for severe “hypos” (which had required assistance from another person), it is unlikely to accurately reflect the less severe episodes which the person can manage themselves. There is a consistency of response when looking at the item concerning “hypos” over the past week: 77 (80.2%) answered ‘no’ to that as well.

Blood glucose levels were adequate overall. Eighty-three laboratory samples were gathered, of which 67 (84%) were within the normal HbA₁C range (5.2 -7.9%, $M = 7.50$, $SD = 1.76$). This rate of normal blood glucose results is high for a sample of this kind, perhaps

indicating that people who were conscientious about their self-care regimens were more likely to complete and return the questionnaires, or that the treatment objectives of the providers were being realised to an laudable degree.

Results

Self-Efficacy

Sex and education-level were correlated with generalised self-efficacy and the diabetes-specific self-efficacy scale to see if sex and/or education had a variable impact on self-efficacy. There was no difference between males and females, and age appeared not to impact, which accords with findings from other populations (see Schwarzer, 1993, for a discussion of these and other psychometric variables).

There was a moderate correlation between general self-efficacy and diabetes self-efficacy ($r = .53$) The overall sample mean for self-efficacy was $M = 31.80$ ($SD = 3.94$) out of a possible 40 total score, indicating a high level of perceived self-efficacy. Diabetes self-efficacy was similarly good ($M = 18.76$, $SD = 3.32$) out of a possible 24 total score. The overall alpha for self-efficacy was excellent ($\alpha = .83$) although one question skewed the alpha: it was Item#2 "*If someone opposes me, I can find means and ways to get what I want*", indicating perhaps that this sample overall was not particularly competitive, or at least, not assertive. The alpha for

diabetes self-efficacy was somewhat less robust ($\alpha = .65$), and it is noteworthy that the specific items reducing the overall consistency were the three items relating to diet, exercise and metabolic control.

Risk Perceptions, Illness Appraisals and Control

Carey et al.'s (1991) illness appraisals were correlated with self-efficacy, diabetes self-efficacy, and risk perception to assess whether these people's self-efficacy took into account a realistic perception of risk and of illness threats. Correlation coefficients for these variables appear in Table 1.

Table 1. Pearson correlations of Self-Efficacy, Diabetes Self-Efficacy, Appraisal of Diabetes & Risk Perceptions.

Variables	<i>DSelfEfficacy</i>	<i>App.Diabetes</i>	<i>Risk Perc.</i>
SelfEfficacy	0.56	0.29	-0.13
DSelfEfficacy		0.49	-0.11
App.Diabetes			-0.47

As can be seen, for both types of self-efficacy and illness appraisal, the effects, although moderate, were in a consistent direction. In other words, the higher the general self-efficacy, and diabetes self-efficacy, the more people tended to perceive the impact of their diabetes in a positive light. There was a negligible relationship between risk perception and diabetes self-efficacy, seeming to

indicate that people who felt competent to manage their diabetes did not tend to take risk into account.

Items 2 of the appraisal of diabetes scale, relating specifically to control appraisal was separated out and correlated with self-efficacy and diabetes self-efficacy. Both IDDMs and NIDDMs had a fairly good perception of control, and this had a low positive correlation with general self-efficacy ($r = .29$) and a good positive correlation with diabetes self-efficacy ($r = .50$).

The individual responses for “hypos” were correlated with their HbA_{1C} results and diabetes self-efficacy, self-efficacy, diabetes wellbeing, wellbeing, and the appraisal of diabetes item #2 (relating to control). Table 2 displays the relationships. A relationship between “hypos” and blood glucose levels was anticipated, but our analysis showed no consistent response at all. While overall the sample had remarkably good assay results, they did not merge in any meaningful way with any of the other data.

Table 2. Pearson correlations of Self-Efficacy, Diabetes Self-Efficacy, Wellbeing, Diabetes Wellbeing, “Control” (ADS Item 2) & HbA_{1C}.

Variables	<i>D</i> Selfefficacy	<i>Self</i> efficacy	<i>Well</i> being	<i>D</i> Wellbeing	HbA _{1C}
Control	0.51	0.29	0.52	0.34	-0.26
<i>D</i> Selfefficacy		0.59	0.43	0.35	-0.09
<i>Self</i> efficacy			0.42	0.14	-0.11
<i>Well</i> being				0.55	-0.12
<i>D</i> Wellbeing					-0.15

The six risk perception scores created for this study revealed that this sample had only a moderate overall perception of risk ($M = 28.7$, $SD = 9.8$) out of a possible 42 total score, despite the known direct link between diabetes and the development of these specific morbidities. The item was worded in such a way as to elicit respondents' own perception of risk. The two most accurately perceived diabetes-specific risks were problems with eyes and with circulation. On a 1-7 Likert scale, 58 respondents (58.6%) assessed themselves at high risk for eye problems, and 53 (53.5%) for circulation problems. For all other risk areas, less than half the sample considered themselves at high risk (i.e. indicated by circling 6 or 7 on the scale). It is possible that attention to eyes and circulation are emphasised by clinicians as an 'early-warning' risk area, or that they are the two areas of the body which are accessible to personal invigilation for damage.

When correlated with a scattering of items from various other instruments thought to assess similar constructs, the overall effect was similar. These included a DCCT item relating to perception of complications (*how often do you worry that you will get complications from your diabetes?*), an item created for this study relating to seriousness of diabetes, and a few items designed for this study relating to illness severity. All three areas were moderately positively correlated. Thus, understanding complications, the seriousness of the illness, and its potential severity were similarly

viewed by the respondents. If people thought their illness was serious then it more severely affected their life, and that if this were so, then they were less likely to perceive their diabetes as treatable or curable.

Two categories were selected from Carver et al.'s (1989) coping strategies scale ("acceptance" and "planning", four items in each category), relating in a general sense to acceptance of the reality of diabetes, and strategising. These were correlated with risk perception, self-efficacy and diabetes self-efficacy to see if they could illuminate the relationships between the variables (Table 3). The realism of risk perception may be anchored by a conscientious approach to self-care, and it was hoped the coping strategies items would draw out whether or not this was happening.

Table 3. Pearson correlations of Self-Efficacy, Diabetes Self-Efficacy, Risk Perceptions & "Acceptance" & "Planning".

Variables	<i>DSEfficacy</i>	<i>Risk Perc.</i>	<i>Accept</i>	<i>Plan</i>
SelfEfficacy	0.55	-0.09	0.22	0.46
DSEfficacy		-0.07	0.32	0.36
Risk Perc.			0.04	0.01
Accept				0.31

There was a good relationship between "planning" and self-efficacy, indicating perhaps that people's perceived self-efficacy was related to their belief in their ability to plan strategies for day-to-day life.

However, the relationship was not as good between “planning” and diabetes self-efficacy, perhaps because carrying out the strategies (in terms of behaviour) is thwarted by the barriers of diet, exercise and metabolic control issues. Conversely, the relationship between “acceptance” and diabetes self-efficacy was better than that for general self-efficacy, possibly indicating the focus on diabetes provides a relevant marker for people’s ability to be accepting of adversity. However, risk perception did not enter the picture at all. It is as if people’s risk perceptions disappeared from their cognitive appraisals when they considered other categories.

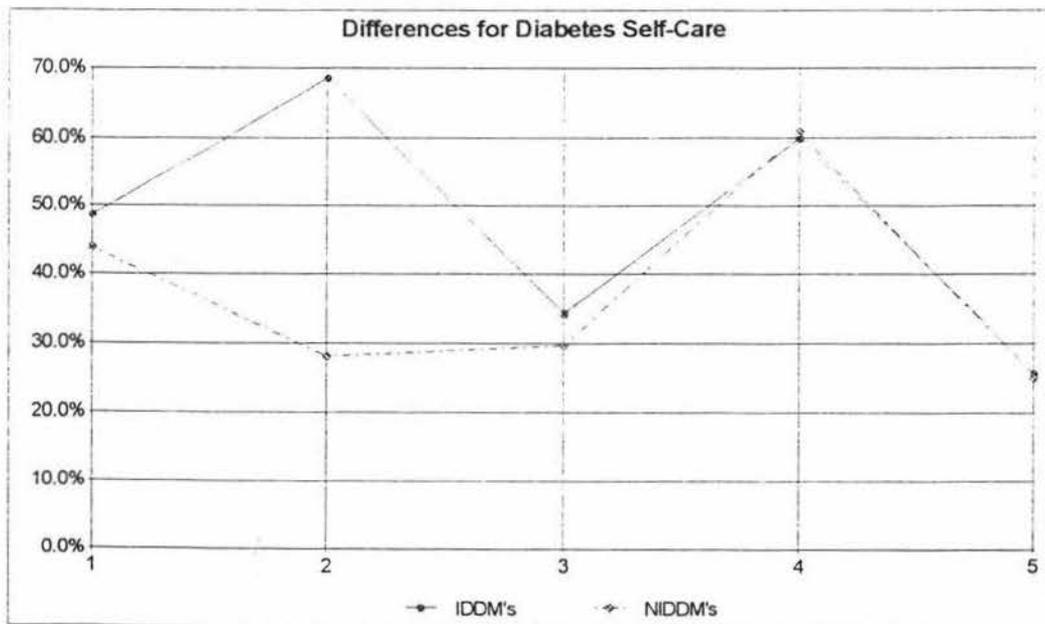
Aids to Self-Management

A small grouping of heterogeneous questions was created to further clarify the respondent’s views about ease of management, relating to medication, personal support, public awareness, more information, and an open category for comments. This was sought to try to elucidate the areas which are known to create difficulties for self-care, and also to provide the respondents with a forum for personal expression.

Frequencies for NIDDMs and IDDMs are included in Figure 1. A full transcript of the Comments are presented in Appendix A, itemised by numerically-ordered code, diabetes type, and age and sex of respondent. The responses received have provided valuable information concerning the respondents’ own ideas about their

illness, which often reproduces the inconsistencies found in others' research endeavours. Some of the comments actually stated the ways in which people interpreted the questions, and applied them to their own situation, and some also - somewhat poignantly - stated the personal difficulties they encountered. The greatest consistency of response between the two groups was the need for better public awareness and understanding, followed by a desire for more information. The greatest discrepancy between the two groups was that IDDMs were keen for easier forms of medication, not surprising given their self-injection requirements.

Figure 1. Frequencies of IDDMs and NIDDMs Responses to "What would make a difference to the Management of your diabetes?"



Legend: 1 = more information 2 = easier forms of medication
 3 = someone to talk to about it 4 = better public awareness &
 5 = other (comments) understanding

Wellbeing and Self-efficacy

General self-efficacy, diabetes self-efficacy and wellbeing (Bradley, 1994c) were correlated to see whether they were capable of demonstrating similar effects, which would seem reasonable given the nature of the constructs (Table 4). People's attitudes to their day to day life in the face of illness and their perception of their competence to manage that illness, ought to be connected, because both types of variables are thought to impact directly on quality of life.

The analysis showed this consistent main effect: all demonstrated a low to moderate direct relationship. In particular, general wellbeing, and diabetes specific wellbeing showed a moderately good relationship, indicating perhaps that people who maintained a feeling of wellbeing did not in the main allow diabetes to alter this perception. However, some relationships here were interesting: diabetes self-efficacy was moderately correlated with general wellbeing, but reduced for diabetes wellbeing. This seems to indicate that the respondents' overall reasonably positive sense of wellbeing was adversely affected when the feelings and thoughts representing the more negative side of diabetes were taken into consideration.

Table 4. Pearson Correlations of Wellbeing, Diabetes Wellbeing, Self-Efficacy and Diabetes Self-Efficacy.

Variables	<i>DWellbeing</i>	<i>SelfEfficacy</i>	<i>DSelfEfficacy</i>
Wellbeing	0.55	0.39	0.44
DWellbeing		0.16	0.29
SelfEfficacy			0.57

While on the surface the results do not indicate many strong relationships between the variables under study, the next section will offer an interpretation of the findings in light of the theories and constructs which have been outlined in the literature.

Discussion

It's all very well completing surveys, but what changes will this have for me as a diabetic - what feedback will I get? And will any of the points identified be looked into? Appendix A, 123).

On the whole, the respondents in this study appeared to have a reasonably good quality of life, as indicated by their assessment of the impact of variables used in the study. There are a number of explanations for the outcomes demonstrated by the data to support various hypotheses arguing the effects of risk perception, control plasticities, and self-efficacy.

1. **Risk Perceptions.** People seemed able to appraise their illness adequately in general terms, but unable or unwilling to appraise

specific risk resulting from diabetes. This may indicate that defensive optimism persisted when the risks were specified, a process, according to Schwarzer (1995) which reduces the likelihood of genuine self-efficacy being achieved.

With this in mind, it is perhaps possible to surmise an effect for the risk perception questions which compelled people to consider the disagreeable risks their illness exposed them to. Weinstein and Klein (1995) argued this as one of the two ways in which they found people in their study were actually able to accurately perceive risk. In this study, one respondent, a 25-year-old male IDDM, said:

Are you interested in my knowledge of diabetes in general (i.e. that it generally increases the chances of these problems) or my perceptions of my own health? - I assumed the latter. (Appendix A, 112).

He appeared therefore to make a distinction between his own likelihood of vulnerability and the risks associated with the illness for others - a classic case of defensive optimism. Given his age (25) and condition (insulin-dependent), this is not surprising, but it is impossible to know how many others made a similar cognitive error. Another, an 82-year-old male NIDDM, appeared oblivious to the fact that his amputation was related to diabetes. He said:

...As for climbing stairs up and down, diabetes does not help but I am an amputee right leg 5 inches below knee and this affects me more. (Appendix A, 590).

Still others were left unclear by their physician about whether their symptoms (e.g. of heart conditions, eye problems or leg pains) were caused by their diabetic illness. Some Comments indicated this concern more explicitly:

If this questionnaire has any bearing on the future of the Diabetic Clinic at the Palmerston North Hospital, I hope its results indicate that diabetics require ongoing visits to a diabetic specialist,,to check there's no deterioration in one's condition. The average G.P. sometimes doesn't seem to have this expertise. (Appendix A, 140).

Several respondents commented on the confusion between the information they received from their diabetic specialist, and from their G.P., or expressed concern about the lack of consultation between the two medical groups.

Thus, by comparing the results from the quantitative measures with the individual comments it is possible to derive a glimmering of understanding into the discrepancies which have emerged from the diabetes literature. Scott and Palasti Brown (1989), Lundman et al., (1990) Lang (1989) and Roberson (1992) interviewed their respondents in person and were told of the difficulties of self-care in far greater detail than was able to be achieved in this study. At the very least, these results appear to suggest that perception of control is likely to be due in part to optimistic - rather than realistic - appraisal.

2. Control. The results gave some support for the notion that diabetics sideline control in favour of enhanced quality of life. They showed a consistency of effect between items relating to perceived seriousness, severity and reduced perceptions of control, and a similar consistency between enhanced perception of control and self-efficacy. Thus, while the illness appraisal items were helpful in showing consistency of response - especially when correlated with similar constructs - they were unable to shed any light onto what the respondents thought they themselves meant by 'control'. The Comments only occasionally offered clarification. One comment from a 35-year-old female IDDM suggests that - at least for her - metabolic control was a constant irritant. She said:

It's a condition you constantly have to attempt to control, and it is frustrating when blood sugar controls are not reacting to constant monitoring and 100% input on a 24 hr/daily/weekly/monthly year after year basis. (Appendix A, 123).

Another respondent, a female NIDDM, aged 62, voiced a concern about the misunderstandings of the public about metabolic control versus insulin control.

However, few of the comments addressed themselves to metabolic control at all, possibly lending support to the notion that for most diabetics, this aspect is not an important quality-of-life issue. One respondent, a female NIDDM, aged 41, summed it up:

I sometimes find my diabetes easy to ignore. I have no physical symptoms so am not reminded to take heed of it. Only the doctor's concern reminds me to put my health on a higher priority. I use denial a lot - it's easier! (Appendix A, 565).

Other respondents identified metabolic control obliquely, by way of Comment, in citing reasons why their blood glucose levels might be abnormal for the time period under study. They mentioned, for example, stress at home, work pressures, illness (viral infection, arthritis) and the vagaries of insulin type and effectiveness.

The most accurate estimation of control as a metabolic construct was probably the appraisal of diabetes Item 2 (*How much control over your diabetes do you have?*). This showed a moderate relationship between perceived good diabetic control and diabetes self-efficacy, and between control and wellbeing. However, the blood glucose results somewhat confounded these findings, showing no meaningful correlation with any of the test instruments. Perceived control, therefore, seems to be the construct-of-interest for the respondents, which accords with the arguments of Brownlee (1991), Taylor et al., (1991), and Eitel (1995), that it is perceived control, rather than actual control that enhances self-efficacy, and contributes in a meaningful way to people's quality of life. Carey et al.'s (1991) commentary on illness appraisal and HbA_{1c} is recapitulated by this data, in finding the relationship between the two variables difficult to establish conclusively because of the complex factors impacting on blood glucose. The respondents in this study provided some

knowledge of these factors. Some of them were themselves aware of the elements which could upset their HbA₁C result, and articulated them via Comment.

A number of people in the sample identified difficulties with diet by way of Comment. For example, a male IDDM (age not stated) said:

[I have] food problems...find it hard to cut down on food intake. (Appendix A, 127).

And a 57-year-old male NIDDM suggested:

There should be more food shops for diabetic people. (Appendix A, 587).

These results may be showing a tendency towards secondary control. As Heckhausen and Schulz (1995) have argued, this is more likely to operate in the lives of people who are (a) older and (b) have experienced some failure of their bodily systems. If perceived control enhances a feeling of quality in day-to-day life, then people may gloss over the anxieties which accompany revelations of blood glucose whimsies, perhaps telling themselves that the next test will be better. Certainly the HbA₁C levels in this study, while good on the whole, did not correlate at all with any of the other measures. Since the other measures showed a degree of inter-test consistency, HbA₁C isolates itself from meaningful analysis as a variable which impacts on quality of life.

Self-Efficacy and Wellbeing. As has already been noted, self-efficacy was moderately good for the sample, both in general notions of competence and diabetes-specific competence.

The overall low to moderate correlations give few clear indicators of what was going on for these people. On the one hand, respondents showed moderate self-efficacy, moderate diabetes self-efficacy and wellbeing, adequate appraisal of illness and moderate strategising and planning (“management”), in isolation, but these effects tended to drop when say, diabetes **wellbeing** was related to diabetes **self-efficacy**. It may be that Bradley’s (1994a) diabetes-specific wellbeing scale invites people to disagree with negatively-worded statements, thereby inducing rumination on the more disagreeable aspects of diabetes, while the diabetes-specific self-efficacy scale designed for this study invites people to locate themselves in relation to generally more positively-worded statements, thereby possibly inducing a more “can-do” frame of mind.

Schwarzer’s (1995) explanation of self-efficacy is that it correlates with the “active coping” mechanisms outlined by Carver et al.’s coping strategies scale (1989), in requiring planning, action and maintenance of effective behaviours. This study compared the coping variables relating to planning with the self-efficacy scale and found a moderate correlation ($r=.4643$) which however, reduced for diabetes self-efficacy ($r=.3598$), again suggesting a diminution in perception of self-efficacy when confronting specific barriers in

diabetes. The consistency of these results, taken together, offer an argument that the respondents in this study were not able to maintain consistent levels of self-efficacy when confronted with the specific risks, barriers and metabolic control vagaries of diabetes.

One aspect of the analysis offers support for the concepts put forward in the literature on hardiness and active coping. Where people scored higher on wellbeing and self-efficacy (without the specifics of diabetes factored in), they may have been demonstrating an increased hardiness component, by being more likely to designate difficulties as **challenges** rather than as threats. As Kobasa (1970) and Florian et al. (1995) noted, some people - who may view themselves as highly self-efficacious - are reluctant to acknowledge any impediment to this view of themselves. One respondent, a female NIDDM, aged 77, said:

I just live from day to day, keep busy...never think about diabetes, visit friends - just keep myself busy all day. Provided I keep to a plain diet I don't seem to have any trouble. (Appendix A, 592).

Part of the difficulty in assessing the reliability of responses is that, as Lundman et al., (1990) found, it is actually very difficult to know what respondents mean when they say they are using strategies, for example, diet. However, in this particular case, the low incidence of “hypos”, the abundance of normal-range HbA₁C levels, and the adequacy of weight indices taken together provide a useful cross-check and suggest that overall this sample were using diet

effectively. However, they were not doing so **because** of a realistic appraisal of the risks of diabetes. It is arguable that what is emerging from the data is a combination of *resistance self-efficacy* (Schwarzer, 1995) which is belief in one's capability to avoid putting oneself at risk, and *coping self-efficacy*, which involves anticipatory coping with intermittent crises - for example, unacceptable blood glucose levels, a threatening situation for the diabetic. Coping self-efficacy would also enable the diabetic to make adaptive decisions about what to do to normalise the risky situation. Having done so, the person might then return to a resistance self-efficacy mode - for example dietary management. Defensive optimism being what it is, diabetics would be unlikely to see the need to move to other forms of self-efficacious behaviours unless the crisis was unmanageable utilising the current strategies. An example of this may be "hypos" requiring another person's assistance (which in our sample was rare), or the onset of complications, which often occurs only after a person has had diabetes for a number of years. *Recovery self-efficacy* (Schwarzer, 1995), the mechanism for retrieving optimistic self-belief after a crisis, enables the person to retain their belief in their competence to manage in future situations, but there was little evidence of a need for this strategy in this sample.

People appeared to want to know more about diabetes. Several respondents commented quite knowledgeably about the need for specific information, and the portion of the questionnaire directed towards obtaining their input showed this as well. Forty-five

(49.5%) wanted more information (presumably for themselves) and 60 (65.9%) of the overall sample wanted *better public awareness and understanding*. In the open categories inviting comment, several people were quite specific:

Updated information on human versus animal insulin - what is happening in research and new treatment strategies for diabetics. Female IDDM, aged 35 (Appendix A, 123).

The invention of long-acting insulin which increases its action 7-8 hours after taking it, to counteract pre-dawn blood sugar rises. Female IDDM, aged 31 (Appendix A, 109).

I find issues such as easier medication and better circulation of research findings could be useful in promoting "normality" in a diabetic's life... where there is misunderstanding about the consequences and impact of diabetes in the lifestyle and workplace of diabetics. Male IDDM, aged 38 (Appendix A, 122).

Insightful comments of this nature, while infrequent, did indicate some people were engaged in the process of trying to understand their illness, were keen to know more, and had not abandoned hope. These people may have been demonstrating *harm-reduction self-efficacy* (Schwarzer, 1995), which may be described as the strengthening of beliefs in one's ability to minimise risk, once acceptance of the disagreeable situation has occurred. These people were not obviously resistant to the fact of their illness, and were seeking to gain knowledge, competence and skill to manage it effectively. Of all the results, these few comments provide perhaps the most interesting estimation of self-efficacy 'in action', because they open a window onto the mechanism by which people employ

cognitive-affective processes to maintain choice behaviours and expenditure of effort, and also show us the degree of persistence and conscientiousness that can exist in the face of chronic illness.

Conclusion

Diabetes does appear to affect people's quality of life, but in ways that are imperfectly understood. In this sample, people's responses to most questionnaire items indicated on the surface few of the difficulties known to affect other diabetic populations - that is, struggles with obesity, "hypos", metabolic control and diet. Yet the tantalising glimpse of the 'interior' of their thoughts and feelings about the illness revealed a complex menu of needs wants and intentions which were not able to be stated within the parameters of a single-response questionnaire format. This menu included concerns about diet, about better and more accessible information about diabetes, about fantasies of cure via pancreas transplant or at least easier methods of medication. The respondents also stated complaints about access to specialists, about the lack of knowledge among general practitioners about diabetes, and about inadequate follow-up. They had useful ideas about further research needs: for example, the notion of different questionnaire formats for different age groups, or for a questionnaire for families and/or friends of diabetics. Yet, in the end one is left with the impression of a group of people getting on with their life, making plans, and keeping whatever suffering they may endure pretty much to themselves.

Because not everyone returned the questionnaire, and fewer still went to the trouble of providing comments, it is not possible to generalise from either the qualitative data or the quantitative. What can be said is that the notion of self-efficacy is a useful and possibly very powerful personal tool to sustain people through the vagaries of chronic conditions affecting health and lifestyle. It appears to be a sustainable resource in that it is capable of growth, flexibility, self-reliance and continuation. That it continues to operate in the lives of people who are faced with the daily, ominous challenges of diabetes is a tribute both to the nature of the “average person’s” psychological response repertoire, and to the researchers whose painstaking work has led them to identify this cognitive-affective resource. Further directions for research might include the development of a means to determine what it is that generates self-efficacy, and how people are able to evolve it further in response to barriers and challenges. Eventually it may then be possible to create assessment tools for use in clinical settings to assist clinicians in knowing where, when, and at which intervention stage the various types of self-efficacy are most likely to assist people.

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Appendix A - Comments

Code/Sex/Category/Age/Comment:

109/F/I/31: "The invention of a long-acting insulin which increases its action 7-8 hours after taking it, to counteract pre-dawn blood sugar rises".

112/M/I/25: "Some questions I found rather ambiguous - e.g. those on the lower part of P.4. Are you interested in my knowledge of diabetes in general (i.e. that it generally increases the chances of these problems) or my perception of my own health? - I assumed the latter".

116/F/I/30: "I always find it easier to be accepted as a person (e.g. not special). If people have known more than one diabetic so public education on what to expect may need looking at. I feel space should have been allowed to qualify some answers especially question on tiredness etc. can be influenced by other factors apart from diabetic control e.g. money worries, children or for women simply the time of the month we completed this questionnaire. I would also like to thank you for giving me the opportunity to be asked what I think".

122/M/I/38: "A very timely study - I would be interested in obtaining a copy of the report. Personally, I find issues such as easier medication and better circulation of research findings could be useful in promoting "normality" in a diabetics life and promoting well informed advocates of diabetes who can disseminate "truth" where there is misunderstanding about the consequences and impact of diabetes in the workplace and lifestyle of diabetics. I have pain from arthritis...diabetes stops me tramping[and doing] vigorous sports".

123/F/I/35: "Updated information on human versus animal insulin - what is happening in research and new treatment strategies for diabetics more concerned with blood

monitoring from Life Style Centre - the financial burdens that are put on diabetics and their necessary equipment. The poor appointment timing of clinics at PN Hospital - you always have to wait and a very clinical atmosphere. Communications between specialist and patients needs to be improved so as the patient doesn't feel intimidated and on parole. Support and back-up from doctors to patients. Doctors need to be able to relate to patients.

Its all very well completing surveys - but what changes will this have to me as a diabetic - what feedback will I get? and will any of the points identified be looked into?

Its great that we have the Diabetes Lifestyle Centre - but in reality do staff and doctors really appreciate what it is like to be a diabetic? You physically don't have to live with this condition - how can you actually relate to what a diabetic constantly has to go through - I suppose you will never actually know. Its a condition that you have to constantly attempt to control, and it is frustrating when blood sugar controls are not reacting to constant monitoring and 100% input on a 24 hr/daily/weekly/monthly year after year basis".

The understanding of blood laboratories and a Diabetic's need for immediate attention when having "hypos" - they need to be educated.

What different options are available for better control i.e. insulin sliding scale - after 22 years of being a diabetic this system has only just been identified for me by a doctor filling-in for specialist. Why has this not been explained/offered prior to this?

127/M/I/? : "Food problems. Find hard to cut down on food intake".

"Problem with less food - "OBESITY"".

132/F/I/56: "I feel very informed and take advantage of any relative (sic) articles that will help improve my understanding. The only thing that would help would be a complete cure!!"

133/F/I/69: "I'm under special treatment from Dr.Dixon but its not proving to be satisfactory".

135/F/I/56: "Useful in understanding diabetes problems that can arise".

136/M/I/27: "A cure" [would make a difference].

137/ /I/ : "A questionnaire for family and/or friends of the diabetic" [would be helpful].

139/F/I/47: "I found some of the questions didn't apply to me and were difficult to answer as I have other health problems as well as diabetes".

140/M/I/43: "If this questionnaire has any bearing on the furthur (sic) of the Diabetic Clinic at the P.Nth Hospital I hope its results indicate that diabetic's require ongoing visits to diabetic specialist such as Dr. Paul Dixon to check there's no deterioration in one's condition. The average G.P. sometimes doesn't seem to have this expertise".

150/ /I/ : "Being able to have a successful pancreas transplant" [would make a difference].

179/M/I/73: "Two sets of these forms would be an advantage, one for older age group, and one for younger age group, as some questions do not apply to everyone".

506/M/N/54: "[Would like] future types of possible treatment i.e. transplant of pancreas, insulin implants under the skin" "A lot of these questions were hard to answer as I am not insulin-dependent (yet). I am married with three grown children so some of these questions were irrelevant. I have a complicating factor. I lost my hand in an industrial accident - this doesn't help".

507/F/N/58: "Some of my answers could be influenced by the fact my husband has recently undergone a major cancer operation. Stress could influence some of the emotional questions also the blood sugar level which has been unusually high during this time".

515/F/N/58: "Personally I feel that other physical ailments may have been caused by the diabetes i.e. my painful leg, etc.

But I cannot be positive about this as the specialists (doctor) feel that I was diagnosed much later than when I had actually got it”.

525/M/N/56: “Found format very simple to follow”.

527/M/N/49: “I know it is hard to write the perfect questionnaire but I do feel sometimes the required response is not entirely relevant to the question. I also feel the questions could have been asked re type of occupation etc. Also relevant I feel the questions regarding income and pressures etc. related to obtaining income etc. of interest should be for, e.g. people coping quite adequately with social and home life but not coping with work life, or vice versa”.

539/F/N/65: “I think the questions are good, some don’t relate to me because of my age but on the whole very good, and I also say that we have a wonderful diabetic clinic here in Palmerston North, and I wouldn’t hesitate to contact them if I had any problems”.

551/M/N/39: “I feel that the way the questionnaire is set out by nature to you being contradicting yourself. You get into one avenue answering questions, then get into the same tack of asking the same thing again. I don’t feel that my glucose level will be very normal for me as I’ve been suffering from a virus for the last 4 weeks which has affected my diabetes drastically and I may say my patience has been sorely tested”.

559/M/N/69: “I have been on a waiting list for cataract treatment for over 2 years. As of yet I do not think it has had much bearing on this questionnaire, as in Page 11”.

518/F/N/59: “You should ask about other health problems, maybe arthritis - say, 45+ years”. “Have difficulty doing my finger pricks - very hard to inflict pain on yourself”.

522/M/N/57: "Meeting some person same age and condition, same social strata and profession [would make a difference]"

527/M/N/49: "I feel a combination of above (p. 13) all help in a combined effort to help each individual's needs".

531/M/N/58: "Conflicting beliefs by D.L.C. (sic) and my G.P. regarding normal blood sugar levels. D.L.C. say between 9 and 11 too high, G.P. says aim for 12".

560/M/N/52: "Being able to resist all the sugary foods that I really love [would make a difference]"

561/M/N/72: "Some questions weren't explained clearly enough to know what was needed".

562/F/N/53: "There should be more weight on groups for people with diabetes so patient can come and talk about their illness. Dr., Nurses, Dietitians. It was more about the diabetes side of it, not enough on the dietitians side of it, also feet, weight and eyes".

564/M/N/64: "six months ago I had a heart attack".

565/F/N/41: "Stress Management, counselling". "I sometimes find my diabetes easy to ignore. I have no physical symptoms so am not reminded to take heed of it. Only the doctor's concern reminds me to put my health on a higher priority. I use denial a lot. It's easier!"

566/M/N/78: "Heart & not diabetes is my problem - too interwoven for accuracy".

584/F/N/69: "Satisfied with advice available if required. I have been a diagnosed Crohn's patient since 1983. Medical treatment at Endoscopy till 20/7/92 - colostomy. When attending Lifestyle Diabetic Centre found similar symptoms to Crohns. Changes within healthcare very distressing at times, especially Core".

582/M/N/68: "No account appears to have been taken of recent changes in treatment effect. Practical steps taken like consultations with a G.P. may give an indication of concern and satisfaction. [Need] more effective medication - possibly insulin".

587/M/N/57: "There should be more food shops for diabetic people".

590/M/N/82: "As far as sex questions I am 82 yrs and widowed. As for climbing stairs up and down Diabetes does not help but I am an amputee right leg 5 inches below knee and this affects me more".

591/F/N/64: "Info. is adequate and lifestyle available if required. Have had coronary thrombosis 10/5/95 which affected general health; have had no indication that diabetes contributed directly to this. Some questions seem irrelevant".

592/F/N/77: "Just live from day to day, keep busy knitting and I have my clubs to attend. Never think about diabetes, visit friends - just keep myself busy all day. I'm alone - no worries. [I tell others about my diabetes] when cakes etc. are for afternoon tea. I occasionally eat pavlova and choc. eclairs my weakness. Provided I keep to a plain diet I don't seem to have any trouble".

600/F/N/62: "The difference in public (luncheons, etc.) between diet control and insulin control".

Appendix B - Questionnaire

Diabetes Quality of Life Project

Instructions

This questionnaire is about issues and factors relevant to the quality of life experienced by people with diabetes. It asks you about how you view and understand diabetes, what you do to cope with diabetes, and what levels of well-being and quality of life you experience, as well as some background information about yourself.

All of the information you give us is in confidence to the researchers and will be used only for the purposes of the study.

For many of these questions there are no right or wrong answers - an answer is correct if it is true of you. For most questions, all you need to do is circle a number which best describes *your* situation. Please do not write anything in the boxes.

Remember that you do not have to answer any particular questions, but we would like you to answer every question if possible, and to be careful not to skip any pages.

Occasionally you may think that we have asked a similar question before. This will be true. We are not trying to trick or confuse you by this, but we are trying out different ways to ask questions in order to find the best way to obtain the information.

Do not linger too long over each question, usually your first response is best. This questionnaire should take you about 45 minutes to complete.

Please write in today's date _____

--	--	--

In what year were you born? _____

Please circle the number next to correct responses below:

Are you? male 1 female 2

What is your present marital status?

- Never married 1
- Married/ Remarried (including defacto) 2
- Separated / divorced 3
- Widowed 4

What are your usual living arrangements?

- Living with partner (including defacto) **and** children 1
- Living with partner (including defacto), **no** children 2
- Sole adult with children 3
- Living alone 4
- Living with other adults (e.g., relatives, friends) 5
- Other, specify _____ 6

Which ethnic group do you belong to?

- New Zealander of Maori descent 1
- New Zealander of European descent 2
- New Zealander of Pacific Island descent 3
- Other, specify _____ 4

What is your highest educational qualification?

- No school qualification 1
- School certificate passes 2
- University Entrance (or equivalent), or
higher school qualification 3
- Trade certificate or Professional certificate or diploma 4
- University degree, or diploma 5

What height are you? _____

--	--	--

What weight are you? _____

--	--	--	--

People differ in how they deal with problems. We would like to know how you generally deal with problems. Please circle the one number, using the scale below, that is the best answer *for you* on each of the following statements.

- 1 = Not at all true
- 2 = Barely true
- 3 = Moderately true
- 4 = Exactly true

- I always manage to solve difficult problems if I try hard enough 1 2 3 4
- If someone opposes me, I can find means and ways to get what I want 1 2 3 4
- It is easy for me to stick to my aims and accomplish my goals 1 2 3 4
- I am confident that I could deal efficiently with unexpected events 1 2 3 4
- Thanks to my resourcefulness, I know how to handle unforeseen situations 1 2 3 4
- I can solve most problems if I invest the necessary effort 1 2 3 4
- I can remain calm when facing difficulties because I can rely on my coping abilities 1 2 3 4
- When I am confronted with a problem, I can usually find several solutions 1 2 3 4
- If I am in a bind, I can usually think of something to do 1 2 3 4
- No matter what comes my way, I'm usually able to handle it 1 2 3 4

The following statements are about issues which are specific to your diabetes.

- I can handle my diabetic medication requirements in spite of any difficulties 1 2 3 4
- I am confident I could adhere to a diabetic diet plan if I wanted to 1 2 3 4
- I usually can't resist the temptation of delicious but unhealthy food 1 2 3 4
- I am certain I can follow a regular exercise regime even when I'm tired 1 2 3 4
- I am confident I can monitor my blood glucose level, no matter what happens . . . 1 2 3 4
- I feel unable to control my diabetes even when I follow the prescribed programmes 1 2 3 4

People differ in their thoughts and feelings about having diabetes. We would like to know how you feel about having diabetes. Please circle the answer to each question that is closest to how *you* feel about your understandings and experience of your diabetes.

- How upsetting is having diabetes for you?

1 ----- 2 ----- 3 ----- 4 ----- 5 ----- 6 ----- 7
not at all extremely

- How much control over your diabetes do you have?

1 ----- 2 ----- 3 ----- 4 ----- 5 ----- 6 ----- 7
none at all total control

- How much uncertainty do you currently experience in your life as a result of being diabetic?

1 ----- 2 ----- 3 ----- 4 ----- 5 ----- 6 ----- 7
none at all extremely
large amount

How likely is your diabetes to worsen over the next several years?

1 ----- 2 ----- 3 ----- 4 ----- 5 ----- 6 ----- 7
not likely at all extremely likely

Do you believe that achieving good diabetic control is due to your efforts rather than factors which are beyond your control?

1 ----- 2 ----- 3 ----- 4 ----- 5 ----- 6 ----- 7
totally because of me totally because of other factors

How effective are you in coping with your diabetes?

1 ----- 2 ----- 3 ----- 4 ----- 5 ----- 6 ----- 7
not at all extremely

To what degree does your diabetes get in the way of your developing life goals?

1 ----- 2 ----- 3 ----- 4 ----- 5 ----- 6 ----- 7
not at all extremely large amount

How serious do you think your diabetes is?

1 ----- 2 ----- 3 ----- 4 ----- 5 ----- 6 ----- 7
not at all extremely

How curable do you think your diabetes is?

1 ----- 2 ----- 3 ----- 4 ----- 5 ----- 6 ----- 7
not at all extremely

How severely does your diabetes affect your life?

1 ----- 2 ----- 3 ----- 4 ----- 5 ----- 6 ----- 7
not at all extremely

How treatable do you think your diabetes is?

1 ----- 2 ----- 3 ----- 4 ----- 5 ----- 6 ----- 7
not at all extremely

How many times have you experienced a severe "hypo" (where you needed help from someone else) in the last year? _____

How many times have you experienced symptoms of a "hypo" in the last week? _____

How true are the following statements of you?

Because I have diabetes, I am more likely than others of my own age and sex to...

...suffer from eye problems

1 ----- 2 ----- 3 ----- 4 ----- 5 ----- 6 ----- 7
not at all true extremely true

...suffer from circulation problems

1 ----- 2 ----- 3 ----- 4 ----- 5 ----- 6 ----- 7
not at all true extremely true

...suffer from heart disease

1 ----- 2 ----- 3 ----- 4 ----- 5 ----- 6 ----- 7
not at all true extremely true

...suffer from kidney disease

1 ----- 2 ----- 3 ----- 4 ----- 5 ----- 6 ----- 7
not at all true extremely true

...have a stroke

1 ----- 2 ----- 3 ----- 4 ----- 5 ----- 6 ----- 7
not at all true extremely true

...die prematurely

1 ----- 2 ----- 3 ----- 4 ----- 5 ----- 6 ----- 7
not at all true extremely true

What treatment are you currently following to manage your diabetes? (Please answer more than one of the following if relevant).

Are you using diet yes no

Are you taking tablets yes no

please **print** the name of any tablets you are taking here
use the name stated on the front of your pill containers

Are you taking insulin yes no

if insulin, how many injections per day 1 2 3 4

How long have you been taking tablets? _____ months _____ years

--	--	--

How long have you been taking insulin? _____ months _____ years

--	--	--

We are interested in how people cope with having diabetes. There are lots of ways to try to deal with this, and we want you to think about what you *generally* do in order to manage your diabetes.

For each of the following items, circle the one number which best describes what you usually do to manage your diabetes. There are no "right" or "wrong" answers. Only some items will apply to you. Choose the most accurate answer for **YOU**, not what you think "most people" would say or do.

Indicate what you usually do to manage your diabetes.

- 1 = I usually don't do this at all
- 2 = I usually do this a little bit
- 3 = I usually do this a medium amount
- 4 = I usually do this a lot

I try to grow as a person as a result of the experience 1 2 3 4

I turn to work or other substitute activities to take my mind off things 1 2 3 4

I get upset and let my emotions out 1 2 3 4

I try to get advice from someone about what to do 1 2 3 4

I concentrate my efforts on doing something about it 1 2 3 4

I say to myself "this isn't real" 1 2 3 4

I put my trust in God 1 2 3 4

I laugh about the situation 1 2 3 4

I admit to myself that I can't deal with it, and quit trying 1 2 3 4

I restrain myself from doing anything too quickly 1 2 3 4

I discuss my feelings with someone 1 2 3 4

I use alcohol or drugs to make myself feel better 1 2 3 4

1 = I usually don't do this at all
 2 = I usually do this a little bit
 3 = I usually do this a medium amount
 4 = I usually do this a lot

- I get used to the idea that it happened 1 2 3 4
- I talk to someone to find out more about the situation 1 2 3 4
- I keep myself from getting distracted by other thoughts or activities 1 2 3 4
- I daydream about things other than this 1 2 3 4
- I get upset, and am really aware of it 1 2 3 4
- I seek God's help 1 2 3 4
- I make a plan of action 1 2 3 4
- I make jokes about it 1 2 3 4
- I accept that this has happened and that it can't be changed 1 2 3 4
- I hold off doing anything about it until the situation permits 1 2 3 4
- I try to get emotional support from friends or relatives 1 2 3 4
- I just give up trying to reach my goal 1 2 3 4
- I take additional action to try to get rid of the problem 1 2 3 4
- I try to lose myself for a while by drinking alcohol or taking drugs 1 2 3 4
- I refuse to believe that it has happened 1 2 3 4
- I let my feelings out 1 2 3 4
- I try to see it in a different light, to make it seem more positive 1 2 3 4
- I talk to someone who could do something concrete about the problem 1 2 3 4
- I sleep more than usual 1 2 3 4
- I try to come up with a strategy about what to do 1 2 3 4
- I focus on dealing with this problem, and let other things slide a little 1 2 3 4
- I get sympathy and understanding from someone 1 2 3 4
- I drink alcohol or take drugs, in order to think about it less 1 2 3 4
- I kid around about it 1 2 3 4
- I give up the attempt to get what I want 1 2 3 4
- I look for something good in what is happening 1 2 3 4
- I think about how I might best handle the problem 1 2 3 4
- I pretend that it hasn't really happened 1 2 3 4
- I make sure not to make matters worse by acting too soon 1 2 3 4

A vertical column of 20 empty square boxes, each aligned with a corresponding item in the list to its left, for marking the response.

- 1 = I usually don't do this at all
- 2 = I usually do this a little bit
- 3 = I usually do this a medium amount
- 4 = I usually do this a lot

I try hard to prevent other things from interfering with my efforts at dealing with this	1 2 3 4	<input type="checkbox"/>
I go to movies or watch TV, to think about it less	1 2 3 4	<input type="checkbox"/>
I accept the reality of the fact that it happened	1 2 3 4	<input type="checkbox"/>
I ask people who have had similar experiences what they did	1 2 3 4	<input type="checkbox"/>
I feel a lot of emotional distress and I find myself expressing those feelings a lot	1 2 3 4	<input type="checkbox"/>
I take direct action to get around the problem	1 2 3 4	<input type="checkbox"/>
I try to find comfort in my religion	1 2 3 4	<input type="checkbox"/>
I force myself to wait for the right time to do something	1 2 3 4	<input type="checkbox"/>
I make fun of the situation	1 2 3 4	<input type="checkbox"/>
I reduce the amount of effort I'm putting into solving the problem	1 2 3 4	<input type="checkbox"/>
I talk to someone about how I feel	1 2 3 4	<input type="checkbox"/>
I use alcohol or drugs to help me get through it	1 2 3 4	<input type="checkbox"/>
I learn to live with it	1 2 3 4	<input type="checkbox"/>
I put aside other activities in order to concentrate on this	1 2 3 4	<input type="checkbox"/>
I think hard about what steps to take	1 2 3 4	<input type="checkbox"/>
I act as though it hasn't even happened	1 2 3 4	<input type="checkbox"/>
I do what had to be done, one step at a time	1 2 3 4	<input type="checkbox"/>
I try to learn something from the experience	1 2 3 4	<input type="checkbox"/>
I pray more than usual	1 2 3 4	<input type="checkbox"/>

These next questions are about how you feel and how things have been with you over the last few weeks. Please indicate how often you feel each of the following phrases has applied to you in the past few weeks.

- 1 ----- 2 ----- 3 ----- 4 ----- 5
 not at all all the time

I feel that I am useful and needed	1 2 3 4 5	<input type="checkbox"/>
I have crying spells or feel like it	1 2 3 4 5	<input type="checkbox"/>
I find I can think quite clearly	1 2 3 4 5	<input type="checkbox"/>
My life is pretty full	1 2 3 4 5	<input type="checkbox"/>
I feel downhearted and blue	1 2 3 4 5	<input type="checkbox"/>
I enjoy the things I do	1 2 3 4 5	<input type="checkbox"/>

- I feel nervous and anxious 1 2 3 4 5
- I feel afraid for no reason at all 1 2 3 4 5
- I get upset easily or feel panicky. 1 2 3 4 5
- I feel like I'm falling apart and going to pieces 1 2 3 4 5
- I feel calm and can sit still easily 1 2 3 4 5
- I fall asleep easily and get a good night's rest 1 2 3 4 5
- I feel energetic, active or vigorous 1 2 3 4 5
- I feel dull or sluggish 1 2 3 4 5
- I feel tired, worn out, used up, or exhausted 1 2 3 4 5
- I have been waking up feeling fresh and rested 1 2 3 4 5
- I have been happy, satisfied or pleased with my personal life 1 2 3 4 5
- I have felt well adjusted to my life situation 1 2 3 4 5
- I have lived the kind of life I wanted to 1 2 3 4 5
- I have felt eager to tackle my daily tasks or make new decisions 1 2 3 4 5
- I have felt I could easily handle or cope with any serious problem or
 major change in my life 1 2 3 4 5
- My daily life has been full of things that were interesting to me 1 2 3 4 5

Please note that the following items are concerned with the effects of your diabetes.

- Because of my diabetes I cry or feel like crying 1 2 3 4 5
- Talking or thinking about my diabetes gets me upset or feeling downhearted . . 1 2 3 4 5
- Because of my diabetes I get depressed 1 2 3 4 5
- I blame my diabetes for stopping me doing things 1 2 3 4 5
- I find life a struggle because of my diabetes 1 2 3 4 5
- When things get on top of me I wish my diabetes would just go away 1 2 3 4 5

Please circle the one number that best indicates how satisfied you have been with each of the following issues over the last few weeks.

- How satisfied are you with..
- .. the amount of time it takes to manage your diabetes? 1 2 3 4 5
 - .. the amount of time you spend getting checkups? 1 2 3 4 5

How satisfied are you with..

.. the time it takes to determine your sugar level?	1	2	3	4	5	<input type="checkbox"/>
.. your current treatment?	1	2	3	4	5	<input type="checkbox"/>
.. the flexibility you have in your diet?	1	2	3	4	5	<input type="checkbox"/>
.. the burden your diabetes is placing on your family?	1	2	3	4	5	<input type="checkbox"/>
.. your knowledge about your diabetes?	1	2	3	4	5	<input type="checkbox"/>
.. your sleep?	1	2	3	4	5	<input type="checkbox"/>
.. your social relationships and friendships?	1	2	3	4	5	<input type="checkbox"/>
.. your sex life?	1	2	3	4	5	<input type="checkbox"/>
.. your work, school and household activities?	1	2	3	4	5	<input type="checkbox"/>
.. the appearance of your body?	1	2	3	4	5	<input type="checkbox"/>
.. the time you spend exercising?	1	2	3	4	5	<input type="checkbox"/>
.. your leisure time?	1	2	3	4	5	<input type="checkbox"/>
.. life in general?	1	2	3	4	5	<input type="checkbox"/>

Please indicate how much impact the following issues have had on you over the last few weeks.

	1 ----- 2 ----- 3 ----- 4 ----- 5					
How often..	not at all	always				
.. do you feel pain associated with the treatment for your diabetes?	1	2	3	4	5	<input type="checkbox"/>
.. are you embarrassed by having to deal with your diabetes in public?	1	2	3	4	5	<input type="checkbox"/>
.. do you have low blood sugar?	1	2	3	4	5	<input type="checkbox"/>
.. do you feel physically ill?	1	2	3	4	5	<input type="checkbox"/>
.. does your diabetes interfere with your family life?	1	2	3	4	5	<input type="checkbox"/>
.. do you have a bad night's sleep?	1	2	3	4	5	<input type="checkbox"/>
.. do you find your diabetes limiting your social relationships and friendships?	1	2	3	4	5	<input type="checkbox"/>
.. do you feel good about yourself?	1	2	3	4	5	<input type="checkbox"/>
.. do you feel restricted by your diet?	1	2	3	4	5	<input type="checkbox"/>
.. does your diabetes interfere with your sex life?	1	2	3	4	5	<input type="checkbox"/>
.. does your diabetes keep you from driving a car or using a machine (e.g. a typewriter)?	1	2	3	4	5	<input type="checkbox"/>
.. does your diabetes interfere with your exercising?	1	2	3	4	5	<input type="checkbox"/>
.. do you miss work, school, or household duties because of your diabetes? ...	1	2	3	4	5	<input type="checkbox"/>

- .. do you find yourself explaining what it means to have diabetes? 1 2 3 4 5
- .. do you find that your diabetes interrupts your leisure-time activities? 1 2 3 4 5
- .. do you tell others about your diabetes? 1 2 3 4 5
- .. are you teased because you have diabetes? 1 2 3 4 5
- .. do you feel that because of your diabetes you go to the bathroom more than others? 1 2 3 4 5
- .. do you find that you eat something you shouldn't rather than tell someone you have diabetes? 1 2 3 4 5
- .. do you hide from others the fact that you are having an insulin reaction? . . . 1 2 3 4 5

Please indicate how much the following issues have worried you over the last few weeks.

How often do you worry..

- .. about whether you will get married? 1 2 3 4 5
- .. about whether you will have children? 1 2 3 4 5
- .. about whether you will not get a job you want? 1 2 3 4 5
- .. about whether you will be denied insurance? 1 2 3 4 5
- .. about whether you will be able to complete your education? 1 2 3 4 5
- .. about whether you will miss work? 1 2 3 4 5
- .. about whether you will be able to take a vacation or a trip? 1 2 3 4 5
- .. about whether you will pass out? 1 2 3 4 5
- .. that your body looks different because you have diabetes? 1 2 3 4 5
- .. that you will get complications from your diabetes? 1 2 3 4 5
- .. about whether someone will not go out with you because you have diabetes? 1 2 3 4 5

The following questions are concerned with treatment for your diabetes (whether insulin, tablets, and/or diet) and your experience over the past few weeks. Circle the number that best describes your opinion.

How satisfied are you with your current treatment?

How often have you felt that your blood sugars have been unacceptably high recently?

How often have you felt that your blood sugars have been unacceptably low recently?

1 ----- 2 ----- 3 ----- 4 ----- 5 ----- 6 ----- 7
 none of the time most of the time

How convenient have you been finding your treatment to be recently?

1 ----- 2 ----- 3 ----- 4 ----- 5 ----- 6 ----- 7
 very inconvenient very convenient

How flexible have you been finding your treatment to be recently?

1 ----- 2 ----- 3 ----- 4 ----- 5 ----- 6 ----- 7
 very inflexible very flexible

How satisfied are you with your understanding of your diabetes?

1 ----- 2 ----- 3 ----- 4 ----- 5 ----- 6 ----- 7
 very dissatisfied very satisfied

Would you recommend this form of treatment to someone else with your kind of diabetes?

1 ----- 2 ----- 3 ----- 4 ----- 5 ----- 6 ----- 7
 no, definitely not yes, definitely

How satisfied would you be to continue with your present form of treatment?

1 ----- 2 ----- 3 ----- 4 ----- 5 ----- 6 ----- 7
 very dissatisfied very satisfied

These next questions are about your view of your health generally. Circle the appropriate number for each question.

In general, would you say your health is

- excellent 1
- very good 2
- good 3
- fair 4
- poor 5

Compared to a person of the same sex and age as you, would you say your health is

- excellent 1
- very good 2
- good 3
- fair 4
- poor 5

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

- much better now than one year ago 1
- somewhat better now than one year ago 2
- about the same 3
- somewhat worse now than one year ago 4
- much worse now than one year ago 5

These questions are about activities you might do during a typical day. Does *your health* limit you in these activities?

1 = yes, limited a lot
 2 = yes, limited a little
 3 = no, not limited at all

- vigorous activities*, such as running, lifting heavy objects, participating in strenuous sports 1 2 3
- moderate activities*, such as moving a table, pushing a vacuum cleaner, bowling, or playing golf 1 2 3
- lifting or carrying groceries 1 2 3
- climbing *several* flights of stairs 1 2 3

1 = yes, limited a lot 12
 2 = yes, limited a little
 3 = no, not limited at all

- climbing *one* flight of stairs 1 2 3
- bending, kneeling or stooping 1 2 3
- walking *more than a mile* 1 2 3
- walking *several blocks* 1 2 3
- walking *one block* 1 2 3
- bathing and dressing yourself 1 2 3

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

- cut down on the *amount of time* you spent on work or other activities? . . . 1 yes 2 no
- accomplished less* than you would like? 1 yes 2 no
- were limited in the *kind* of work or other activities 1 yes 2 no
- had *difficulty* performing the work or other activities (for example, it took extra effort)? 1 yes 2 no

During the *past four 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)?

- cut down on the *amount of time* you spent on work or other activities? . . . 1 yes 2 no
- accomplished less* than you would like? 1 yes 2 no
- didn't do work or other activities as *carefully* as usual? 1 yes 2 no

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

- not at all 1
- slightly 2
- moderately 3
- quite a bit 4
- extremely 5

How much *bodily* pain have you had during the *past four weeks*?

- none 1
- very mild 2
- mild 3
- moderate 4
- severe 5
- very severe 6

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

- not at all 1
- a little bit 2
- moderately 3
- quite a bit 4
- extremely 5

These questions are about how you feel and how things have been with you *during the past four weeks*.

- 1 = all of the time
- 2 = most of the time
- 3 = a good bit of the time
- 4 = some of the time
- 5 = a little of the time
- 6 = none of the time

How much of the time during the *past four weeks*....

- did you feel full of pep? 1 2 3 4 5 6
- have you been a very nervous person? 1 2 3 4 5 6
- have you felt so down in the dumps that nothing could cheer you up? 1 2 3 4 5 6
- have you felt calm and peaceful? 1 2 3 4 5 6
- did you have a lot of energy? 1 2 3 4 5 6
- have you felt downhearted and blue? 1 2 3 4 5 6
- did you feel worn out? 1 2 3 4 5 6
- have you been a happy person? 1 2 3 4 5 6
- did you feel tired? 1 2 3 4 5 6
- has your *health limited your social activities* (like visiting friends or close relatives)? 1 2 3 4 5 6

How true or false is each of the following statements for you?

- 1 = definitely true
- 2 = mostly true
- 3 = not sure
- 4 = mostly false
- 5 = definitely false

- I seem to get sick a little easier than other people 1 2 3 4 5
- I am as healthy as anybody I know 1 2 3 4 5
- I expect my health to get worse 1 2 3 4 5
- My health is excellent 1 2 3 4 5

In your opinion, what would make a difference to the management of your diabetes?

- more information 1 yes 2 no
- easier forms of medication 1 yes 2 no
- someone to talk to about it 1 yes 2 no
- better public awareness and understanding 1 yes 2 no
- anything else (please explain) 1 yes 2 no

FOLLOW-UP STUDY

If funding is available, we may be doing a follow-up study in about two years time. At that time, we would send you a similar questionnaire to see what changes have occurred for you. If you would be willing to take part in a follow-up, would you please indicate here:

I would be willing to be contacted about taking part in a 2-year follow-up study

Yes No

As part of the follow-up study, we may want to talk to some of the people who have participated this time around. We would conduct a face-to-face interview with those people, to find out some more in-depth detail about how they manage their diabetes. If you would be interested to participate in an interview (which would be conducted by one of the present research team), please indicate here:

I would be willing to be contacted about taking part in an interview

Yes No

If you have answered Yes to either of the above questions, please print your name, address and telephone number below. Note that by doing this, you are not agreeing to take part in any further research. You are only agreeing to be approached and asked to take part. You will, as with this study, have a chance to ask questions, to refuse to answer any particular questions, or to withdraw from the study at any time. If you do not provide these personal contact details, no information about your identity will reach the researchers, and you will not be personally contacted about this follow-up research.

Name: _____

Address: _____

Telephone: _____

Finally, we would be very interested to have feedback from you about this questionnaire. Please write below here any comments you have about the study and the questions we have asked, or about any important issues you feel we may have left out. (Please continue on the back of the page if necessary).

Thank you very much for your help with this research. We will send you a summary of our findings once all the results are collected and the analysis of the data has been completed. We greatly appreciate the time you have taken to complete this questionnaire. Please place it in the envelope provided and post it back to us. Remember that you do not need to put a stamp on this.