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**Type 2 Diabetes:
Understanding the Self-Regulatory Experience**

**A thesis presented in partial fulfilment of the requirements for
the degree of Doctor of Philosophy in Psychology at
Massey University, Palmerston North**

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2006**

Abstract

This research investigates type 2 diabetes using a psychological approach grounded in self-regulatory theory. Diabetes mellitus is usually described as a long-term illness with serious physical consequences, and biomedical perspectives predominate in published diabetes research. Findings from the present study add to accumulating knowledge about diabetes by addressing an identifiable gap in the literature, namely, an understanding of the psychological processes involved in managing type 2 diabetes. The common sense model (CSM) of illness self-regulation was used as the conceptual framework for this study.

The research sample ($N = 1145$) was identified from a medical database. A mailed questionnaire survey was used to obtain psychological and self-report data, and this was subsequently merged with clinical data from a review of the medical database. A response rate of 55% provided a total of 629 completed questionnaires. The age, gender, and cultural composition of the sample were a close match with those reported for the New Zealand type 2 diabetes population.

Research findings contribute to self-regulatory theory by testing key relationships specified in the CSM. The identification of a relationship cluster connecting emotional illness responses with cyclical symptoms, serious consequences, strong illness identity, and low coherence, highlights an emotional pathway in diabetes self-regulation. Observed relationships support the interaction between cognition and affect proposed in the CSM.

Results show significant relationships between treatment perceptions and diabetes self-management, and draw attention to the importance of family relationships in explaining diet and exercise patterns. Perceived consequences of diabetes play a pertinent role in explaining variance in quality of life, and diabetes-related distress. The CSM postulates coping responses mediate between representations and illness outcomes; current findings, showing that medication use mediates the relationship between treatment representations and HbA_{1c}, support the predicted mediating relationship.

It is concluded the common sense model provides a useful theoretical framework for research investigating self-care and wellbeing among people with type 2 diabetes. Potential implications for psychological theory and clinical practice are discussed, and

three areas – examining the roles of appraisal, emotion, and culture in illness management – are identified as priority targets for further research and conceptual development.

Acknowledgements

Many people have played an important role in the present research, none more so than those who made time to share their experiences of living with diabetes. To each person who supported this project by taking part - thank you. I would also like to convey my appreciation for the professional support provided by members of the health care community. Dr. Paul Dixon has been particularly generous. The Wellington Regional Diabetes Trust played a huge role in the practical aspects of this study, and I am very grateful for their support.

Financial sustenance for the present research has come from a variety of sources. First and foremost, thanks are extended to the School of Psychology at Massey University. In addition, grateful acknowledgement is given to; the Ryochi Sasakawa Foundation, Foundation for Research Science and Technology, Freemasons New Zealand, Palmerston North Medical Foundation, Claude McCarthy Fund, New Zealand Society for the Study of Diabetes, and Novo Nordisk New Zealand.

*The Owl and the Pussy-Cat went to sea
In a beautiful pea-green boat:
They took some honey,
And plenty of money
Wrapped up in a five-pound note
(Edward Lear - 1871)*

Completing a PhD is much like sailing: you shouldn't do it alone. I am very grateful to the many people who have helped bring this academic adventure safely into port. All the errors, inconsistencies, and misplaced full stops belong to me. However the credit does not. The lion's share belongs to other people.

It is with sincere gratitude that I acknowledge the support of my supervisors; Dr. Fiona Alpass, Dr. Christine Stephens, and Dr. Nancy Pachana. Their guidance has been invaluable. When the boat beached, as it was wont, timely advice re-launched in the next outgoing tide. It would be difficult to overstate the contribution Dr. Fiona Alpass, as primary supervisor, has made to this research. I have found it a privilege to work closely with someone whose academic nous and personal approach to life I greatly admire.

A PhD can be a dry academic endeavour; best completed in good and salubrious company. I have been fortunate to find in friendship, such company is plentiful. To each who lent an arm to row this waka forward – thank you. This has been a team effort and I would not have reached the finish line without you. Special thanks are reserved for my partner in coffee crime. Associate Professor Phil, good humour and a sense of fun abound in the chateau - I am have been very fortunate to have on officemate whose company is such a pleasure.

In many exploratory adventures some small thing goes wrong. At one point in this journey a hurricane hit; we lost the mast, and a man overboard. There are no words to convey the depth of sadness – I can only say we miss your smile my friend. This was a critical point in the journey, and a test of my tenacity as helmswoman. At this moment, decisive action by other crewmembers saved the ship from sinking.

Four deserve particular recognition. Rob held the torch, while Jo reached out to grab my arms. I was hauled from dank water back to the captain's seat; wet, shaken, but not too much the worse for wear. Andrew and Sheila – your skill in boat (re) building would win an America's Cup. Tirelessly, you have patched the leaky bits. And prepared nourishing meals for those suffering a bout of seasickness. Together these four people are the compass that has guided me safely through uncharted waters. Above all, it is your unconditional love and support that enables my hair brained schemes, including this one, to bear fruit. Jo you, especially, have been a tower of support.

To summarise, a number of people have played a key role in supporting my doctoral research. I remain, deeply, grateful to each of you. I own the copyright. But you own much of the credit.

For Doreen, Susie, Arthur, Ernest, and Annabelle – in recognition of accidents of birth and celestial timing

Charlotte Paddison, November 2006

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CHAPTER 1
INTRODUCTION TO TYPE 2 DIABETES

DIABETES MELLITUS

Diabetes mellitus is “a syndrome consisting of metabolic, vascular, and neuropathic components that are interrelated. It is defined as a group of metabolic diseases that are characterized by hyperglycemia resulting from defects in insulin secretion, insulin action, or both” (Harmel & Mathur, 2004, p. 1). Accordingly, the dominant symptom is elevated blood glucose levels (Edelwich & Brodsky, 1998), which functions as the primary diagnostic criteria for diabetes mellitus. There is considerable variation within the ‘diabetes mellitus’ label (Slama, 2003). The primary axis of differential diagnosis is between type 1 and type 2 diabetes (Harmel & Mathur, 2004; New Zealand Guidelines Group, 2003). These are “highly distinct in terms of aetiology, treatment and age of onset” (Eiser, Riazi, Eiser, Hammersley, & Tooke, 2001, p. 101). However, compromise to metabolic processing is a shared feature, as is the absence of a known cure. Thus diabetes mellitus is a chronic condition, rather than an acute illness (with the exception of gestational diabetes). Diagnosis instigates a lifetime of careful management; with self-care playing a salient role in the maintenance of wellbeing. The primary goal of therapeutic intervention for diabetes is to achieve good metabolic control (New Zealand Guidelines Group, 2003; Pennings-Van der Eerden, 1990), and through this decrease the likelihood of future microvascular and macrovascular complications (Griva, Myers, & Newman, 2000; Rose, Fliege, Hildebrandt, Schirop, & Klapp, 2002). The etiological nomenclature for diabetes mellitus reveals four primary distinctions: type 1 diabetes; type 2 diabetes; gestational diabetes; and a final category comprised of ‘other specific types’ (Harmel & Mathur, 2004). These are outlined briefly below.

Types of Diabetes

Type 1 diabetes is usually diagnosed during childhood or early adolescence (Slama, 2003). Three-quarters of people with type 1 diabetes are diagnosed before the age of 30, but onset can occur at any age (Harmel & Mathur, 2004). Although the term ‘insulin-dependent diabetes mellitus’ (IDDM) was utilized in early literature, this is no longer accepted custom (Edelwich & Brodsky, 1998; Slama, 2003). Generally, type 1 diabetes is characterised by impairment in pancreatic β -cell function as a result of autoimmune processes (Harmel & Mathur, 2004). Although the immediate cause of this form of type 1 diabetes appears to be a destructive autoimmune response, the

underlying causal agents have proved difficult to identify. There is evidence of a genetic component (Slama, 2003) and people with type 1 diabetes have greater vulnerability to other forms of autoimmune disease, but environmental factors are also hypothesised to play a role in the onset of symptomatic expression. A small minority of people with type 1 diabetes fall into a second aetiological group labelled 'idiopathic' type 1 diabetes (Slama, 2003); markers of autoimmune dysfunction (e.g., islet cell antibodies) are often conspicuously absent in this form of diabetes. Published literature suggests there is a strong genetic component to idiopathic diabetes (it is more prevalent among Americans of African descent); a Japanese study has presented evidence of viral agents as another possible causal factor (Harmel & Mathur, 2004). Latent autoimmune diabetes in adults (LADA) is a third form of type 1 diabetes (Slama, 2003). Because onset is progressive, people with this condition have historically been classified as having type 2 diabetes. In fact people with LADA exhibit symptoms associated with type 1 diabetes (e.g., evidence of autoimmune destruction), and type 2 diabetes (insulin resistance that progresses over time) (Harmel & Mathur, 2004). Treatment for type 1 diabetes relies on the availability of exogenous insulin. Many people find the therapeutic regimen intensely demanding (Griva et al., 2000). There is no cure for type 1 diabetes at the present time. To stay well, those who are diagnosed with this illness must maintain a lifelong commitment to the prescribed treatment regimen.

In contrast to the absolute insulin deficiency observed in type 1 diabetes, type 2 diabetes is characterised by insulin resistance coupled with a relative reduction in insulin secretion. Type 2 diabetes is more prevalent than type 1 diabetes. Worldwide, approximately 85–95% of people with diagnosed diabetes mellitus have type 2 diabetes (International Diabetes Federation, 2006b; Katsilambros & Tentolouris, 2003). The precise causes of type 2 diabetes are not well understood; although it is clear they are multifarious (Harmel & Mathur, 2004). Type 2 diabetes is not characterised by the markers of autoimmune destruction observable in type 1 diabetes. Because symptoms are progressive, there may be a considerable time lag between onset of hyperglycaemia and diagnosis; in many cases this delay may reach a decade (Harmel & Mathur, 2004). Typical presentation occurs in middle adulthood (Clark & Asimakopoulou, 2005) although, increasingly, there is evidence of type 2 diabetes affecting adolescents and children (International Diabetes Federation, 2006b; Katsilambros & Tentolouris, 2003). This is causally connected to the 'obesogenic'

environment that prevails in modern societies. Published literature estimates that 80–90% of people with type 2 diabetes are obese (Harmel & Mathur, 2004). As with type 1 diabetes, there is no cure for type 2 diabetes; however, the therapeutic regimen for each is quite different. People with type 2 diabetes do not often require immediate implementation of insulin therapy; though some will go on to need this at a later stage in the course of their illness. Treatments for type 2 diabetes are discussed in detail in the following section; a succinct summary could note that these treatments are more varied, and generally less invasive, than those for people with type 1 diabetes (Eiser et al., 2001). People with type 2 diabetes are more likely to suffer from macrovascular complications than those with type 1 diabetes; cardiovascular disease, for example, is very common. While almost 60% of people with type 2 diabetes will die of ischaemic heart disease, the comparative mortality rate for people with type 1 diabetes is 15% (Clark & Asimakopoulou, 2005). Another important clinical difference is that people with type 1 diabetes are ketosis-prone, while those with type 2 diabetes are not (Harmel & Mathur, 2004).

Gestational diabetes can occur in women who do not have a previous history of diabetes mellitus before their pregnancy. Thus for some women, glucose intolerance becomes apparent on becoming pregnant. The risk profile for gestational diabetes (GD) includes; age > 25, overweight, first-degree relatives with diabetes, and ethnic group (Hispanic, African-American, Native American, or Asian ethnicity is associated with greater prevalence of GD) (Harmel & Mathur, 2004). If undiagnosed, or left untreated, this can result in serious risks during both neonatal and post-natal periods. For the foetus these include higher than normal risk of spontaneous abortion, congenital malformation, stillbirth and respiratory distress. The prospective mother is also at risk of hypertension and, among those with coronary artery disease, cardiac-related death (Harmel & Mathur, 2004). Gestational diabetes is treated with a combination of lifestyle and pharmacological therapies: intensive management is common and insulin is prescribed in approximately one-quarter of cases because even small reductions in glucose control cause significant risk to both foetus and prospective mother (Harmel & Mathur, 2004). Although gestational diabetes is by definition glucose intolerance with initial onset or recognition in pregnancy (Harmel & Mathur, 2004), and intolerance is substantially reduced after delivery, research has shown 14% of women who experience gestational diabetes will meet the criteria for diabetes mellitus in formal diagnostic tests taken 1 to 4 months postpartum (Schaefer-Graf,

Buchanan, Xiang, Peters, & Kjos, 2002). Because pregnancy causes stress to the pancreatic β -cells, women with gestational diabetes are at greater risk of type 2 diabetes: evidence suggests almost 50% of those with GD will go on to meet the diagnosis for type 2 diabetes within a 5-year period (Metzger, Cho, Roston, & Radvany, 1993).

The label 'diabetes mellitus' encompasses a heterogeneous collection of metabolic syndromes (Slama, 2003), including other forms of diabetes that do not appear to fit well with the labels 'type 1' or 'type 2' diabetes. Compromise to mitochondrial DNA can result in phenotypic expression that fits the description of diabetes mellitus. For example, specific abnormalities have been located in the genetic material of people with maturity-onset diabetes of the young (MODY); essentially these impair the functioning of β -cells in the pancreas and result in reduced insulin secretion (Harmel & Mathur, 2004). Other factors that produce symptoms of diabetes include: mutations in the insulin receptor gene; damage to the pancreas; endocrine abnormalities; and viral infections.

In general, the aetiology of diabetes mellitus is poorly understood. In many instances, the expression of symptoms related to diabetes mellitus is liable to be the result of combined causal factors. For example, in type 1 diabetes this might include the amalgamation of genetic vulnerability and exposure to adverse environmental stimulants (e.g., enteroviruses such as Coxsackie B4 that closely resemble aspects of β -cell antigens (Hyoty et al., 1995)). Childhood immunisations have also been highlighted as potentially significant, although evidence remains controversial at present (Harmel & Mathur, 2004). The pathogenesis of type 2 diabetes remains enigmatic. The mechanism(s) producing impairment in insulin action are not well understood, and there is no cogent explanation for why the function of pancreatic β -cells deteriorates (Harmel & Mathur, 2004; Katsilambros & Tentolouris, 2003). As a result we have poor ability to account for the insulin resistance and reduction of insulin secretion observed among people with type 2 diabetes. This lack of knowledge acts as a barrier to research programmes aiming to develop a curative treatment for diabetes mellitus. At present there is no known cure for type 2 diabetes, and once diagnosis is made individuals must maintain a lifelong commitment to the prescribed treatment regimen in order to stay well.

DIABETES AS A MAJOR HEALTH ISSUE

The Global Epidemic

International Diabetes Federation estimates for the year 2003 indicate there are 194 million people with diabetes mellitus worldwide (International Diabetes Federation, 2006b). However, this condition is substantially under diagnosed: it is estimated 50% of people with diabetes are unaware of having it (New Zealand Guidelines Group, 2003). Thus there are many millions who have diabetes and do not know it. Among those diagnosed with diabetes mellitus, the majority (85–95%) have type 2 diabetes (International Diabetes Federation, 2006b; Katsilambros & Tentolouris, 2003; New Zealand Guidelines Group, 2003). The rising tide of diabetes has frequently been referred to as an 'epidemic' (Vinicor, 2005), and statistical analysis suggests the term is warranted. Between 1995 and 2025 the prevalence of diabetes among adults (age \geq 20) can be expected to increase by 35%; the total number of adults with diabetes will rise by 122% (King, Aubert, & Herman, 1998). Factors driving this trend in countries with industrialised economies (e.g., United Kingdom, United States of America, Australia, and New Zealand) include an aging population structure, and a sedentary lifestyle accompanied by excess calorific intake. However, the greatest increase in diabetes will not come from so-called 'developed' countries, rather, those nations experiencing economic and social change toward industrialisation will make the largest contribution to the increasing incidence of diabetes (Katsilambros & Tentolouris, 2003): in 'developing' countries the number of adults with diabetes will rise by 170% (King et al., 1998). The greatest increase is likely to occur in China and India (King et al., 1998). Extrapolation of current trends suggests there will be 333 million people with diabetes by 2025; based on this figure, the prevalence of diabetes mellitus among the global adult population is expected to be 6.3% (International Diabetes Federation, 2006b).

The financial costs of diabetes are tremendous. In the United States of America the total (direct and indirect) costs of diabetes were estimated at \$132 billion for the year 2002 (Harmel & Mathur, 2004). As noted by Roglic et al. (2005), in many nations diabetes consumes approximately one tenth of the total health care budget; however, in some countries this may be as high as 40% (International Diabetes Federation, 2006b). Recent estimates suggest the direct health cost of diabetes mellitus among

adults is approximately 153 billion international dollars (International Diabetes Federation, 2006b), and this is likely to be a conservative figure. By 2025 the figure is predicted to reach almost 400 billion dollars, representing between 7% and 13% of the world's direct health care budget. Approximately half of this will be consumed by the cost of managing diabetic complications, particularly cardiovascular disease (International Diabetes Federation, 2006b).

The costs of diabetes are more than just financial. Published literature provides a clear picture of the personal impact diabetes can have, through the devastating complications that often accompany this condition (Clark & Asimakopoulou, 2005). Microvascular complications (e.g., retinopathy and neuropathy) are common, and represent a significant source of morbidity. In the United States each year 56,000 people lose a lower limb as the result of diabetes (Harmel & Mathur, 2004). An analysis by Roglic and colleagues using the World Health Organisations DisMod II software (developed specifically for estimating the global burden of a single disease) showed that diabetes rates as the fifth most common global cause of death (International Diabetes Federation, 2006b; Roglic et al., 2005). Of the 7.5 million people with diabetes estimated to have died in the year 2000, 2.9 million of these deaths were causally related to diabetes, suggesting that, at 2000, excess mortality attributable to diabetes accounted for 5.2% of all deaths worldwide (Roglic et al., 2005). Excess mortality associated with diabetes ranges from 2% to 3% among developing countries, to 8% or more in the United States of America and the Middle East. Results from Roglic et al.'s analysis imply excess mortality associated with diabetes is three times greater than previous estimates based on death certificates. Published literature reports that, on average, diagnosis of diabetes equates to a 10-year decrease in life expectancy (Clark & Asimakopoulou, 2005). The global burden of diabetes is substantive.

Diabetes in New Zealand

While there is limited recent information on the prevalence of diabetes mellitus in New Zealand, estimates made in 2003 suggest the prevalence of diagnosed diabetes is likely to sit between 3% and 4%. Thus in 2003 there were approximately 115,000 people in New Zealand with diagnosed diabetes mellitus (New Zealand Guidelines Group, 2003). However, approximately 50% of people with diabetes are undiagnosed

(New Zealand Guidelines Group, 2003). Therefore, the actual incidence of diabetes mellitus in New Zealand is likely to be much larger than these figures indicate (Ministry of Health, 2002). Predictions made by PricewaterhouseCoopers in 2001 suggest that by 2006 there will be 119,338 people with diagnosed type 2 diabetes, and a further 59,669 who have type 2 diabetes but do not yet know it. These figures imply that, at the year 2006, there are approximately 179,000 people with type 2 diabetes in New Zealand (PricewaterhouseCoopers, 2001). These figures have significant financial ramifications. The PricewaterhouseCoopers (2001) report *Type 2 diabetes: Managing for better health outcomes* estimated that by 2006 diabetes services will cost the New Zealand health system NZ\$ 200 million annually; however, the projected total cost of health services for people with type 2 diabetes (undiagnosed and diagnosed) is likely to sit in the vicinity of NZ\$ 400 million for the 2006/2007 financial year (PricewaterhouseCoopers, 2001). In 2001 the cost of diabetes health services consumed approximately 3% of the health care budget; in 2021 they are expected to commandeer between 10% and 12% of the budget. These figures may be overly conservative (PricewaterhouseCoopers, 2001). The National Health Committee has concluded that "Diabetes . . . generates high costs, to the health system, individuals and families, and the wider community" (National Advisory Committee on Health and Disability, 2005, p. 10).

It is predicted that the prevalence of diabetes will increase substantially over the next 15 to 20 years. In New Zealand, the number of people with Type 2 diabetes (diagnosed and undiagnosed) is likely to reach 250,000 by 2021 (PricewaterhouseCoopers, 2001). This increase is consistent with international trends as discussed in the preceding section. The International Diabetes Federation estimated that in 2003 the prevalence of diabetes in New Zealand was between 5% and 7%; by 2025 this is expected to sit between 8% and 11% (International Diabetes Federation, 2006a). The prevalence of diagnosed diabetes varies across ethnicity. Published literature has estimated that the prevalence of diagnosed diabetes among New Zealand Europeans is around 3%; the prevalence estimates for Māori (5% to 10%), and Pacific peoples (4% to 8%) are much higher (New Zealand Guidelines Group, 2003). While the predicted increase in diabetes (1996–2011) among New Zealand Europeans is significant (62% for males, and 54% for females), this is much larger among Māori and Pacific populations, where an increase of between 131% and 149% is expected. Thus there is substantial ethnic variance in the burden of growing

diabetes prevalence. Evidence suggests cultural differences also extend to the *impact* of having diabetes (Dawson, 2003); diabetes-related mortality is worse in some ethnic groups. Once they have diabetes, New Zealand Europeans are less likely to die as a result of diabetes in comparison with Māori and Pacific peoples. As noted by the New Zealand guidelines group “Almost two-thirds of Māori and Pacific peoples with diabetes will probably die from their diabetes, compared to one-third of New Zealand Europeans with diabetes” (New Zealand Guidelines Group, 2003, p. 5).

Culture and Diabetes Mellitus

It is interesting to observe that the burden of diabetes does not fall equally on all people. There is a strong ethnic component that appears to influence both prevalence rates, and the distribution of diabetes related morbidity and mortality among those who have a diagnosis of diabetes (Durie, 2003). Across the developed world, indigenous peoples and those belonging to ethnic minority groups are more likely to get diabetes, are more likely to suffer serious complications (e.g., blindness, limb amputation, and renal failure), and are likely to die younger as a result of diabetes. For example, in the United States African-American women experience higher prevalence of diabetes, and greater disease burden than other demographic groups (Samuel-Hodge et al., 2000). This is also true of Latino and Native American groups (Harmel & Mathur, 2004). For example, the prevalence of diabetes among Native Americans is estimated at 12.2%, and 25% of African Americans aged between 65 and 74 have diabetes (Harmel & Mathur, 2004). These groups (African American, Latino, Native Americans) also exhibit more severe complications than Caucasian Americans; for example, Native Americans are three to four times more likely to lose a lower limb to diabetes in comparison with an individual from the non-indigenous diabetes population (Nelson et al., 1988). Ethnic differences in the burden of diabetes are well recognised in New Zealand (Barnes, Moss-Morris, & Kaufusi, 2004; Durie, 2003), and are highlighted as being an issue of importance in published evidence-based guidelines for the management of type 2 diabetes (New Zealand Guidelines Group, 2003). Information released by the Ministry of Health indicates that “Diabetes ‘explains’ about one-quarter of the gap in life expectancy (at age 25) between Māori and European ethnic groups, and about one-third of the corresponding gap between Pacific and European ethnic groups” (Ministry of Health, 2002, p. 25).

The mounting statistical evidence tells a tale of striking ethnic differences in both the prevalence and severity of type 2 diabetes. Various explanations for these ethnic differences have been promulgated. First, genetic vulnerability appears to be greater in some ethnic groups (Durie, 2003; Foliaki & Pearce, 2003; Harmel & Mathur, 2004). While the 'thrifty genes' hypothesis suggests certain ethnic groups are genetically predisposed towards fat storage, and insulin resistance (Katsilambros & Tentolouris, 2003), the explanatory power of the thrifty genotype proposition has been questioned. It would appear that, relative to social and environment factors, genetics play a small part in determining cultural disparities in the prevalence and impact of diabetes (Fee, 2006). Second, indigenous peoples are more like to suffer from what could be described as a constellation of health problems associated with modern living. Thus ethnic differences in the prevalence and impact of diabetes are partially explained by the adoption of lifestyles that often accompany the process of 'westernisation' (high in obesity, low in exercise and good nutritional practices) (Harmel & Mathur, 2004). Third, there is evidence that vulnerable groups (including ethnic minority members) are less likely to gain access to professional help to assist in managing their diabetes – for example, diabetes education (Glasgow et al., 2001). Thus differential access to, or utilisation of, health care is also an important issue (Harmel & Mathur, 2004).

At a superficial level, it may appear that 'culture' is responsible for poor diabetes outcomes. Indeed, there is a plethora of diabetes literature highlighting associations between variables labelled 'culture' 'ethnicity' or 'race', and differences in self-care behaviour, glycaemic control, and diabetes complications (Barnes et al., 2004; Davidson, 2003; Durie, 2003; Foliaki & Pearce, 2003; Harmel & Mathur, 2004; Schectman, Nadkarni, & Voss, 2002; Simmons, 1996, 1999; von Hofe, Thomas, & Colagiuri, 2002). However, this descriptive approach does not teach us about the *underlying* contributors that are responsible for the notable ethnic distribution of diabetes and its adverse health consequences. Heredity is one factor. This is reasonably well recognised within the professional diabetes community (Foliaki & Pearce, 2003). However, the role of socio-political determinants has been less thoroughly scrutinized (Thompson & Gifford, 2000). This may be because it is more difficult to map out such causal pathways in a way that is attractive to, or understood by, positivist empirical science. Nonetheless, it should not preclude discussion of the issue. Alongside genetics, the historical impacts of colonisation (and subsequent displacement, disempowerment, and marginalisation) experienced by many indigenous

groups could therefore also be identified as important underlying causal contributors to observed ethnic differences in type 2 diabetes (Durie, 2003; Thompson & Gifford, 2000). Although quantitative evidence is unavailable, it is suggested that the cumulative impacts of colonisation have led (directly and indirectly) to unhealthy lifestyles characterised by poor nutrition and inadequate exercise, which in turn lead people down the path towards type 2 diabetes. It is not coincidental that those groups who have fared worst in the colonial battle for supremacy are, in many cases, also the same groups who wear the heaviest yoke as a result of type 2 diabetes.

As noted above, it is suggested certain ethnic groups may have more difficulty gaining access to health professionals (von Hofe et al., 2002). Recent diabetes literature has highlighted the need to consider issues of social justice for particular subgroups within the diabetes population (Vinicor, 2005). While history and genetic disposition are difficult to change, such rigidity should not apply within the health care system. Medical organisations ought to be responsive to the health needs of the communities they serve, and aim to meet the needs of all people with diabetes. As has been noted previously, "for many years, the burden of diabetes has been highest among minority populations, and these groups have had very limited access to diabetes self-management resources or support" (Glasgow et al., 2001, p. 125). A number of studies published in the last decade show encouraging evidence that the needs of indigenous groups and ethnic minority members with diabetes are being proactively addressed (Abel & Iles, 2006; Brown, Garcia, Kouzekanani, & Hanis, 2002; Davidson, 2003; Mau et al., 2001; Powell, Vulikh, Jones, & Schroen, 2003; Pratt & Jackson, 2003; Simmons, Voyle, Fou, Feo, & Leakehe, 2004; Williams, Simmons et al., 2006). Still, pervasive ethnic differences in the prevalence and impact of type 2 diabetes continue to persist. This issue demands greater attention from the international health community, and positive action from professionals involved in caring for people with diabetes. Recently published global guidelines for the management of type 2 diabetes provide explicit recognition of this issue, stating that standard care delivery should "offer care to all people with diabetes, with sensitivity to cultural wishes and desires" (International Diabetes Federation Clinical Guidelines Task Force, 2006, p. 580).

TYPE 2 DIABETES

As noted in the previous section, type 2 diabetes is the most common form of diabetes mellitus. In New Zealand, 85–90% of people diagnosed with diabetes have type 2 diabetes (New Zealand Guidelines Group, 2003). In 1996 there were approximately 81,500 people in New Zealand known to have type 2 diabetes; by 2011 this is estimated to reach 145,000 (New Zealand Guidelines Group, 2003). This represents a 78% increase in prevalence across a 15-year period. The present study will focus upon people with type 2 diabetes. A brief discussion of aetiology and diagnostic processes will be followed by an overview of common elements in the treatment regimen.

Aetiology

It is clear that an 'epidemic' of type 2 diabetes is upon us (Barnett, Pearce, & Howes, 2006; Fox & Kilvert, 2003; Ministry of Health, 2002; PricewaterhouseCoopers, 2001; Vinicor, 2005). However, the precise causal agents responsible for this are difficult to define. As emphasised in the preceding section, a good understanding of the pathogenesis of type 2 diabetes continues to elude us. Although a plethora of scientific evidence has shown that insulin resistance and reduction of insulin secretion are responsible for the presentation of symptoms that mark type 2 diabetes, the precise mechanisms responsible for these changes remain elusive. Autoimmune destruction of pancreatic β -cells is not a feature of type 2 diabetes (Katsilambros & Tentolouris, 2003). Although early diabetes research focused on the role of insulin and identified the pancreas as the primary organ in diabetes mellitus, it is now clear that the maintenance of glucose homeostasis involves more than one organ, and several key hormones (e.g., insulin, glucagon, and amylin) (Kruger, Martin, & Sadler, 2006). Diabetes literature highlights a number of underlying factors that may contribute to the onset, and worsened progression, of type 2 diabetes (Katsilambros & Tentolouris, 2003). Scientific evidence points to genetic vulnerability as a significant determinant, although as yet "the genetics of type 2 diabetes are complex and are not clearly defined" (Harmel & Mathur, 2004, p. 14). Behavioural and lifestyle choices also contribute to the incidence and progression of type 2 diabetes. One of the most important is excessive body weight, particularly around the abdomen (Harmel & Mathur, 2004; International Diabetes Federation, 2006b; Katsilambros & Tentolouris,

2003). Thus health-promoting dietary habits and adequate exercise are very important for people who are at risk of, or already have, type 2 diabetes (Farmer, Pearson, & Strong, 2004). While sedentary lifestyle and obesity make important contributions to the odds of getting diabetes, greater age is also associated with an increase in the risk of type 2 diabetes. After the age of 40 the chances of getting diabetes double every 10 years (Harmel & Mathur, 2004). In the United States and Europe the average age at diagnosis is 60 (Clark & Asimakopoulou, 2005).

Some hypothesised causal agents are amenable to change. For example, adjustment to dietary intake and increased exercise can lead to a reduction in body weight; this may have a positive impact of glucose regulation, particularly among those who are on the cusp of diagnosable diabetes. Such changes may also help to reduce the intensity of the required therapeutic regimen. For example, with a significant weight loss those who were previously clinically obese may find their diabetes can be controlled through lifestyle management (exercise and diet) rather than requiring the use of hypoglycaemic agents (Edelwich & Brodsky, 1998). However, such behavioural interventions have limited efficacy. They can delay the diagnosis of diabetes, or slow the progress towards serious complications, but it would seem misleading to suggest that good self-care can *prevent* (that is, permanently forestall) diabetes. Nonetheless, weight reduction is an important lifestyle goal; particularly given the prevalence of obesity among the global adult population. The International Diabetes Federation (2006b) has calculated that 1.1 billion people in the world today are overweight; among this group, 320 million people are obese.

Recent research has shown growing evidence of a connection between depression and diabetes (Wearden et al., 2005). Until recently, explanations of the proposed causal direction implied that diabetes was likely to increase the risk of depression (for example, through experience of complications and reduced quality of life). However, there is some suggestion that depression predates development of diabetes (Rubin, 2005). Disturbances in metabolic function may form a common causal pathway. Empirical evidence to support this proposition is scant at present. It is possible only to state with certainty that people with diabetes are two to three times more likely to experience depression than members of the general, non-diabetic, population. Clark and Asimakopoulou (2005) suggest that about 15–20% of adults with type 2 diabetes experience depression. The direction of this relationship remains equivocal and further

research is required before statements regarding causal effects can be made with confidence. Nonetheless, it is very clear that depression is a “prevalent, serious, and costly comorbidity of diabetes” (Tibbetts, 2003, p. 190).

Diagnosis

The onset of type 2 diabetes is often preceded by an extended period during which glucose tolerance progressively worsens. People in this stage are sometimes described as having ‘impaired glucose tolerance’ or being ‘prediabetic’ (Edelwich & Brodsky, 1998; Harmel & Mathur, 2004). During this period, hyperglycaemia increases over time until symptoms become noticeable and the person seeks advice from a health professional. It is common for the early symptoms of diabetes to go unnoticed, or to be ignored by the person who is experiencing them (Katsilambros & Tentolouris, 2003), which often results in a significant delay in the diagnosis of type 2 diabetes, estimated to be between 9 and 12 years (Harris, Klein, Welborn, & Knuiiman, 1992). Consequently, at the time of diagnosis, 20% of people have at least one microvascular complication (Harmel & Mathur, 2004). For the most part, diagnosis of type 2 diabetes is opportunistic (Clark & Asimakopoulou, 2005). It is estimated that only one quarter of diagnoses are the result of a patient presenting with symptoms that instigate an investigation of diabetes (Harmel & Mathur, 2004). Presenting symptoms that alert health professionals to the possible presence of diabetes include polyuria, polydipsia, and frequent urinary tract or skin infections (Katsilambros & Tentolouris, 2003).

In accordance with international guidelines, many screening programmes use measurement of plasma glucose as an initial indicator of diabetes (International Diabetes Federation Clinical Guidelines Task Force, 2006). For people without diabetes, in a fasting state, plasma glucose levels commonly rest between 3.9 and 5.6 mmol/L (70 and 100 mg/dL) (Kruger et al., 2006). A fasting plasma glucose test greater than or equal to 7.0 mmol/L (126 mg/dl) is needed for a diagnosis of diabetes mellitus (Harmel & Mathur, 2004). In New Zealand, two fasting venous plasma glucose results ≥ 7.0 mmol/L (taken on different days) are diagnostic of diabetes (New Zealand Guidelines Group, 2003). Oral glucose tolerance tests have been presented as the ‘definitive test’ for diagnosing diabetes (Harmel & Mathur, 2004); but these are not encouraged as part of everyday standard clinical practice (New Zealand Guidelines Group, 2003). The International Diabetes Federation recommends an oral glucose

tolerance test (OGTT) for those with a fasting blood plasma glucose ≥ 5.6 mmol/L and < 7.0 mmol/L (International Diabetes Federation Clinical Guidelines Task Force, 2006). For many people, the diagnosis of type 2 diabetes is often greeted with distress and confusion (Fox & Kilvert, 2003). As mentioned previously, type 2 diabetes is under diagnosed, and thus the actual prevalence of type 2 diabetes worldwide is substantially greater than the number of known cases.

Treatment

As described early in this chapter, diabetes is best understood as a collection of metabolic syndromes of varying aetiology (Edelwich & Brodsky, 1998; Katsilambros & Tentolouris, 2003). The heterogeneous nature of type 2 diabetes means it is necessary to modify the prescribed treatment regimen to the physiological presentation of each individual. Insulin resistance is a hallmark of type 2 diabetes (Katsilambros & Tentolouris, 2003). Essentially this means the liver and muscles are not able to make effective use of insulin (which is necessary for transport and storage of glucose) (Edelwich & Brodsky, 1998; Harmel & Mathur, 2004). Some people with insulin resistance will still retain a considerable degree of functional capacity in the pancreatic β -cells (that is, an ability to secrete insulin), others will not. For people who do not have vast impairment in their ability to secrete insulin, hyperinsulinemia may act to compensate for insulin resistance, and therefore prevent hyperglycaemia (Katsilambros & Tentolouris, 2003). However, as β -cell function decreases over time (Wittlin, 2006), impaired glucose tolerance will become apparent and hyperglycaemic symptoms will emerge (Harmel & Mathur, 2004). Thus the prescribed therapeutic regimen varies, depending on the severity of compromise to the glucose/insulin metabolic pathway (Katsilambros & Tentolouris, 2003). Treatments commonly include dietary modification, recommendation of exercise, use of oral hypoglycaemic agents, and subcutaneous injection of insulin. Most people will require a combination of treatments (Harmel & Mathur, 2004), and these often change across time as β -cell function reduces. At present, pharmacological therapy for people with diabetes aims to “treat diabetes by stimulating or replacing insulin secretion, reducing insulin resistance in peripheral tissues, or modulating the rate of glucose absorption” (Kruger et al., 2006, p. 226). Because they generally retain some functioning in the pancreatic β -cells, people with type 2 diabetes are not entirely dependent on exogenous insulin. This means that, unlike people with type 1 diabetes, individuals with type 2 diabetes are not prone to

ketoacidosis, instead they are described as 'ketosis-resistant' (Harmel & Mathur, 2004). However, it must be noted that ketoacidosis can occur among people with type 2 diabetes under conditions of acute stress, for example, infection or trauma (Katsilambros & Tentolouris, 2003).

The goal of the therapeutic treatment regimen is to achieve an HbA_{1c} below 7% (New Zealand Guidelines Group, 2003). Recent international guidelines suggest an HbA_{1c} below 6.5% is optimal in order to minimise the risk of complications (International Diabetes Federation Clinical Guidelines Task Force, 2006). Evidence suggests there is no clear glycaemic threshold, and any sustained reduction in HbA_{1c} is worthwhile (Harmel & Mathur, 2004; New Zealand Guidelines Group, 2003). Initially, some people with diabetes may find that making adjustments to lifestyle behaviours (eating and exercise) provides improved glycaemic control. However, over time it is common for glucose intolerance to increase, requiring the use of medical treatments. About 40% of people with type 2 diabetes will require the use of insulin at some point in their diabetes trajectory (Harmel & Mathur, 2004). Usually this involves subcutaneous self-administered injections, although a small proportion use insulin pump therapy. Although pump therapy is not suitable for everyone, it may offer notable benefits such as greater flexibility regarding eating patterns, reduction in risk of hypoglycaemia when exercising, improved glycaemic control overnight, and enhanced perceptions of personal control over diabetes (Wittlin, 2006). Psychological research suggests people with diabetes may perceive the movement to insulin-based therapy as significant, viewing this as a sign that their diabetes has become more severe, and possibly, inferring personal responsibility for this change. As suggested in previous literature, "great care should be taken when explaining to patients why they need to go onto insulin therapy" (Wearden et al., 2005, p. 17). Where insulin is required, dose adjustment for normal eating may be useful to maximise dietary freedom, and quality of life, while also offering potential improvements in glycaemic control (DAFNE Study Group, 2002). Results from the United Kingdom Prospective Diabetes Study (UKPDS) suggest tight glycaemic control can result in a significant increase in hypoglycaemic episodes among people with type 2 diabetes (UK Prospective Diabetes Study (UKPDS) Group, 1998b). Further, some forms of treatment (e.g., insulin and sulphonylureas) can lead to weight gain (Clark & Asimakopoulou, 2005), and are also associated with greater vulnerability to hypoglycaemia among people with type 2

diabetes (Farmer et al., 2004). Thus intensive management of blood glucose can sometimes come at a price.

The importance of good self-care behaviour is strongly emphasised in diabetes literature. This constitutes the basis of treatment for type 2 diabetes, as discussed above. However one caveat deserves mention. Although active self-management helps to achieve good glycaemic control, the connection between self-care and illness outcomes is less than watertight (Leventhal et al., 1992). Even people who strictly adhere to medical advice regarding self-care may experience serious diabetes complications. For example, good glycaemic control does not always appear to have a protective effect on macrovascular complications among people with type 2 diabetes (UK Prospective Diabetes Study (UKPDS) Group, 1998b). Thus, good self-management does not necessarily 'buy' you wellness at the other end or at least, you might get less than you paid for. In some cases, people with good self-care practices show greater disease progression and worse outcomes than those who are less concordant with medical advice (H. Snell, personal communication, January 12, 2005). Because individual differences in underlying aetiology, comorbidities, genetic vulnerability, and other non-behavioural factors do influence disease outcomes, good self-care does not guarantee good outcomes for people with diabetes and it is necessary to concede there is 'noise' in the diabetes self-management system.

Paterson, Russell and Thorne (2001) provide an excellent critical overview of self-care decision making in chronic illness, identifying a number of assumptions that are not consistent with the nature of self-care decisions as they occur within the every-day, real-world environment. They challenge the assumption that "everyday self-care decisions are successful only if they are congruent with the advice of practitioners, that is if the person complies with the prescribed regime of disease management" (Paterson et al., 2001, p. 336). Further, Paterson et al. suggest the belief that "compliance is necessary to ensure that the person with chronic illness will experience few, if any, untoward symptoms or disease-related complications" (p. 337) is a myth. This position, while strongly stated, has a truthful element. Certainly it seems important to accept that good self-management is not the only determinant of microvascular and macrovascular complications. With this caveat acknowledged, collective diabetes literature shows evidence that good self-management makes a significant contribution to long-term wellbeing among people diabetes. On average, good self-care will always

offer better illness outcomes than no attempt to actively manage one's diabetes. Clinical literature argues emphatically that "tight diabetic control has a major role in forestalling diabetic retinopathy, nephropathy, and neuropathy" (Harmel & Mathur 2004, p. 40). Indeed, the New Zealand evidence-based guidelines for management of type 2 diabetes concur with this proposition, stating, "tight glycaemic control reduces the risk of and slows the progression of microvascular and macrovascular complications" (New Zealand Guidelines Group, 2003, p. xiii). An HbA_{1c} below 7% is recommended as the physiological target in both New Zealand guidelines for clinical management of type 2 diabetes (New Zealand Guidelines Group, 2003). The positive impact of good metabolic control has been demonstrated by large, robust studies such as the UK Prospective Diabetes Study (UKPDS) and the Diabetes Control and Complications Trial (DCCT) (The Diabetes Control and Complications Trial Research Group, 1993; UK Prospective Diabetes Study (UKPDS) Group, 1998b).

Most people with type 2 diabetes will experience complications at some point in the course of their illness. In the UKPDS, follow-up 9 years post-diagnosis revealed 9% of participants had evidence of microvascular disease; further, macrovascular complications were present in one in five participants (UK Prospective Diabetes Study (UKPDS) Group, 1998b). Cardiovascular disease is a significant health issue for people with diabetes (Katsilambros & Tentolouris, 2003): people with diabetes are more likely to experience cardiac events, and when these events occur, the outcomes are worse (Clark & Asimakopoulou, 2005). The New Zealand guidelines for management of type 2 diabetes emphasise the importance of assessing cardiovascular (CV) risk. An annual assessment is recommended; specific clinical goals are clearly indicated (total cholesterol < 4 mmol/L; blood pressure < 130/80 mm Hg; triglycerides < 1.7 mmol/L (New Zealand Guidelines Group, 2003)). People with diabetes are also at risk for microvascular disease. Published New Zealand guidelines state, "regular screening for renal, retinal and foot complications should occur from diagnosis of type 2 diabetes" (New Zealand Guidelines Group, 2003, p. xiii), and clear diagrammatic instruction is given for stepwise management of three aspects of microvascular disease (retinopathy, nephropathy, and neuropathic foot disease). Ongoing monitoring is essential; New Zealand guidelines recommend a review of lifestyle issues every 3 to 6 months, and an annual (free) diabetes check-up is available to all people with diabetes as part of the national 'get checked' programme.

Historically, medical treatment for diabetes has been predicated upon a disease-focused approach to chronic illness. The disease model positions diabetes as:

A deviation from normalcy as defined by specific, measurable parameters. In addition, there is a basic belief that diabetes as a disease is independent of individual psychological, social, and cultural variation. Diabetes in Peoria is identical to diabetes in Somalia. (Galazka & Eckert, 1984, p. 30)

Essentially, this presents diabetes as a physical illness defined by bodily abnormalities, devoid of any social context. However, contemporary medicine has witnessed growing recognition of the role social, psychological and cultural factors may play in therapeutic interventions for people with diabetes (Farmer et al., 2004; Fisher et al., 2005; Fisher et al., 1998; Pouwer, Beekman, Lubach, & Snoek, 2006; Pratt & Jackson, 2003; Scott & Brown, 1989). Great advances in pharmaceutical treatments have been made in the last century; however, as we move towards to the upper limits of medical technology, the improvement offered by new pharmaceutical treatments becomes increasingly marginal. Further, the efficacy of drug therapy is clearly dependent on people taking their medication, and taking it as recommended (e.g., dose, frequency). Research has consistently demonstrated that many people simply do not do this. It is apparent that a substantial proportion of people with diabetes do not take their diabetes medication, or use it in a way that substantially decreases the efficacy of recommended treatments (Delamater, 2006; Peyrot, Rubin, Lauritzen, Snoek et al., 2005). There is wide variation in the degree of concordance with prescribed therapeutic regimens among people with type 2 diabetes. As a result, many people struggle to achieve good metabolic control. Evidence suggests adherence to pharmaceutical aspects of the regimen (oral hypoglycaemic agents/insulin) is generally greater than compliance with lifestyle recommendations regarding exercise or diet (Griva et al., 2000).

THE IMPACT OF TYPE 2 DIABETES

Complications Associated with Type 2 Diabetes – The Medical Perspective

The long-term health consequences of having diabetes can be serious. These commonly include: neuropathy, foot ischaemia, renal disease, retinopathy, and

cardiovascular disease (Clark & Asimakopoulou, 2005; Farmer et al., 2004; Gerich, 2005; Harmel & Mathur, 2004; International Diabetes Federation, 2006b; Skinner & Hampson, 1998; Turner, Cull, & Holman, 1996; UK Prospective Diabetes Study (UKPDS) Group, 1998a; Vinicor, 2005). Complications of diabetes are frequently divided into two groups labelled 'microvascular' and 'macrovascular'. Microvascular complications can include neuropathy, retinopathy, and nephropathy. Damage to nerve fibres leading to limb endings (e.g., feet) often results in a loss of sensory perception (neuropathy). Thus foot care becomes an essential part of the diabetes regimen; people with diabetes simply may not notice that they have a large blister, or a cut on their toe that has become infected, because of sensory impairment in this area. Without good foot care, people with diabetes run an increased long-term risk of lower limb amputation. An individual with type 2 diabetes is 10 to 15 times more likely to undergo lower limb amputation than a person who does not have diabetes (Gerich, 2005). Diabetes can also impact on eyesight. Damage to the retina can lead to impaired sight (retinopathy), and in some cases, blindness. Retinopathy is present in around 15% of people with type 2 diabetes (Clark & Asimakopoulou, 2005). Impairment in kidney function (nephropathy) is also a frequently experienced complication of diabetes. Progressive compromise to renal function can lead to the need for dialysis treatment.

However, it is macrovascular complications that present the greatest burden to people with type 2 diabetes (Gerich, 2005). These complications include ischemic heart disease, cerebrovascular disease, and peripheral vascular disease. As discussed in the preceding section, proactive treatment of macrovascular risk factors is an important priority in clinical management of diabetes. A person with type 2 diabetes is between two and four times more likely to die from a myocardial infarction or stroke than someone who does not have diabetes (Gerich, 2005). Data from the UKPDS indicates that 20% of people diagnosed with type 2 diabetes will develop macrovascular complications with a 9-year period (Turner et al., 1996). Macrovascular disease explained a substantive 59% of mortality among participants in this study (UK Prospective Diabetes Study (UKPDS) Group, 1998b), and it is suggested that the efficacy of the prescribed treatment regimen in producing positive clinical endpoints may depend largely on the extent to which the regimen protects against the macrovascular complications of diabetes (Turner et al., 1996). Recent research has suggested that compromise to cardiovascular functioning might occur in the

'prediabetic' stage, that is, long before blood glucose levels reach the threshold for a formal diagnosis of diabetes. There is considerable interest in the relationship between impaired glucose tolerance and cardiovascular disease. Particular attention has been focused on the role of postprandial hyperglycaemia (Harmel & Mathur, 2004), and therefore alongside this the consumption of foods that have a low glycaemic index (New Zealand Guidelines Group, 2003). To summarise, type 2 diabetes can have wide-ranging effects on the body through changes in the physiological processes that underpin healthy function. When the impact of diabetes is described in medical publications, it is the compromise to bodily function that is emphasised.

Medical literature presents metabolic control as pivotal in preventing complications. Assessment of glycated haemoglobin is the most commonly used indicator of metabolic control (Harmel & Mathur, 2004). Findings from the DCCT and UKPDS demonstrate that improved metabolic control can have a significant positive impact on diabetes complications, in terms of both delayed onset and slower progression (The Diabetes Control and Complications Trial Research Group, 1993; UK Prospective Diabetes Study (UKPDS) Group, 1998b). There are two elements to good metabolic control. The first refers to the *average* level of blood sugars. This is assessed using standardised assays to provide an indication of glycated haemoglobin levels across the preceding 8 to 12 weeks. This is commonly referred to as a measure of HbA_{1c}. Published New Zealand guidelines recommend an HbA_{1c} below 7% as a target for people with type 2 diabetes (New Zealand Guidelines Group, 2003). Values below this are held to represent 'good' glycaemic control. The second element of good metabolic control is referenced to the amount of variation in blood glucose levels. Ideally, this should be low. This is commonly referred to as 'tight' glycaemic control (Gerich, 2005; Jenkins, 2003; New Zealand Guidelines Group, 2003). Although high blood glucose levels are dangerous to people with diabetes, and significantly increase the risk of long-term complications; low blood glucose also poses the risk of hypoglycaemic episodes. With tight glycaemic control, people may occasionally find their blood glucose level has dropped too low. Hypoglycaemic episodes (very low blood glucose) can have serious consequences, and is a significant problem for people with type 1 diabetes. However, severe hypoglycaemia is much less common among people with type 2 diabetes (Gerich, 2005; Harmel & Mathur, 2004; Katsilambros & Tentolouris, 2003).

Medical discourse places heavy emphasis on the pathways connecting self-care, metabolic control, and complications. Thus, working backward, the proximal determinant of complications is glycaemic control, and the primary determinant of metabolic control is self-care. In effect, this positions patients as responsible for the course of their diabetes – if their self-care is good, they will stay well. Conversely, strong emphasis on this pathway has the potential to place blame for poor metabolic control and complications on the patients' shoulders (Loewe, Schwartzman, Freeman, Quinn, & Zuckerman, 1998; Paterson et al., 2001). It is now clear that the connections between self-care, metabolic control, and complications are imperfect. Privately, many physicians may acknowledge this (Loewe et al., 1998); however, this issue is not often discussed openly in the course of clinical consultations.

One reason for this is that good self-care, though not a guarantee against serious complications, still represents an attempt to lower the odds of experiencing complications. On average, this investment will pay off, and it is the best advice current medical knowledge can offer. Further, it is difficult for health practitioners to state in one breath that self-care is important to prevent complications, and in the next say 'but you should probably know that good self-care does not buy better diabetes health outcomes, some people with good self-care still experience serious complications.' Clearly, if one wants to encourage greater motivation and active engagement in behavioural management of diabetes, discussing the lack of connection between self-care and complications is probably not helpful.

In medical literature, the impact of diabetes is discussed in terms of physical manifestations. As a New Zealand diabetes physician has stated: "Generally, people who provide health care are preoccupied with the body" (Scott & Brown, 1989, p. 182). The consequences of diabetes are described as physiological changes (e.g., nephropathy, retinopathy, and neuropathy) as discussed previously. However, the Diabetes Attitudes, Wishes, and Needs (DAWN) study has drawn attention to the emotional impact of diabetes (Peyrot, Rubin, Lauritzen, Snoek et al., 2005). Recently published global guidelines have specified the key elements that should constitute standard, comprehensive, and minimal care for people with type 2 diabetes. Psychological care is specifically addressed under the fourth subheading (International Diabetes Federation Clinical Guidelines Task Force, 2006). Although the importance of adopting an approach that focuses on the 'person with diabetes' is emphasised,

these recommendations are vague in places. Furthermore, they provide limited encouragement for the provision of in-house psychological services as part of standard care for people with diabetes. In New Zealand, few diabetes teams have a clinical psychologist included in the multidisciplinary team and access to professional support for dealing with diabetes related worries is often difficult, “this is an area that is very under-developed” (Farmer et al., 2004, p. 124). The situation is similar in most other countries (Hughes, 2006). However, as people with diabetes have argued:

The serious and sometimes dangerous psychological complications of diabetes merit attention just as much as the more traditionally recognised physiological complications. The DAWN Study validated what we have known intuitively for years – that the psychosocial repercussions of both types of diabetes are rampant, and more importantly, that these feelings all too often interfere dramatically with patients' ability to follow treatment plans. (Weiss, 2006, p. 30)

In summary, the impact of type 2 diabetes, as presented in medical literature, focuses on the presence of microvascular and macrovascular complications associated with diabetes. This reflects the pre-eminence of a disease-focused approach to diabetes mellitus in biomedicine, and can be contrasted with the illness-centred view that dominates psychological literature (Galazka & Eckert, 1984). The importance of good metabolic control is strongly emphasised. Assessment of HbA_{1c} thus becomes the yardstick against which patients' self-management efforts are measured (Wolpert & Anderson, 2001). According to dominant medical discourses, people with type 2 diabetes must strive to achieve an HbA_{1c} below 7% in order to stay well and avoid or delay complications. Both national guidelines, and everyday clinical practice in New Zealand, emphasise the connection between type 2 diabetes and physical wellbeing. Although international recognition of the emotional impact of diabetes is emerging, to date the clinical community in New Zealand has not been a strong contributor in such discussions.

Living With Type 2 Diabetes – The Personal Impact

Good research is premised on a sound understanding of the clinical description of diabetes and its consequences; alongside should sit an appreciation of the personal

impact to this disease. "Medicine has tended to view disease biologically, neglecting the psychological and cultural aspects that constitute illness from the patient's perspective" (Hampson, Glasgow, & Toobert, 1990, p. 633). Thus, it seems important to contextualise the clinical description given above by including some discussion of the lived experiences of people with diabetes. This is a growing area in the published diabetes literature.

Health psychology urges researchers to consider how health threats are viewed by people whose everyday experiences include living with illness (Leventhal et al., 1992). Narratives provided by people with diabetes are extremely useful to gain insight into how diabetes looks and feels, from the point of view of the person carrying the diagnosis (e.g., Matthews & Lloyd, 2005). Medical literature focuses on the physical impact of diabetes. Literature on the experiences of people with diabetes is a repository of information for understanding the impact of diabetes from a personal, holistic viewpoint. This highlights the impact diabetes can have on, for example, functional abilities, family life, relationships, and views of self. It also gives some insight into the emotional burden of diabetes, and the complex self-management regime that often accompanies this diagnosis. Rigorous research requires us to look at the same issue from multiple perspectives.

Narratives from people with diabetes suggest that diagnosis of diabetes is a hugely significant life event that often requires big life changes. Many people will ask 'why me?' (Edelwich & Brodsky, 1998; Scott & Brown, 1989). Emotional distress is frequent (Ramachandran, 2006; Weiss, 2006). Once diagnosis is made, the responsibility for taking care of your diabetes (self-management) is "non-negotiable and inescapable" (Funnell & Anderson, 2005, p 96). Some people find it difficult to accept that they have diabetes, and denial of diabetes is not uncommon (Edelwich & Brodsky, 1998; Garay-Sevilla, Malacara, Gutierrez-Roa, & Gonzalez, 1999; Macdonald, 2006b). Although diabetes is a lifetime condition, some believe it is temporary. For example, in Scott and Brown's book *Stories of Life with Diabetes*, Amanda White tells us "I believed that my diabetes was only temporary. Just for a short while. That it would be cured. . . . It'll go away" (Scott & Brown, 1989, p. 85). Guilt is an emotion that often accompanies diagnosis. As noted by Heller (2005, p. xv) "Type 2 diabetes develops largely because individuals make the 'wrong' lifestyle choices during their lives." At diagnosis people may find their own behaviour is placed under the spotlight; health professionals

(doctors, nurses, dieticians) may point out that they are overweight, don't exercise enough, and eat badly. It is easy to appreciate why people may come to feel the diagnosis of diabetes is something they have earned through past 'bad' behaviour (Weiss, 2006). Emotional support at the time of diagnosis is particularly crucial (Apfel, 1995). People with diabetes have expressed the desire that "a psychologist should be an important member of the health care team" and that the inclusion of a psychological component within guidelines for diabetes care is "long overdue" (Apfel, 1995, p. 276).

Diabetes can have a profound effect on one's view of oneself (Tilden, Charman, Sharples, & Fosbury, 2005) – described by some as a loss of confidence in their own body. Diabetes imposes so many restrictions that quality of life can be substantially reduced, which has been described as a move towards marginal existence by some people with diabetes. Helen Barnes expresses this new awareness: "I understood that from that moment on I would be dependent on a drug for the rest of my life. I was tied to pharmacies. To refrigerators. . . . And to clocks. I could never climb Kilimanjaro" (Scott & Brown, 1989, p. 123). Results from a qualitative study into the experience of living with diabetes suggest that attainment of positive emotional outcomes is enhanced by a process referred to as 'personal transformation' (Paterson, Thorne, Crawford, & Tarko, 1999). The differentiation of self from bodily illness is a core component of transformation. Thus, restructuring the concept of 'self' may be an important part of dealing with diabetes. Initial diagnosis can sometimes prompt very negative self-perceptions. For example Helen Barnes reported a strong feeling that she was 'defective'; she suggested to her husband that perhaps he would like to leave their marriage rather than continue a relationship with "a defective woman" (Scott & Brown, 1989, p. 128).

Many people with diabetes describe difficulties with the prescribed treatment regimen. This can include problems with prescriptions for lifestyle change (e.g., following dietary advice) (Woodcock & Kinmonth, 2001), and trouble with medical aspects of treatment such as blood glucose monitoring and injections. Few people embrace the idea of regular self-injections; patient narratives tell us that, for the majority, this is a frightening prospect (Scott & Brown, 1989). General consensus within diabetes literature indicates that dietary modification may be one of the most difficult aspects of treatment (Glasgow, Hampson, Strycker, & Ruggiero, 1997; Snoek, 2006), and is seen as a significant challenge for most people with diabetes. Research using the Audit of

Diabetes-Dependent Quality of Life (ADDQoL) measure has shown reduced dietary freedom has a negative impact on quality of life among people with diabetes (Bradley & Speight, 2002). However, some cultural groups might face additional barriers. Among Māori, altering eating habits can be a big issue; first, because dietary changes can equate to a feeling of deprivation (Samuel-Hodge et al., 2000). For example Tim Napoleon (59, Māori) describes it this way:

With diabetes, you are expected to give away the good things you like. Sweets. Drinking. I am not allowed to eat fatty meat. . . . When we were kids, we used to cook brisket, which is full of fat. You get a taste for it. You don't see many thin Maoris around. Some of us regard being told to stop eating what we like as the end of life. That's it. What's left? What's the use? (Scott & Brown, 1989, p. 140)

A second issue involves shared meals, which are the foundation of relationship building because food functions as a social connector. Jane Peterson tells that:

As far as diabetes goes, it is very hard to manage for Maoris. It doesn't suit their way. It has to do with the diet and with their casual way of life. Straight away when anybody comes into the house, they must have something to eat. . . . I still find it hard to eat when others don't eat around me. I was brought up to eat in company. (Scott & Brown, 1989, pp. 173-174)

Tim Napoleon echoes these sentiments:

There are a lot of level-headed Maoris around who will follow a diet, but for the rest of us, it is hard to stop doing what we like. We don't want to look different. When we go to a marae, we like to eat what's there. We eat together. We can't turn around and be on a different diet. People may say, "Isn't our food good enough for him?" That's the way it's looked upon. (Scott & Brown, 1989, p. 140)

Food can also be connected to one's sense of cultural identity. After a life time of "boil-ups, brisket and mutton" (Macdonald, 2006b, p. A10) it can be hard to get used to a

diet dominated low-fat cooking and vegetables you've never seen before. As Ailini Maka (Tongan, living in New Zealand) tells "I miss the island food. Taro, kumara, they are too starchy" (Scott & Brown, 1989, p. 107). Some people respond to this dilemma by cooking separately for themselves, others try to avoid separating their meals from family meals because eating together is important to them. Changes in traditional family meals can become a source of conflict in families where one or more members are resistant to modification of their normal dietary habits (Samuel-Hodge et al., 2000). Another aspect of the treatment regimen that can be problematic to some people with diabetes is that of insulin administration. Although the majority of people with type 2 diabetes do not require administration of insulin to control their diabetes, those who do report this is a significant burden (Vijan, Hayward, Ronis, & Hofer, 2005). In social situations, insulin injections can become difficult. For example, when eating at restaurants it is not always easy to find a convenient place to inject, or dispose of the needle.

People with diabetes often describe the social impact diabetes can have. For many people, as noted above, shared meals are a central part of family life. Often one person in the family takes primary responsibility for meal preparation. When a member of the family is diagnosed with diabetes, this commonly entails changes to the eating habits of the family as a group. Dietary modification may place strain on the person responsible for meal preparation: they may be forced to take on a role that could be described as the 'food police' because it involves monitoring food intake and, potentially, denial of unhealthy food choices (Farmer et al., 2004; Kelleher, 1988).

Other aspects of social wellbeing can also be affected by diabetes. Edelwich and Brodsky (1986) make good use of patient quotes to illustrate how diabetes can function as a significant obstacle to romantic relationships. A prospective partner may be unsure about what a future with someone who has diabetes might look like and, moreover, whether they wish to include themselves in this picture. Diabetes can affect many aspects of interpersonal relationships, including sexual functioning (Kelleher, 1988). Clark and Asimakopoulou (2005) suggest one third of males with type 2 diabetes experience some level of impairment in erectile functioning.

Young adults may find that diabetes interferes with their desire to participate in social events, and establish healthy peer relationships. They may be faced with a trade off

between taking part in what Kelleher (1988) describes as 'non-scheduled eating and drinking' and impaired blood glucose control. Teenagers may consciously decide to engage in behaviour they know will compromise their health, in exchange for group acceptance (Kelleher, 1988). Social interactions may also become problematic for adults with diabetes. For example, Kelleher (1988) describes a couple whose participation in social activities was being compromised by the refusal of a diabetic husband to go out because of concern regarding the timing of his insulin injections. This example suggests that while strong adherence to the recommended self-care regimen may have benefits in terms of good glycaemic control, this can come at the cost of healthy interpersonal relationships and social wellbeing.

The overwhelming proportion of successful diabetes management takes place in the everyday environment, and for many people this is their home and/or work. In essence, this is where the everyday battle with diabetes is won or lost (Scott & Brown, 1989). Family support can play a vital role in assisting the person with diabetes (Oomen, Owen, & Suggs, 1999). Many people report that a helpful spouse makes a huge difference. This role may include practical support (a sandwich in the middle of the night when a hypo has set in) or emotional support that encourages the person with diabetes to see themselves as 'normal'. For African-American women with diabetes, adult female relatives (e.g., daughters) were a significant source of support (Samuel-Hodge et al., 2000). The flipside is that the family environment can also have a significant negative impact on diabetes management. For example, family crises can compromise metabolic control. This can occur because of the impact of stress on the physiological processes that underpin glucose homeostasis, or because dealing with a difficult family situation interferes with the lifestyle aspect of self-management (e.g., regular meals and blood glucose testing).

Even seemingly benign changes in the home environment, such as going on holiday, can affect blood glucose management. For example, Jane Peterson recounts the impact of a holiday with her daughter's family (who owned a take-away bar). This resulted in a significant drop in metabolic control, primarily due to dietary changes: "I went astray. They've got chicken, and all the burgers. Change of climate, change of diet, they all make a difference" (Scott & Brown, 1989, p. 172). In some cultures, the expectations of others/self can form a barrier to good diabetes self-management. For example, Samuel-Hodge et al. (2000) discuss the impact a role as 'multi-caregiver' can

have on the self-care of African-American women with diabetes. This can substantially reduce the time, and emotional energy, available for dealing positively with diabetes. In these circumstances it may very difficult to say 'no' to somebody who is asking for your help, because of the psychological impact of this behaviour (e.g., emerging sense of guilt) (Samuel-Hodge et al., 2000). Results from this study also suggest the *absence* of emotional support (distinct from presence of overt conflict) can be stressful.

On occasion, family members will actively undermine the relationship between the health care team, and the person with diabetes. For example, in Scott and Brown's book *Stories of Life with Diabetes*, Amanda White explains that her spouse "doesn't have much time for doctors at the best of times. It's wise to keep him away" (Scott & Brown, 1989, p. 87). When they decided to start a family, her husband encouraged her to ignore the doctor's advice about pregnancy management: "My husband said, 'Don't worry, it's only temporary, it's going to go away. You don't have to do this. You don't have to do that.' I was caught in the middle and ended up in hospital. I lost the baby at 30 weeks" (Scott & Brown, 1989, p. 86). Thus the attitude of family members toward diabetes can have a pertinent impact on the self-management choices made by the individual. A spouse's belief that diabetes is not very serious, is unlikely to encourage personal prioritisation of diabetes self-care. A negative attitude towards the medical profession may mean the family is not able to help in times of crisis. For example, Amanda White tells of an episode where she became ill with a serious cold and her husband did not know how to care for her (e.g., the need to keep taking insulin) – as a result she almost died. This contrasts with the picture presented by Jane Peterson, who has a son who reminds her to take her oral medication at family dinner on Sunday, a husband who helps her manage her diet using a 'diet book', and a granddaughter who checks for air bubbles in the insulin syringe. As stated by Jane's husband, Bart, "once we understood what diabetes was about, the whole family could help" (Scott & Brown, 1989, p. 175).

Such narratives from people with diabetes illustrate the valuable contribution family members can make to keeping diabetes management 'on track'. However, diabetes can also have a negative impact on the relationships between family members (Weiss, 2006). For example, Tim Napoleon describes the 'nagging' he gets from his wife about his lifestyle choices: "My wife said, when I told her I was diabetic, 'Now, you have to stop all that drinking.' She always tells me, I can't have this, I can't have that" (Scott &

Brown, 1989, p. 142). Research focused on African-American women suggests dietary changes can be the cause of arguments between husband and wife (Samuel-Hodge et al., 2000).

Serious complications can also place significant strain on a marriage. Edelwich and Brodsky (1998) draw on patient narratives to illustrate this: they describe a woman who was finding it very difficult to cope with retinal haemorrhages. Although her husband was initially supportive, at times he was unable to deal with his wife's behaviour and would try to extract himself from the situation "when he couldn't take it any more, he'd just give me a lot of Valium and leave the house" (Edelwich & Brodsky, 1998, p. 82). Thus the impact of diabetes stretches beyond the individual. The diagnosis of diabetes on the family can be pervasive. It may potentially affect many dimensions of family life. It may instigate changes in family meal management, or cause emotional conflict within a marriage. As suggested by Farmer et al. (2004), the family and friends of people with diabetes should perhaps be referred to as having 'type 3 diabetes' – diabetes has a significant impact on their life through their relationship with someone who has been diagnosed with this condition.

One of the most salient features in narratives from people with diabetes is the emotional burden of having diabetes (Samuel-Hodge et al., 2000). Frustration, guilt, and anger are commonly experienced but are not emphasised in medical descriptions of the impact of diabetes mellitus (Fisher, 2006; Matthews & Lloyd, 2005; Polonsky et al., 2005; Rubin, 2005; Skovlund & Peyrot, on behalf of the DAWN International Advisory Panel, 2005). Many aspects of diabetes may engender an emotional response. As mentioned previously, the initial diagnosis of diabetes is a stressful event in itself (Ramachandran, 2006). Failure to achieve good blood glucose control can also be identified as a common source of frustration for many people with diabetes (H. Snell, personal communication, July 7, 2006). As noted in the preceding section, assessment of HbA_{1c} becomes the yardstick against which patients' self-management efforts are measured. If blood glucose control is above the recommended level, the implication is that the patient is responsible for this (Loewe et al., 1998). They need to make more vigorous or disciplined efforts with self-care so they can achieve better glycaemic control in the future. This type of approach can create huge frustration.

Good glycaemic control is hard to achieve, and the majority of people with diabetes struggle to do this (Dunn, 2006). An analysis of regional data from the MidCentral district shows that approximately one third of people in this area have an HbA_{1c} greater than or equal to 8% (Manwatu Horowhenua and Tararua Diabetes Trust, 2003). National data provided by Dawson (2003) suggest that while approximately 77% of New Zealand Europeans with diabetes achieve an HbA_{1c} < 8, these figures are lower for Māori (58%) and Pacific groups (49%). Although medical discourse strongly emphasises the connections between self-care and metabolic control, and metabolic control and complications, this pathway is less than watertight. It is clear there are many individual difference variables that may affect metabolic parameters or produce greater vulnerability to complications. As a result there are people with diabetes who experience serious adverse complications despite a lifetime of active and disciplined self-care. This represents a serious effort-reward imbalance (Snoek, 2006). Thus the difficulty of obtaining good metabolic control, and the possibility of experiencing complications even with a genuine commitment to active self-care, can be hugely frustrating for people with diabetes (Weiss, 2006).

Fear of diabetes-related complications can be identified as a source of stress for many people with type 2 diabetes. It is often not until after complications appear that people truly appreciate the seriousness of diabetes (Davis, 2006; Macdonald, 2006c; Scott & Brown, 1989). In a study of people with newly diagnosed type 2 diabetes, the most frequently reported concern was 'fear of getting worse'; the third most common concern was 'damage caused by diabetes' (Woodcock & Kinmonth, 2001). This suggests that many patients worry about the future burden of diabetes complications. For some people, seeing others with diabetes-related amputations becomes a source of distress. This is expressed by a participant in Samuel-Hodge et al.'s study of day-to-day self-management among African-American women: "When I think about the people that . . . already have diabetes and they lose their limbs, you know sometimes I get kind of numb, my legs. And I'm worried am I next. It bears on your mind a lot" (Samuel-Hodge et al., 2000, p. 930).

Further, dealing with the onset of complications when these do arrive can create a significant psychological burden. Complications such as retinal haemorrhaging are not infrequently greeted with "terror, panic, anxiety" (Edelwich & Brodsky, 1998, p. 81) often accompanied by guilt, because people feel they should have 'looked after

themselves better'. Thus complications can promote self-blame (Matthews & Lloyd, 2005). Sometimes the response from health professionals further multiplies these feelings: in New Zealand it appears some people with diabetes fear they will be 'told off' by doctors (Macdonald, 2006a).

Fear of experiencing hypoglycaemia is another salient issue for many people with diabetes (Matthews & Lloyd, 2005; Snoek, 2006). Even people who see themselves as "an undisciplined and rebellious diabetic patient" (Scott & Brown, 1989, p. 84) carry an emergency source of glucose in case a hypoglycaemic episode emerges. Helen Barnes provides an excellent description of what a 'hypo' feels like. Her words convey some of the depth of fear and inability to make rational sense of the world around that can accompany hypoglycaemia. For people without diabetes, such narratives are helpful in communicating the emotional experiences that are part of living with diabetes, and the profound sense of horror hypoglycaemia can cause:

It was a hot summer day. . . . I stopped for no reason and just stood looking at that thriving and bright yellow clump of gorse. As I stood there, this bush seemed to metamorphose into a torture instrument with ten thousand teeth ready to pierce my skin. I felt panicky. I had to move. But because I was low on sugar, I couldn't muster the resolution to move. (Scott & Brown, 1989, p. 126)

It is interesting to note that when discussing the impact of diabetes, health professionals tend to take a long-term approach that focuses on future wellbeing; in contrast, people with diabetes appear to emphasise the impact of diabetes in the present, that is the demands of treatment as they are currently being experienced (Wolpert & Anderson, 2001). This might help explain why some people intentionally keep their blood sugar higher than recommended in order to minimise the changes of experiencing hypoglycaemia (Rubin, 2005), despite the impact this has on the likelihood of experience complications in the long term.

As Rubin (2005) states "people who have diabetes frequently say they feel frustrated, fed up, overwhelmed or burned out by the demands of their disease" (p. 171). However, it is important to recognise that diabetes can also bring positive changes (Snoek, 2006). Increased exercise and/or modified dietary habits can generate

positive wellbeing for the person with diabetes, which can also extend to other family members. For example, taking regular walks together can improve physical wellbeing, and may also help build emotional strength in relationships between family members (Rubin, 2005). Diabetes can also bring about other positive emotional changes such as greater self-awareness and self-confidence (Rubin, 2005; Snoek, 2006).

Living with diabetes has also been presented as a transformational experience for some people. Paterson, Thorne, Crawford and Tarko (1999) provide an insightful analysis of this experience. They suggest that facing new challenges (from self and others) can lead to positive personal growth (e.g., increased mastery, greater balance). One key aspect of this process is the differentiation of self from bodily disease; connected to this was a repositioning of power so that the person had *control over* their diabetes rather than being an object *controlled by* their diabetes. This was associated with a view of oneself as a person who has diabetes; from this point of view diabetes is positioned as one aspect of the self, rather than the summary or most important part of 'who I am'. This differentiation of self from bodily illness contrasts with other viewpoints that position diabetes as the central definition of self (represented by the statement 'I am a diabetic'). Transformational experiences may have a positive impact on quality of life; people in this study defined transformation as "a profound new awareness of what you could be" (Paterson et al., 1999, p. 791). In this instance, the experience of diabetes could be life affirming.

The process of transformation is not, however, straightforward – it is unlikely to proceed in a linear fashion, and recursive movement is hypothesised. Further, transformation can have negative implications for the self (feelings of isolation and excessive responsibility) and interpersonal interaction with medical professionals (aggressive resistance to situations where perceived control over diabetes is reduced by the actions of health professionals who believe they know better) (Paterson et al., 1999). Nonetheless, this study is important because it illustrates that while the emotional burden of diabetes is, in many cases, substantive, "not all emotional consequences of diabetes are negative" (Rubin, 2005, p. 188).

To summarise, people with diabetes may view the impact of their illness quite differently from medical professionals (Hornsten, Sandstrom, & Lundman, 2004). In medical literature, good glycaemic control is the stated goal of therapy for type 2

diabetes. However, integration of medical and patient viewpoints suggests it is necessary to take into account more than the singular impact of treatment on metabolic parameters. The impact of treatment on quality of life is also a pertinent consideration (Clark & Asimakopoulou, 2005; International Diabetes Federation, 2006b). Research shows that this is very important from the patients' perspective, in fact in some instances the success of treatment changes may be defined largely in terms of the impact on quality of life (e.g., family functioning), rather than modifications to glycaemic control (Primomo, 1989, cited in Paterson, 2001). A more balanced perspective could therefore identify dual goals for diabetes treatment: good glycaemic control, and quality of life (Colagiuri & Peyrot, 2006). Equal weight should be placed on each. This agrees with the suggestion made by Rose et al. (2002) that "the goals in treating patients with diabetes are, most importantly, a sufficient blood glucose regulation and a quality of life with as few restrictions as possible" (p. 40). Although health rhetoric promotes both goals, treatment guidelines too often focus solely on physical and physiological targets (Wolpert & Anderson, 2001).

Culture, Health, and Self-Management of Diabetes

As emphasised earlier in this chapter, the burden of diabetes does not fall equally. Indigenous people the world over experience higher prevalence, greater complications, and earlier death as a result of diabetes. There are a number of reasons for these differences. Genetics provide some explanation, but this is partial (Foliaki & Pearce, 2003). Other contributing factors may include differential provision and uptake of screening services (equating to later diagnosis), and barriers to use of secondary services once diagnosis has been made (e.g., financial barriers (Simmons & Voyle, 1996; von Hofe et al., 2002), and language barriers (Simmons, 1999)). There is some evidence of greater dissatisfaction with systems of health service provision among indigenous groups in New Zealand (Durie, 1998). Thus systems of health service delivery are likely to make some contribution to the ethnic distribution of negative diabetes outcomes.

However, as noted previously, self-management is a core determinant of long-term wellbeing among people with diabetes. There is evidence of ethnic differences in diabetes knowledge (Simmons, 1999; Simmons, Shaw, Kenealy, Scott, & Scragg, 1994), and social norms regarding exercise and dietary behaviours (Moata'ane,

Muimui-Heata, & Guthrie, 1996). These cultural differences in knowledge about diabetes, and health-related behaviours may help explain observed differences in glycaemic control across ethnic groups (MidCentral District Health Board, 2005). It is important that ethnic disparities in diabetes are reduced. In order to do this, it becomes necessary to unpack the complex relationships between culture and health. In particular, research needs to examine cultural differences in diabetes self-management, and generate a better understanding of mechanisms underpinning these behaviours. The first aim of the following section is to explore the connection between culture and health at a conceptual level; the second aim is to illustrate the way cultural factors can impact on self-management of diabetes using examples from the South Pacific region.

Culture and health interact at a profound level. Assumptions about the nature of our physical and social world often vary between cultural groups and permeate all aspects of everyday lived experience. This includes ontological assumptions regarding our definitions of wellbeing (what it means to *be well*), and epistemological prescriptions about who can or cannot act as a repository of expert knowledge regarding health (i.e., who can be the knowledge holder) and what different people within the group are 'allowed' to know (control of knowledge). Thus cultural beliefs can result in fundamental differences in the way people view health and illness (Anderson et al., 2000; Baumann, 2003; Cameron & Moss-Morris, 2004; Marks, Murray, Evans, & Willig, 2000), and where they seek treatment.

It is useful to consider Māori (indigenous peoples of Aotearoa/New Zealand) views of health, as an illustrative example. According to Te Ao Māori (a Māori worldview), wellbeing is comprised of four interconnected dimensions. These are presented by Durie (1998) in his seminal publication *Whaiora: Māori Health Development*. The Whare Tapa Whā framework incorporates te taha whānau, te taha tinana, te taha hinengaro, and te taha wairua. These elements are connected to conceptions of extended family, physical, mental, and spiritual wellbeing, respectively. Together, they constitute the "four basic ingredients for good health" (Durie, 1998, p. 69). These are best considered as a singular integrated entity (Durie, 1998); a reductionist approach that attempts to separate physical health from the other three dimensions of wellbeing is incompatible with a Māori worldview. As a result, the connections between physical and emotional/spiritual wellbeing espoused in health literature predicated upon a Māori

worldview (e.g., Durie, 1998; Durie, 2001) are stronger and more pervasive than those commonly found in health psychology. Further, although western biomedicine privileges bodily wellbeing, and contemporary health systems reflect this, distillation of the meaning of wellbeing from a Māori view point reveals *te taha wairua* (spirituality) as the “most essential requirement for health” (Durie, 1998, p. 70). Thus general consensus among Māori is that the cornerstone of wellbeing is spiritual, not physical, health. This view does not fit closely with the way most health services are delivered in New Zealand, and has been identified as a source of dissatisfaction. As noted by Durie (1998) “Māori were not impressed by the overemphasis on physical aspects of health with its biological constructs and increasing preoccupation with cellular phenomena” (p. 73).

These differences in perspective take on another layer of significance when considering the overwhelming evidence of cultural disparity in the prevalence and impact of diabetes, as outlined earlier in the current chapter. The burden of diabetes is not shared equally across cultural groups – indigenous peoples carry a much greater load. Previous literature suggests that glycaemic control among Māori and Pacific groups in New Zealand is notably worse than among the New Zealand European diabetes population (Foliaki & Pearce, 2003; Simmons, 1997, 1999). For example, in the MidCentral District Health Board, overall, 29% of people with diabetes had an HbA_{1c} greater than or equal to 8% (indicative of poor glycaemic control). When this was broken down by ethnicity, salient between-group differences were noticeable. Among Māori, the proportion of people with an HbA_{1c} \geq 8% was 44%, and among people of Pacific descent this reached 58% (MidCentral District Health Board, 2005). Alongside health service delivery, self-management has been explicitly identified as an area with potential to create health gains for Māori. In a prospective exploration of the key determinants of Māori health for the ensuing 25 years, Durie (2000) emphasises the importance of encouraging self-management, and draws attention to the benefits of “enabling people to assert greater control over their own health including the management of disorders such as diabetes” (p. 9).

Good self-management is key for all people with diabetes, but the factors that influence self-management differ across individuals. It is important to appreciate that cultural factors may have a salient influence on diabetes self-care behaviour. For example, as noted above, articulation of the connection between physical and emotional wellbeing

is stronger in Māori models of health, than most western-based health frameworks. High emotional distress about diabetes may interfere with active self-care; one common way of attempting to reduce distress is engagement in avoidant behaviour, or denial of diabetes diagnosis. In this way, compromise to *te taha hinengaro*, emotional wellbeing, can be connected to variation in health-related behaviour. It is plausible that this association between high distress about diabetes and poor self-care may be moderated by ethnicity, in that the association is stronger among cultural groups that view emotional and physical wellbeing as closely interconnected. There may also be important links between cultural variables, and specific self-care behaviours associated with diabetes, for example, healthy eating and exercise.

Some forms of cultural activity (e.g., *kapa haka*) are connected to adoption of positive health behaviours such as increased physical exercise. Health promotion programmes built explicitly on cultural frameworks have shown positive benefits in a number of behavioural domains, particularly smoking and exercise, and across a range of physical locations (e.g., on the sports field, at the *marae*, within the home) (Durie, 2001). Furthermore, these have demonstrated greater benefit than previous interventions that did not take cultural factors into account. For example, the Kai o Te Hauora scholarship programme has had an identifiable positive impact, helping to produce efficacious interventions for improving dietary practices. In contrast, previous approaches based in informational persuasion were much less effectual (Durie, 2001, 2003).

It is important to appreciate the centrality of cultural identity to health. As noted by Durie (2000, p. 8) "good health depends on many factors, but among indigenous peoples the world over, cultural identity is considered to be a critical prerequisite." Involvement in cultural activities is important to many Māori. These activities often take place upon the *marae* (traditional meeting area), and participation shows a positive connection with health (Durie, 1998). However spending time on the *marae* may not always offer benefit to your health, particularly your dietary health. Preparation of healthy cuisine (low fat, low glycaemic index) has not often been a strong characteristic of *marae*-based cooking. Thus cultural norms regarding meal preparation (e.g., choice of low versus high fat meat cuts) may make it more difficult for people with diabetes to find healthy food choices when staying on the *marae*.

Although contemporary cuisine on the marae frequently includes healthy foods (e.g., fresh fruit), the creamed trifle and sticky golden steamed pudding usually disappear before the bottom of the fruit salad bowl is found. Such observations suggest even when healthy options are available, these may not be the food of first choice. This reiterates points made earlier in the current chapter; quotes from people with diabetes illustrate that certain foods are connected to (and nourish) cultural identity. It is not always easy to pass these over. It is important to appreciate that, particularly in a marae-based context, food is linked to both physical and non-physical wellbeing for Māori. For example, being involved in your marae plays an important role in promoting whakawhānaungatanga (kinship linkages). These relationships, based on shared ancestry, are salient to te taha whānau, the family dimension of wellbeing incorporated within the Whare Tapa Whā framework. Shared meals are a central part of traditional marae-based events such as tangihanga (ceremonies associated with death of a member of the whānau/hapū/iwi). Thus the choice to abstain from shared meals (if healthy options are not available) comes at considerable cost in terms of lost opportunities for whakawhānaungatanga and, therefore, whānau (family) wellbeing. The host hapū/iwi may also view any decline to participate in a shared meal as culturally offensive behaviour (B.M. Campbell, personal communication, September 25, 2006).

For most Māori, of even greater significance to wellbeing is the role of food in removing tapu. It is difficult to find English words that enable the meaning of tapu to be expressed with clarity, and there is plurality of description even within Māori literature (Durie, 2001). Something that is tapu is sacrosanct – it has spiritual qualities and latent potential. Transgression of tapu is causally linked to ill health. Marae kawa (protocol) functions to protect against tapu, through prescription of appropriate behaviours. One of the most important, is sharing a meal with manuhiri (visitors). On entering a marae, visitors are tapu. As such, the people of that marae (tangata whenua – those with kinship connections to the marae) will show much care in their interactions with visitors, until such time as it is possible to move the manuhiri from a state of tapu (associated with latent spiritual potential) to noa (no potential for spiritual harm). As stated by Durie (2001, p. 81) “cooked food is always noa, so the way of reducing tapu is to enjoy a meal together”. Thus, after the formalities of welcome have been completed, this is what usually occurs. For Māori, including those with diabetes, participation in shared meals on the marae is of the utmost importance; transgression of tapu is considered to

have serious consequences, to be avoided vigilantly. This detailed discussion serves to illustrate the difficult tightrope people with diabetes may find themselves walking. They may feel caught between (a) the need for cultural involvement and promotion of whānau wellbeing through whakawhānaungatanga, coupled with care to avoid transgression of tapu (partaking in shared meals is identified above as a core component of both), and (b) the desire to manage their diet in a way that is healthy for their diabetes. The issue of cultural norms regarding food and, in particular, the role of food in social practice, has also been identified as presenting a dilemma for Pacific people with diabetes living in New Zealand (Moata'ane et al., 1996), as well as for Chinese Americans (Chun & Chesla, 2004).

In summary, for many Māori (including those with diabetes) food functions as so much more than a simple nutritional agent. Although this is also true for people from other ethnic backgrounds, the connection between identity, non-physical wellbeing, and food may be more pronounced among people who identify as belonging to indigenous cultures of the south pacific (e.g., Māori, Tongan, Samoan). Healthy management of diabetes often entails dietary changes. But these changes may be hard to implement. There is potential for compromise to cultural identity as a result of dietary changes that limit participation in valued cultural activities. Attempts to make dietary changes and, somewhat ironically, even success in making these changes (Moata'ane et al., 1996), can have a negative impact on other dimensions of health (e.g., family and emotional wellbeing). The key point here is to show how sociocultural factors can influence health behaviour, using practical examples. This is consistent with international literature which has, for example, emphasised the importance of sociocultural factors in day-to-day management of diabetes among African-Americans (Samuel-Hodge et al., 2000).

It is important that diabetes researchers and clinicians appreciate the profound connections between culture and health. Specifically, there is a need to promote greater recognition of the complex interactions between culture and diabetes self-management. Workshops providing cultural education for diabetes health professionals constitute a key recommendation in recent New Zealand literature (Paddison, 2004). As noted by von Hofe et al. (2002):

Lack of culturally specific knowledge by health professionals has been found to affect access to services across cultures. This is often due to the health professionals' lack of awareness about specific religious and/or cultural factors resulting in inappropriate dietary advice, education and treatment that is not complied with. This results in the person being labelled as difficult or non-compliant by the health professional resulting in a decrease or withdrawal of their assistance. (p. 28)

Plurality of Viewpoints: Compatible or Not?

The presence of divergent viewpoints implies potential for plurality in the way type 2 diabetes is perceived. For example, health professionals describe the impact of type 2 diabetes in ways that vary substantial from those voiced by people with diabetes. As noted previously, health professionals tend to emphasise the physiological implications of diabetes, and its effect on the body. In contrast, people with diabetes describe the impact of diabetes in more holistic terms, pointing to the changes diabetes can bring about in social functioning, and the ongoing stress and frustration that often accompany self-management. This distinction has been highlighted in previous empirical research (e.g., Hornsten et al., 2004). Cultural differences regarding the nature and meaning of 'health', as outlined at the beginning of the preceding section, further increase the potential for differences in opinion. It is plausible that people looking at diabetes from different angles will identify different factors as the cause of variation in health-related behaviour, or clinical outcomes associated with diabetes.

A practical example may help illustrate this point. Lower limb amputation is a highly distressing, long-term consequence of uncontrolled diabetes. From a biomedical viewpoint, this is due to underlying biochemical and metabolic pathology; from a behavioural psychology viewpoint, failure to complete necessary self-care behaviours (poor diet, missed medication, lack of exercise) is to blame. A person with diabetes may state that their own inability to accept they had diabetes for a period of years after diagnosis (denial), and frustration over the difficulty of achieving good glycaemic control, meant they did not take good care of their diabetes and these psycho-social factors are held responsible for the amputation. Viewed from Te Ao Māori, the experience of compromised bodily wellbeing is inextricably tied to family (te taha

whānau), emotional (te taha hinengaro), and spiritual (te taha wairua) wellbeing. These differing perspectives on the experience of illness may appear to contrast with each other. However, in the view of the present author, these are not incompatible, and each has validity.

These viewpoints may coalesce to form a chain of causal associations. The first link in this chain is the connection between psychosocial and cultural factors, and health-related behaviour. The examples given in the previous section serve to explicate clear connections between sociocultural environment and health related behaviour (e.g., diet), giving a detailed illustration of the way in which cultural beliefs and norms may influence in diabetes self-management. Psychological attributes (e.g., motivation) and coping styles (e.g., use of avoidance or denial) are also liable to impact on self-care. Differences in health behaviour act as significant determinants of metabolic control, and this in turn influences clinical outcomes such as retinopathy and nephropathy. In this way, a chain of associations between cultural environment, psychosocial characteristics, individual behaviour, metabolic parameters, and clinical outcomes, can be seen. This provides some basis for integrating the divergent viewpoints (cultural, behaviourist, patient, clinical practitioner) identified previously. Diabetes researchers should be encouraged to utilize theoretical frameworks that unify more than one perspective on diabetes. In this way, research findings may assist in creating a more comprehensive understanding of diabetes self-management (Gentili, Maldonato, Grieco, & Santini, 2001; Jack, Liburd, Vinicor, Brody, & Murry, 1999).

One example of a theoretical approach that embodies this idea is the ecological model presented by Fisher et al. (2005). There are four levels in this model: (1) community and policy; (2) system, group, culture; (3) family, friends, small group; and (4) individual, biological and psychological. The four layers are arranged in a hierarchical manner moving from the wider macro-environment to the micro-environment. The implication is that each underlying layer will shape the layer above. For example, culture and group systems might influence the familial environment, and this in turn is likely to have a measurable impact on individual and biological functioning. Fisher et al. present this structure as a model of the potential resources and supports available for diabetes self-management. It is helpful to provide a 'big picture' of the various factors that may coalesce to produce differential patterns of self-care (good versus poor).

This model serves to remind us that it is possible to look at the determinants of diabetes self-care from many angles. The hierarchical structure ties ecological variables such as social context to individual factors (beliefs and behaviours). Further, rather than separating these viewpoints and implying they may be incompatible, the framework suggests these may work together to form a causal 'chain of associations'. For example, good glycaemic control is partly dependent on a healthy diet (with both linked also to body weight); but healthy eating patterns are often dependent on public policy that ensures such foods are affordable, and conveniently accessible (Fisher et al., 2005; Williams, Oehley, Rush, & Simmons, 2006). This model suggests it may be useful for researchers to measure variables at more than one level in the theoretical framework to provide a more comprehensive picture of diabetes self-management and its determinants. Glasgow (2005) presents a similar conceptual framework under the label 'pyramid of psychosocial factors'. This presents four levels (culture, context, close relationships, and personal coping). In the context of the present study, attention will be focused on variables that lie with the first two levels of these models (individual beliefs and behaviour, and key interpersonal relationships). However, the impact of macro-environmental variables (such as community, policy, and culture) is explicitly acknowledged.

STAYING WELL WITH TYPE 2 DIABETES

The second part of this chapter examines the importance of self-care in type 2 diabetes. It begins by focusing on what is known about the self-management process, acknowledging the inherent challenges and complexities that accompany chronic illness. Research shows that poor self-care has high costs, and that a large proportion of the 'burden of disease' created by diabetes is preventable through good self-management. Despite growing technical advancement in the field of medicine, "optimal management is not reaching many, perhaps the majority, of the people who could benefit" (International Diabetes Federation Clinical Guidelines Task Force, 2006, p. 579). In fact, recent literature suggests that mean HbA_{1c} among people with diabetes in the United States has actually *increased* over the past decade (Gerich, 2005). It appears that less than 40% of people with diabetes achieve good glycaemic control (defined as an HbA_{1c} below 7%) (Bergenstal & Gavin, 2005). The puzzle of how best to encourage people to take care of themselves, remains. Above all,

clinicians and researchers struggle to find good answers to two fundamental questions: (1) why is concordance with medical advice so variable? And (2) how best can we encourage good diabetes self-care? Gaps in our scientific knowledge, and directions for future research are discussed.

The Importance of Self-Care

For people with type 2 diabetes, active participation in self-care activities is pivotal to staying well (Fisher et al., 2005; Thorne, Paterson, & Russell, 2003; Watkins et al., 2000). As noted by Bandura (2005, September), "self-management is good medicine. If the huge benefits of these few habits were put into a pill it would be declared a scientific milestone in the field of medicine" (p. 11). Research has demonstrated that self-management is an important determinant of illness outcomes in diabetes. The Diabetes Prevention Program (DPP) (The Diabetes Prevention Program Research Group, 2002) showed that the benefits of lifestyle change extend to those who have impaired glucose tolerance, but have yet to reach the threshold for a diagnosis of type 2 diabetes. Findings reported in the DPP suggest behavioural interventions can be a powerful tool (Herman et al., 2005); in this study the benefits of lifestyle intervention outstripped those produced by a medical intervention (metformin) in terms of delaying the development of type 2 diabetes (by 11 years versus 3 years), and reduction in the absolute incidence of diabetes (20% versus 8%). The UK Prospective Diabetes Study (UKPDS) has also demonstrated that intensive management of blood glucose can improve metabolic control and reduce microvascular complications. At 10 year follow-up the intervention group (intensive management) showed an 11% reduction in HbA_{1c} in comparison with the conventional treatment group (UK Prospective Diabetes Study (UKPDS) Group, 1998b). The intervention group also demonstrated a 25% reduction in the risk of microvascular endpoints (e.g., retinal photocoagulation). However, it should be acknowledged that tight glycaemic control may come at some cost, for example, the UKPDS intervention group experienced more hypoglycaemic episodes than those on conventional treatment ($p < .0001$) (UK Prospective Diabetes Study (UKPDS) Group, 1998b).

Emphasis on the importance of *self*-management is consistent with emerging themes in contemporary medical practice. One example is literature highlighting the benefits of patient empowerment and patient-centred care, both within general medicine (Little et

al., 2001a, 2001b; Michie, Miles, & Weinman, 2003; Paterson, 2001; Stewart, 2001), and for diabetes specifically (Anderson et al., 2000; Anderson & Funnell, 2005; Colagiuri & Peyrot, 2006; Funnell & Anderson, 2005; Gentili et al., 2001; Novo Nordisk Pharmaceuticals, 2004; Pooley, Gerrard, Hollis, Morton, & Astbury, 2001; WHO Regional Office for Europe and International Diabetes Federation, 1989).

The contribution people with diabetes make to the management of their illness is widely recognised by health professionals. For example, a report summarising the literature on quality of health care and patient-provider interactions notes that:

Although health care providers can provide helpful (and sometimes less helpful) recommendations, advice, and counselling, it is the patient who must decide which strategies to put into practice and experience the consequences . . . of self-care actions. Patients and their families, not health care professionals, are responsible for the management of their diabetes. (Glasgow et al., 2001, p. 125)

Although some researchers may position self-care and clinical care as quite separate, recent diabetes literature suggests these are closely linked and interdependent (Fisher et al., 2005). Evidence-based advice, clearly communicated to the patient in a way that is easy to understand and follow, is a key contributor to good self-management. On diagnosis, few people with diabetes will *inherently* know what to do to take care of their diabetes; further, the plethora of information available on diabetes is not always of a similar high standard (in particular, this applies to web-based literature). Nor will most patients be aware of the pharmacotherapy regimen that will offer greater benefit for them. Thus clinical care and sound medical advice play an important role in shaping good self-management strategies. However, the reverse is also true. As noted by Fisher et al. (2005, p. 1529), "without self-management, however, expert clinical care will fall far short of its potential, through patients' failure to use prescribed medications or to implement management plans". This discussion serves to illustrate that self-care cannot be considered in isolation from clinical care, and the reverse is also true.

Variation in Self-Care

There is wide recognition of the importance of self-management for people with type 2 diabetes. Yet evidence shows there is substantial variation in actual self-care practices (Delamater, 2006); many people with type 2 diabetes have suboptimal glycaemic control as a result. As noted by Aikens, Bingham and Piette (2005, p. 682), "Although recent progress in medical therapies has greatly enhanced the management of diabetes mellitus (diabetes), unsatisfactory medical outcomes remain common". The extent of variation in self-care practices is difficult to determine accurately, partly due to the reliance on self-reported behaviour, and the plethora of instruments used to assess diabetes self-care in previous research. The amount of variation in self-care may depend on the self-management dimension. In general, it would appear that people with diabetes follow recommendations regarding oral medication and/or insulin more closely than they follow advice regarding lifestyle changes (diet or exercise prescriptions) (Delamater, 2006). Empirical evidence suggests people report fewer difficulties with insulin treatment compared with other aspects of self-care (Toljamo & Hentinen, 2001). Among the various dimensions of behavioural self-care, barriers to dietary self-management appear to be the most frequently reported (Glasgow et al., 1997). Findings from the Diabetes Attitudes, Wishes, and Needs (DAWN) study indicate that among people with type 2 diabetes self-reported adherence to the prescribed medication regimen was just under 80%; adherence to medical advice regarding blood glucose monitoring was somewhat lower, at 64%. However, adherence to dietary and exercise recommendations was much lower (37% and 35%, respectively) (Peyrot, Rubin, Lauritzen, Snoek et al., 2005).

The benefits of good metabolic control have been verified in large, robust studies such as the UK Prospective Diabetes Study (UKPDS) and the Diabetes Control and Complications Trial (DCCT) (The Diabetes Control and Complications Trial Research Group, 1993; UK Prospective Diabetes Study (UKPDS) Group, 1998b). However, positive changes in glycaemic control demonstrated as a result of comprehensive interventions such as the DCCT, are not easy to sustain over time (Wolpert & Anderson, 2001). The pressures on people with diabetes to maintain good self-management are immense. As a result, some patients may lie to practitioners about modifications they made to the prescribed self-care plan (Matthews & Lloyd, 2005), because they believe open discussion would lead to an expression of disapproval from

their health professional (Paterson, 2001). There are many ways people with diabetes may choose to manage their self-care; some adhere strongly to the prescribed regimen, others use flexible planning, and finally, a number of people neglect to become actively involved in their self-care (Toljamo & Hentinen, 2001). Previous research has sought to make a conceptual distinction between intentional, and unintentional non-adherence (Griva et al., 2000). A recent review of adherence among people with diabetes mellitus highlighted demographic characteristics, psychological factors (belief in the seriousness of diabetes, coping strategies), family relationships, and the patient-provider relationship as playing an important role in determining self-care behaviour (Delamater, 2006).

Previous diabetes literature states “patient non-adherence is a well-recognized although poorly understood phenomenon. . . . Failure to comply with health regimens is extremely costly both in economic terms and the health status of individuals” (Lo, 1999, p. 418). The personal consequences of non-concordance with medical advice among people with diabetes are serious. These can include blindness, lower limb amputation, renal failure, and premature death, as outlined earlier in the current chapter. To summarise, concordance with prescribed medical regimes is highly variable. As DiMatteo et al. (1993) have noted, “failure to adhere to treatment recommendations can significantly limit the effectiveness of modern medical care” (p. 93). Although the prevalence and significance of non-adherence is well recognised, much less is known about why self-care patterns vary so much or what can be done to reduce this variation (Jack et al., 1999). As suggested in previous literature, if we want to improve diabetes self-management, we must first “understand why nonadherence occurs” (Delamater, 2006, p. 71).

Challenges of Self-Management

Diabetes mellitus is accurately described as “one of the most psychologically and behaviourally demanding of chronic medical illnesses” (Ciechanowski, Katon, & Hirsch, 2002, p. 731). It is clear that many people with diabetes struggle to implement good self-care. The challenges associated with self-management are further magnified by the need to maintain these healthy self-care habits for extended periods of time; in most instances, for life. People without diabetes, including researchers, may fail to appreciate the magnitude of such challenges. Therefore, in the context of the present

study, it is important to examine some of the main challenges that commonly accompany the experience of living with type 2 diabetes. There can be many reasons why people struggle to stick to the self-care regime prescribed for them, and a number of key issues emerging from previous research are summarised below. This discussion will focus on the difficulties associated with active behavioural self-care.

Diabetes self-care can be complex and challenging (Hampson et al., 1990). It requires an intensive personal commitment, both in terms of cognitive resources and of emotional energy. Good diabetes management is prefaced on accurate knowledge and sustained motivation. Research shows many people with diabetes have inaccurate perceptions about what they should be doing to take care of their diabetes (Simmons et al., 1994). Further, a large proportion report that diabetes imposes an unwelcome and highly taxing emotional burden; frustration and guilt over poor self-care are common experiences (McCord & Brandenburg, 1995; Skovlund et al., 2005). Many people with diabetes report feeling 'burnt out' by ongoing demands of diabetes self-management (Rubin, 2005). The chronic nature of this illness further exacerbates the emotional burden imposed by diabetes. There is, quite simply, no respite from the demands of good self-management (Funnell & Anderson, 2005).

The treatment regimen prescribed for people with diabetes commonly consists of both lifestyle and medical prescriptions. For example, exercise and dietary changes coupled with oral hypoglycaemic agents and/or insulin. Research intimates that certain aspects of the treatment regimen are particularly problematic. Among prescribed lifestyle changes, moderation of eating patterns appears to be most difficult. Patient narratives presented previously in the current chapter demonstrate this emphatically. Glasgow et al. (1997) asked people with diabetes to indicate the frequency with which they experienced barriers across four dimensions of self-care (diet, exercise, glucose testing and medication use). Averaged scores showed that dietary barriers were most frequently reported, and barriers to medication use were least frequent. Within dietary self-care the home environment was identified as presenting the greatest number of barriers, in comparison with food purchasing and trips away from home. Use of insulin therapy is another aspect of the treatment regimen that holds negative connotations for many people with diabetes (Peyrot, Rubin, Lauritzen, Skovlund et al., 2005). The actual somatic experience of subcutaneous insulin may be unpleasant, particularly in comparison with the euphoria that accompanies elevated blood sugar (Leventhal et al.,

1992). Further, without careful management the use of insulin increases the risk of a hypoglycaemic episode, an unpleasant experience that has serious health consequences if an appropriate and timely response is not forthcoming.

Another important challenge for people with diabetes is to appreciate the seriousness of this illness in the *absence* of noticeable adverse symptoms. Research by Murphy and Kinmonth (1995) using narrative accounts from people with non-insulin dependent diabetes, suggests there is a strong connection between patients' understandings of diabetes and symptoms. The authors of this article provide a very succinct description of this association: no symptoms, no problem. This theme also emerges from physician narratives, which emphasise the "difficulty of getting asymptomatic patients to see the long term consequences of uncontrolled diabetes" (Loewe et al., 1998, p. 1271).

Self-regulatory literature suggests it is harder to convince patients that they have an illness – such as diabetes – when they are largely asymptomatic (Leventhal et al., 1992). From a very young age we learn that symptoms are indicator of illness. If we feel unwell, we should seek advice from a health professional. There is considerable stigma placed on people who appear well, but are claiming to be sick (hypochondriacs). Thus symptoms legitimise a belief that we are sick. Symptoms also prompt efforts to help us become well again. This can include both self-care (e.g., resting, over-the-counter self-medications), and the search for professional assistance (e.g., visiting a doctor or nurse). As noted by Cameron and Moss-Morris (2004, p. 93) "we are conditioned from childhood to view symptoms as reflecting severity and progress of disease." However, many chronic illnesses, including diabetes, have very few symptoms in the initial stages. Because we rely on symptoms to tell us when we are ill, and how seriously ill we are, and because people with newly diagnosed type 2 diabetes often show very few symptoms, it may be difficult for people to comprehend the seriousness of this condition. This is evident in everyday discourses that describe type 2 diabetes as the 'mild kind' (Scott & Brown, 1989). Such cognitive patterns may severely hamper efforts on the part of health professionals to encourage active behavioural self-care, primarily because the patient does not believe they have a serious illness. Thus the absence of significant adverse symptoms may mean it is difficult for people with type 2 diabetes to comprehend the seriousness of this

condition. As a result they may see little need to invest their time in active self-care practices or make any significant changes to their current lifestyle.

The proximity of treatment to outcome may present an additional challenge. Secondary prevention through good self-care is a key aim in diabetes self-management. However, this is often a very distal goal (Wolpert & Anderson, 2001). In the absence of current symptoms, it may be difficult to convince patients of the serious need to increase self-care in order to prevent complications that may compromise wellbeing down the track. Furthermore, they may be encouraged to take oral medication that does not have any immediate positive bodily consequences they can identify (makes them 'feel better'). Both these factors may contribute to non-adherence with medical advice, and treatment drop out over time (Leventhal et al., 1992). As noted by Watkins et al. (2000):

Although adherence to diabetes-specific health behaviour is predictive of increased glycaemic control, the clinical benefits of diabetes self-management are often long term and unobservable to patients, and patients may see no relationship between glycaemic control and quality of life. (p. 1515)

While researchers recognise adherence to recommended self-care routines is often poor (Hampson et al., 1990), the puzzle of how best to encourage people to take care of themselves continues to perplex. Information from psychological research could make a potentially useful contribution. First, by identifying variables that influence self-care practices. Second, by using this information to develop interventions that, through targeting key variables, are efficacious in improving self-management. Because the emergence of effective interventions is reliant on sound scientific inquiry, basic research is needed to help inform and guide the development of interventions to improve self-care.

Although previous research has sought to examine diabetes regimen adherence, this has been plagued by a number of common methodological weaknesses (Glasgow et al., 1997), including failure to develop research questions within an appropriate conceptual framework (atheoretical studies), the use of small samples that do not represent the population of research interest, and failure to employ multivariate

analyses that enable statistical control of medical and demographic characteristics. At present, the process of diabetes self-management is not well understood, which is partially the product of observed limitations in methods of scientific inquiry. In comparison with the voluminous medical literature pertaining to diabetes mellitus, few studies have sought to apply a psychological approach to the study of diabetes, which has also served to further limit our knowledge of the self-management process. We therefore know only a limited amount about the factors that influence diabetes self-care, and as a consequence it is hard to identify intervention strategies that are likely to be most effective in helping people with diabetes to *help themselves* stay well. As noted by Hampson, Glasgow, and Strycker (2000, p. 38), “the psychological processes by which interventions affect self-management behaviour are not well understood”. Creating a better understanding of the self-management process should be a key goal for future diabetes studies. Research that employs rigorous scientific methods of enquiry (representative samples, multivariate analyses, prospective design) will offer greatest benefit.

PSYCHOSOCIAL FACTORS THAT MAY HELP PROMOTE GOOD SELF-MANAGEMENT

As reiterated in the previous sections, there is considerable variation in diabetes self-care practices. It is apparent that clinical advice is only one among many factors that influence decisions about self-management of diabetes. Exploration of psychosocial variables has been identified as a potentially fruitful direction for future research. Health psychology offers a number of conceptual frameworks from which to begin investigating diabetes self-management. For example, the health belief model, social cognitive theory, health locus of control theory, theory of reasoned action, attachment theory, social learning theory, and theory of miscarried helping have all been utilized in the context of diabetes (e.g., Albright, Parchman, & Burge, 2001; Allen, 2004; Ciechanowski et al., 2002; Hayes et al., 2000; Hurley, 1990; Jenkins, 2003; Lewis & Bradley, 1994; McCaul, Glasgow, & Schafer, 1987). Research findings have identified a number of psychosocial variables that are related to differences in diabetes self-management behaviour and/or glycaemic control, including perceived seriousness of diabetes, vulnerability to diabetes, and beliefs regarding the benefits of treatment (Lewis & Bradley, 1994), motivation and knowledge (Pennings-Van der Eerden, 1990),

diabetes-related self-efficacy (Griva et al., 2000; Hurley & Shea, 1992; Williams & Bond, 2002), optimism (Rose et al., 2002), secure versus fearful attachment style (Ciechanowski et al., 2002), neuroticism (Gordon et al., 1993), and internal locus of control (Tillotson & Smith, 1996).

Previous psychological research has identified two core groups of variables that may play pivotal roles in diabetes self-management (Glasgow et al., 1997). The first relates to individual cognition, and has been referred to as the 'internal environment'. The second group of variables are embedded with the interpersonal milieu that surrounds everyday experience, and are labelled as 'social-environmental' or interpersonal factors. There has been limited empirical investigation of social context as a potential determinant of self-care behaviour among people with type 2 diabetes (Fisher et al., 1998). This can be identified as a salient issue for future research to address. The combination of intrapersonal and interpersonal variables offers intuitive appeal. First, it fits with the reported experiences of people with type 2 diabetes. As discussed previously in this chapter, patient narratives emphasise the impact of individual beliefs (e.g., a belief that diabetes is serious as a motivator of self-care), while also explicating the important role interpersonal relationships can play in determining self-care choices (e.g., familial support, the advice of trusted health professionals). Second, the dual focus on social and cognitive variables fits well with the social-cognitive approach prevalent in quantitative health psychology. Thus individual beliefs/representations and social-environment are two of the "most important factors influencing diabetes care" (Glasgow et al., 1997, p. 556). These constitute key areas of interest in the present study. A concise overview of research findings relating to each dimension is therefore presented in the following sections.

Psychological Beliefs and Representations

A number of previous studies have sought to examine psychological beliefs that may shape diabetes self-management behaviour. Research findings have, for example, highlighted the importance of self-efficacy and optimism (Rose et al., 2002). Previous psychological literature has described successful diabetes management as a classic example of the self-regulatory process in action (Petrie, Broadbent, & Meechan, 2003). The common sense model (CSM) (Leventhal et al., 1992; Leventhal, Meyer, & Nerenz, 1980) highlights the pivotal role of 'self' in illness management; conceptually, this sits

nicely with the emphasis on 'self-management' in type 2 diabetes. A further feature to recommend the CSM is its process-orientated presentation of illness management. A number of studies have used this approach to explore the psychological variables that may influence diabetes self-care. A concise overview of research in this area reveals two primary streams: the first focuses on 'personal models' (e.g., Hampson, Glasgow, & Foster, 1995; Hampson et al., 2000; Hampson et al., 1990; Skinner, Hampson, & Fife-Schaw, 2002); the second seeks to examine illness and treatment 'representations' (e.g., Barnes, 2000; Griva et al., 2000).

On close inspection of theoretical foundations, it becomes apparent that both approaches are modelled on self-regulatory theory (Lange & Piette, 2006). Therefore, although the linguistic terminology varies, the conceptual basis for both streams of research has striking similitude. This equivalence is nicely illustrated by Glasgow et al. (1997) who state "personal models are patients' representations of their illness, including disease-related beliefs, emotions, knowledge, and experiences. These representations guide . . . subsequent disease-related behaviors such as self-management" (p. 556). Diabetes research employing self-regulatory theory has shown that psychological cognitions are related to differences in self-management behaviour (e.g., Barnes, 2000; Griva et al., 2000; Hampson et al., 1995; Hampson et al., 1990; Skinner & Hampson, 1998; Skinner et al., 2002; Watkins et al., 2000). Multivariate analyses indicate that illness representations can account for a significant portion of variance in self-care (e.g., Griva et al., 2000; Hampson et al., 2000). Previous literature has suggested two variables may play a particularly salient role in diabetes self-management; these are perceived 'seriousness' (Hampson et al., 2000) and 'control' (Clark & Asimakopoulou, 2005). The relationship between representations and diabetes self-care will be discussed in further detail in chapter 3.

Psychology emerged out of a positivist tradition that has taken a strongly individualised view of behaviour. However, recent health psychology literature has urged researchers to consider the connections between social factors, and behaviour. Steptoe and Wardle (2004) conclude that "health behaviours are determined by a range of personal and sociocultural factors, and need to be understood within the broad context of people's lives" (p. 46). This resonates strongly in relation to type 2 diabetes.

Research applying an ecological approach to diabetes has emphasised the importance of environmental context (Jack et al., 1999), and the value of eliciting explanatory models from people with diabetes (Galazka & Eckert, 1984). As outlined previously in the current chapter, stories from people with diabetes emphasise that this condition has a pervasive impact on their everyday life experiences. Empirical investigation has shown barriers located with the social milieu (e.g., travelling, unexpected events, eating away from home, purchasing food) may have a negative impact on diabetes management. In a large study ($N = 2,056$) multivariate analyses showed greater barriers are associated with less healthy eating patterns, less exercise, and reduced glucose testing (Glasgow et al., 1997). Variables located within the social context may also act in a health-promoting manner. For example, family members and health professionals constitute two of the most important potential resources to encourage good diabetes self-management, and support maintenance of self-care over time. Narratives from people with diabetes illustrate that social communication can play an important role in determining self-care behaviour. In the context of the present study two particular sources of socio-medical communication have been selected as variables of core research interest. These are the familial environment, and patient-provider relationship. At a conceptual level relationships with family and diabetes clinicians are positioned as representatives of illness-related social context. An overview of diabetes research in each area is provided in the following sections.

Clinical Partnerships

Good diabetes management is prefaced on both good *self-care*, and access to high quality *health care*. Almost all people with diabetes seek the advice and opinions of people positioned as 'experts' in the health industry (doctors and nurses). The overwhelming proportion attempt to implement this advice to the best of their abilities, albeit with differing levels of success. If left to their own devices very few people with diabetes will self-diagnose, develop an effective self-care routine, successfully maintain this over multiple years (with appropriate adjustment for changes in metabolic function), and deal appropriately with complications as they, inevitably, arise. This illustrates the extent to which interaction with health-care services is a necessary component of successful diabetes management. Previous psychological literature suggests the doctor-patient dynamic may play a major role in determining concordance with medical advice (Leventhal et al., 1992). Empirical investigation has demonstrated evidence of

a relationship between doctor-patient relationship and active diabetes self-care (Rose et al., 2002). The importance of positive clinical partnerships has been strongly emphasised in diabetes literature reviewing key issues affecting diabetes outcomes (Glasgow et al., 2001).

Previous literature has taken a rather haphazard approach to examining the link between clinical partnerships and diabetes self-care and outcomes. Studies have assessed patient-provider relationship using measures of attachment style (Ciechanowski et al., 2002). Other studies have focused on 'satisfaction' with medical professionals (e.g., Albright et al., 2001; Glasgow & Toobert, 1988; McCaul et al., 1987), or patient-provider communication (Aikens et al., 2005), as predictors of self-care activities. Some studies have used generic measures of the clinical relationship (e.g., the Interpersonal Processes of Care (IPC) questionnaire, or Relationship Scales Questionnaire (RSQ), or Medical Interview Satisfaction Scale (MISS)); others have sought to develop diabetes-specific instruments (e.g., the Diabetes Treatment Satisfaction Questionnaire); and some researchers have also used both approaches within a single study (e.g., Aikens et al., 2005). There is thus considerable variation in the operational definition of patient-provider relationship in the context of diabetes.

Nonetheless, evidence has demonstrated that the quality of interactions between patient and health professionals is associated with differences in self-care (Albright et al., 2001), use of active coping strategies (Rose et al., 2002), and glycaemic control (Aikens et al., 2005; Ciechanowski et al., 2002). Some research findings suggest satisfaction with medical care and patient-provider relationship may show stronger relationships with medical aspects of the self-care routine (insulin administration and glucose testing), than lifestyle elements such as diet and exercise (McCaul et al., 1987); other studies report mixed results (Albright et al., 2001). In the present study, explicit focus was placed on identifying core dimensions that constitute a good patient-provider relationship in diabetes. This was premised on a belief in the value of subjective evaluations by patients, and a privilege of the patients' position in this assessment. This approach was based on two factors: a conviction that it is the patient's *representation* of the clinical relationship not the objective interactions that is most important in determining self-care behaviours; and a perception that the way health professionals view their relationship with the patient is less important than the patients' assessment of this relationship as a *determinant* of self-care. Such

explanatory principles are consistent with the construction of the doctor-patient relationship proposed in previous diabetes research (e.g., Rose et al., 2002).

A systematic review of patient priorities for general practice care has identified five primary dimensions of health care (Wensing, Jung, Mainz, Olesen, & Grol, 1998). The first two relate to organisational characteristics, for example, waiting times, access, and co-ordination. The third, 'medical care', is a description of technical competency and effectiveness in promoting good health. The fourth and fifth aspects are associated with the interpersonal component of care, and are labelled 'relational and communication' and 'information and support'. In the present review, the importance of good organisational systems, technical competence and the use of evidence-based practice are acknowledged. However, attention will focus on those aspects of care that are most central to the creation of a good patient-provider *relationship*. There are many components that may constitute a positive clinical partnership in diabetes care – an overview of key elements is provided below.

Rapport and trust are an important part of constructive clinical partnerships (Delamater, 2006; Galazka & Eckert, 1984; Wensing et al., 1998), forming the prerequisite foundation upon which a therapeutic alliance rests (Pooley et al., 2001). If there is an absence of trust, it becomes very difficult for health professionals to establish any meaningful professional connection with the patient, and this is liable to have a negative impact on concordance with medical advice. Establishing a clinical relationship where the patient feels they (1) can trust their doctor/nurse, and (2) are cared about, appears crucial to successful collaborative management of diabetes (Tibbetts, 2003). Mutual respect is also important (Edelwich & Brodsky, 1986). Evidence suggests health professionals may express a commitment to patient-centred care, but then fail to 'walk the talk' in their clinical practice (Paterson, 2001). An excellent example is the doctor/nurse who asks the patient for their opinion regarding a self-management issue, and then proceeds to discount this on the basis that this knowledge is experiential, and therefore lacks certain validity. Paterson (2001) refers to this as the myth of empowerment. She notes that "individuals with chronic illness can develop sophisticated awareness of their body's patterns and responses that bear little resemblance to the textbook picture, professionals are sometimes reluctant to acknowledge this expertise as credible" (p. 575). This can be a source of great

frustration for people with diabetes, particularly for those who have a high sense of mastery over their diabetes (Paterson et al., 1999).

Such interactions could be partially explained by the nature of medical training, which effectively socialises doctors and nurses to take on the role of 'health experts'. A good patient-provider relationship may require joint sharing of the 'expert' position, and this may be a significant adjustment for many highly qualified health professionals. Even those who make an active effort to treat their patients with care and respect may find they occasionally slip into this, all too familiar, expert position. To summarise: trust, rapport, and respect are crucial components of a healthy patient-provider relationship. These may be subsumed under the label 'humaneness'. Research into patient priorities has shown that humaneness is ranked as the most important attribute of good medical care (Wensing et al., 1998).

Health psychology suggests information sharing between patient and health professional is "far more haphazard and informal than one might expect and the patient is left with a great deal of latitude to invent causes, labels, consequences, and timelines for specific complaints" (Leventhal et al., 1984, p. 232). Diabetes research has emphasised the importance of good communication between patient and health care provider (Fisher et al., 2005; Fisher et al., 1998; Pooley et al., 2001). Health psychology literature has emphasised the importance of congruence between viewpoints (Ogden, 2000). It has been suggested that treatment adherence will be greater when patient and provider share common views about the illness, appropriate treatment, and indicators of successful outcome (Fisher et al., 1998; Leventhal et al., 1992). Conversely, if the patient and health provider see diabetes in very different ways, this is likely to have a negative impact on concordance with medical recommendations (Clark & Asimakopoulou, 2005; Galazka & Eckert, 1984). In a British study of outpatients with insulin-dependent diabetes, routine consultations showed "there was considerable disagreement between doctor and patients about the causes of the problems under discussion and, indeed, about the nature of the problems" (Gillespie & Bradley, 1988, p. 74).

Health professionals may find it difficult to communicate in a way that is easy for patients to understand. As noted by one practice nurse who took part in a study by Pooley and colleagues "I don't think they can often understand that people don't

understand. They can't simplify it enough, they can't draw a picture for the patient to understand" (Pooley et al., 2001, p. 322). Recent research has tested whether the proposed relationship between communication and HbA_{1c} is dependent on self-care behaviour. Results reported by Aikens et al. (2005) did not support the predicted mediating relationship. It would appear that patient-provider communication (PPC) has a direct and positive relationship with glycaemic control. Diabetes-specific PPC also showed significant relationships with four self-care behaviours (eating, exercise, medication use, and blood glucose testing) (Aikens et al., 2005).

The theoretical foundations for diabetes education have shifted in recent years. As noted by Fox and Kilvert (2003, p. 1120), "traditional education for diabetes treats the patient as a receptacle for knowledge or a pot to be filled with information by doctors, nurses, and dieticians". This was often accompanied by a marked power differential between the patient (viewed as naïve layperson), and the 'expert' health professional (Delamater, 2006; Jenkins, 2003; Ogden, 2000). Imparting knowledge is no longer enough because, as noted by Glasgow and colleagues, "knowledge alone is insufficient to produce behavior change" (Glasgow et al., 2001, p. 125). Good communication should also seek to engage patients in dialogue regarding their illness, seek to determine their preferences and needs, and respond to these in appropriate ways. Increasingly, there has been emphasis on empowerment and shared decision making, as outlined below.

For a long time, medicine was a bastion of paternalism. People came to their doctor to be told what was wrong with them, and what to do about it. Today, there is increasing stress placed on shared decision-making and patient choice (Funnell & Anderson, 2005; Little et al., 2001b). A review of patient priorities in general practice found patients' involvement in decisions ranked as the third most important characteristic of good care (Wensing et al., 1998). The preference for active involvement in one's health care can be linked to rising consumerism (and empowerment of the consumer) within the health industry over the last quarter century (Coulter & Magee, 2003; Opie, 1998). Another contributing factor is the increase in literature that considers how health, illness, and treatment look through the patients' eyes (Apfel, 1995; Pooley et al., 2001; Stewart, 2001; Wolpert & Anderson, 2001; Woodcock & Kinmonth, 2001). In part, the movement towards shared decision-making reflects wider recognition that many people do not follow advice given by their doctor/nurse. If our focus is on

concordance with medical advice, the main benefit associated with shared decision-making is that patients who are actively involved in decisions about their treatment are more likely to feel ownership of these decisions – in a nutshell they have greater ‘buy in’ to the treatment plan. As a result, attempts to change health-related behaviour are more likely to be successful (Aikens et al., 2005).

There are many other benefits associated with shared decision-making. For example ‘taking charge’ of one’s diabetes can facilitate patient empowerment, and, most importantly, encourage greater communication about the details of the treatment plan. This creates potential opportunities for people with diabetes to raise any concerns they may have about self-care, or discuss perceived barriers to the designated treatment plan. Again, this type of transparent discussion can facilitate health behaviour change through acknowledgement and resolution of potential barriers identified by the patient. Shared decision-making is one example of patient empowerment in action (Funnell & Anderson, 2005). However, more fundamentally this reflects a shift in mindset among health professionals to recognise “the way in which living with chronic illness is linked to the social, emotional, cultural and psychological fabric of a patient’s life, and requires that patients become experts in the management of their own diabetes” (Pooley et al., 2001, p. 319). As eloquently stated by Colagiuri and Peyrot (2006, p. 12) “patient-centred care starts with the recognition that diabetes care is self-care”.

Coulter (2002) exhorts the benefits of shared decision-making, and links this to recognition of the patient’s expertise in the everyday experience of living with chronic illness:

The key to successful doctor-patient partnerships is to recognise that patients are also experts. Doctors are – or should be – well informed about diagnostic techniques, the causes of disease, prognosis, treatment options, and preventative strategies. But only patients know about their experience of illness and their social circumstances, habits, behaviour, attitudes to risk, values, and preferences. Both types of knowledge are needed to manage illnesses successfully. (p. 649)

This emphasis on partnership echoes sentiments expressed in the St Vincent Declaration on diabetes care and research (WHO Regional Office for Europe and

International Diabetes Federation, 1989). Diabetes literature suggests patient-provider relationships that help to motivate patient self-care can play an important role in creating positive outcomes for people with diabetes (Lo, 1999). This has generated considerable interest in clinical interactions that may encourage motivation, for example, through the use of motivational interviewing techniques (Fisher et al., 2005). To summarise key points, diabetes literature suggests shared decision-making and effective communication may help encourage active self-management and good glycaemic control (Aikens et al., 2005; Fisher et al., 2005). Patient-provider relationships that explicitly seek to empower and motivate the patient may help engage and sustain positive self-care practices.

Another aspect of the clinical partnership that deserves greater discussion is the value of a holistic approach to patient care. People may feel that a clinical consultation is like talking to a 'body mechanic':

For the patient, it is like listening to a mechanic telling him what he thinks of the old family car: ten things badly wrong, some parts will never function again, the best thing to do is to get rid of it. Get a new one for \$34,000. But with our bodies, there is no opportunity for total replacement. (Scott & Brown, 1989, p. 185)

Holistic care incorporates an awareness of life circumstances, and a willingness to make time for addressing psychosocial issues that often arise in the context of living with diabetes. This has been recognised in recent global guidelines for the management of type 2 diabetes (International Diabetes Federation Clinical Guidelines Task Force, 2006). Three areas have been selected for brief discussion. First, the need to address depression and alleviate the impact of elevated diabetes-related distress; second, the importance of factoring in social and life circumstances when planning self-care and treatment goals; and third, the positive impact discussion of psychosocial issues with the patient/family can have on quality of life and successful adaptation to life with diabetes. An overview of each is provided below.

Diagnosis of diabetes has a pervasive impact on one's life. It is not limited to the bodily consequences of this chronic illness. People with diabetes express a desire for health professionals who understand the wider impact of diabetes (Scott & Brown, 1989), and

who offer support for dealing with problems that arise in relation to diabetes, whether these be questions regarding the correct use of insulin, how to deal with social/family relationships that are interfering with diabetes self-management, or the impact of stress/depression on metabolic control. Good clinical care for diabetes should be attuned to the broader impact of diabetes; a holistic approach to patient care is highly recommended. As emphasised earlier in the current chapter, depression is a common comorbidity of diabetes. Research has shown that depression can compromise diabetes self-care because people are “robbed of the energy and motivation they need to follow their treatment plan” (Tibbetts, 2003, p. 190), and as a consequence depression can have a negative impact on metabolic control. Depression also results in a substantial loss of quality of life. Thus, for reasons relating to both quality of life and clinical outcomes, health care professionals must be vigilant in their detection of depression among people with diabetes, and active in their treatment of this condition. Diabetes literature suggests depression, anxiety, and disordered eating are frequently under diagnosed and too often untreated among people with diabetes (Rubin, 2005).

Diabetes-related distress could be described as a subclinical level of worry about diabetes. This should be viewed as distinct from overt clinical pathology in the form of, for example, major depression. Emotional distress about diabetes is highly prevalent (Rubin, 2005). Health professionals should ensure that the way they communicate with patients does not unintentionally exacerbate worries about diabetes, and therefore increase emotional distress. Discussion of diabetes-related complications requires a caring and emotionally intelligent approach. Although doctors and nurses may be highly skilled in the technical competencies of diabetes care, this does not mean they are equally skilful in the interpersonal management of people with diabetes. Some patients may not want to know much detail about diabetes, because they find such knowledge frightening (Pooley et al., 2001). Doctors and nurses need to be aware of this possibility, and adopt a flexible manner of communication depending on patient preferences for information, and existing level of anxiety about diabetes. At times, physicians may use fear of complications as a tool to drive home the message that good control matters (Loewe et al., 1998). Some suggest ‘scare’ tactics are needed to ensure people appreciate the seriousness of diabetes (Clark & Asimakopoulou, 2005); others believe such tactics have a negative impact on adherence to medical recommendations, and may hinder positive behavioural change (Delamater, 2006). Where such techniques are employed, they must be employed with caution. To

summarise, both depression and emotional distress about diabetes are common among people with type 2 diabetes (Pouwer et al., 2006). A good patient-provider relationship therefore requires attention to both the clinical and emotional needs that arise as a consequence of having diabetes.

Emotional support and alleviation of fear and anxiety has been identified as one of the eight primary dimensions of patient-centred care according to the Picker Institute (2003). However, enabling the translation of rhetoric promoting holistic care to standard medical practice is not straightforward. Findings from the DAWN study revealed 41% of people with diabetes had poor psychological wellbeing; further, the majority of health professionals believed psychological problems affected their patients' self-management behaviour (Peyrot, Rubin, Lauritzen, Snoek et al., 2005). However, many health professionals report difficulties accessing psychological services for people with diabetes (Australian Centre for Diabetes Strategies, 2004). Results of the DAWN study suggest current referral pathways do not facilitate easy access to experts in emotional and psychological matters where required. Only 12% of people with type 2 diabetes in this study had received health services to assist with psychological problems in the last 5 years (Peyrot, Rubin, Lauritzen, Snoek et al., 2005). Thus many medical professionals recognise the effect emotional distress has on people with diabetes but, as Rubin (2005) states, "fewer providers feel able to treat these problems, and very few patients are referred for treatment" (p. 172). In summary, many people experience difficulties with diabetes-related distress, but professional support for managing these difficulties is not easy to access.

Health professionals should also try to understand the patient's life circumstances, and factor in such circumstances when determining an appropriate treatment plan (Glasgow, 2005). It is not uncommon for health professionals to make suggestions for behavioural change that seem unrealistic to the patient based on their current life circumstances (resources and limitations) (Paterson, 2001). In recent diabetes literature there has been a strong push to 'address the person behind the disease'; this is exemplified in the Diabetes Attitudes, Wishes, and Needs (DAWN) programme. This appears to be an important component of a successful patient-provider relationship. People with diabetes express dissatisfaction with health professionals who fail to appreciate the difficulties of living with diabetes, for example, those who "don't care that you have to live with diabetes in a real world and that there are times when your

diabetes isn't the most important part of your life" (Paterson, 2001, p. 579). Conversely, practitioners who demonstrate appreciation of the demands of diabetes self-care and the constraints sometimes imposed by the social context of the patients' life (e.g., financial hardship/relationship difficulties) are hugely valued by people with diabetes. Having a doctor who 'understands me' has been identified as one of the most salient characteristics of a good patient-provider relationship by New Zealanders living with diabetes (Scott & Brown, 1989).

Narratives from people with diabetes suggest health professionals who recognise that diabetes affects family relationships, as well as one's physical state, can make a huge difference to helping people with diabetes live a fulfilling life. Edelwich and Brodsky (1986) note that having diabetes can be a significant obstacle to romance, and that prospective partners may be unwilling to make a life-time commitment to someone who they perceive is chronically 'unwell'. As noted by Davis (2006, p. 1019), "meeting a partner and maintaining a happy relationship when you have a long term condition such as diabetes can be a challenge". However, for many people, including those with diabetes, getting married and having a family is often a key life goal. Diabetes may sometimes act to thwart such plans. Prospective partners may be afraid of the effect diabetes might have on eating, socialising, or sex; concerned about the risk of having children with diabetes; or scared to watch a spouse suffer complications such as blindness or limb amputation (Edelwich & Brodsky, 1986; Kelleher, 1988). These are legitimate worries. Doctors and nurses who are open to discussing these issues with the person and their partner can have a huge impact on their patients' lives.

Although the use of clinical time for discussion of psychosocial issues may not sit comfortably in some biomedical circles, it is a good investment when one considers the huge impact it can have on quality of life through enabling achievement of big life goals such as a successful and happy marriage in which both parties are aware of, and prepared to deal with, the long-term consequences of living with diabetes. This is important in terms of quality of life, but the impact of an emotionally content and stable home life on diabetes self-management and glycaemic control also deserves mention. There are many other possible examples of an interactive relationship between glycaemic control, quality of life, and the social environment that the individual inhabits on a daily basis, but the connection between these is not always well recognised in

clinical practice. There are, of course, exceptions. David Scott (a diabetes physician in New Zealand) provides a heartening analysis:

Their concerns outside of physical health have to be integrated with what can be seen or measured in the body in order to be effective. An example would be concentrating on a woman's obesity when she has an alcoholic husband, or urging better diabetic control in a father whose son is facing a criminal court case. (Scott & Brown, 1989, p. 184)

In their study of self-care behaviour among people with type 2 diabetes, Albright et al. (2001, p. 360) conclude "the importance of family context suggests that family physicians, who spend considerable time addressing family issues, are well positioned to improve family understanding of diabetes and thereby the success of diabetes care they provide to patients and their families".

This discussion highlights some of the key features that appear to constitute a successful patient-provider relationship in the context of diabetes management. These features, many of which are described as characteristics of patient-centred care (Delamater, 2006), include: (1) the creation of a positive interpersonal dynamic characterised by high levels of trust, and strong rapport; (2) effective communication; (3) the opportunity for active participation by the patient, and an interactive style that encourages self-empowerment and motivated self-care action; and (4) an appreciation of the wider impact of diabetes, including both social and psychological aspects of the illness experience. Most health professionals are committed to providing good quality care, and many work hard to develop a positive therapeutic relationship with their patients.

It seems important to acknowledge that a successful patient-provider relationship can be difficult to achieve. There are many possible reasons. Some will inevitably relate to the attitudes of doctors and nurses (Haidet et al., 2002; Ogden, 2000), others barriers will come from patient attitudes and behaviour. Diabetes literature suggests poor clinical partnerships are dissatisfying for both parties. As noted by Galazka and Eckert (1984, p. 31), "lack of constructive communication can result in frustration, anger and, ultimately, dissatisfaction on the part of both the physician and the patient". This implies that, alongside positive dimensions of the clinical partnership, it may be

important to include measures of patient-provider conflict in future research. This would enable examination of the relationship between clinical conflict and diabetes self-management behaviour. To date, few studies have sought to explore the potential impact of poor clinical partnerships on diabetes self-care and illness outcomes. This is a pertinent direction for future study.

However, some of the most significant barriers to good diabetes care may lie outside the control of both patient and provider (Glasgow et al., 2001; Larme & Pugh, 2001). It is important to acknowledge some of these barriers, and in doing so, recognise that poor patient-provider relationships can arise from many circumstances that are not specifically related to either of the individuals involved. Even with good intentions and shared commitment from both patient and health care provider, it may be hard to realise the promise of optimal clinical partnerships under the constraints of 'real world' medicine. For example, the instigation of managed care models has placed increasing time pressure on clinical consultations. Doctors and nurses indicate that such pressure acts as a barrier to the provision of patient-centred care for people with diabetes (Woodcock, Kinmonth, Campbell, Griffin, & Spiegel, 1999); patients also report an awareness of time constraints (Paterson, 2001). In this way, organisational constraints imposed by external agencies may have a negative impact on clinical relationships necessary for good diabetes management (Pooley et al., 2001).

Family Context

Diabetes may have a pervasive impact on the family as a whole; clearly this is not limited to the person with diabetes (Edelwich & Brodsky, 1986; Kelleher, 1988; Rubin, 2005; Toljamo & Hentinen, 2001). Diabetes literature suggests the emotional impact of diabetes on family relationships can be strong. This has been alluded to above, as part of discussion explicating the personal impact of diabetes. Family members may feel embarrassed by the diabetes treatment (for example, insulin injections in public places or in front of peers), or find that prospective partners are unable or unwilling to commit to a relationship with someone who has a serious chronic illness (Edelwich & Brodsky, 1986). A husband may find it difficult to deal with sudden mood changes in their wife due to imminent hypoglycaemia, or feel they are being emotionally manipulated by the diabetes-related demands of their spouse. Siblings may feel left out and emotionally neglected because of the greater attention given to their brother or sister who has

diabetes (Edelwich & Brodsky, 1986). On the other hand, diabetes can also have a positive impact. For example, it may stimulate change in family dietary patterns, and help break down unhealthy lifestyle choices that were previously well entrenched as the habits of a lifetime (Edelwich & Brodsky, 1986). Fisher et al. (1998, p. 599) identify “the social network/context of diabetes management as residing with the family”. Essentially, this suggests the influence of other ecological factors (culture, community) work through the family; because the family forms the basis for interpreting health threats, and making decisions about how best to respond when illness is evident.

Previous literature suggests the familial environment can have a pertinent impact on self-management behaviour and adjustment to diabetes (Rubin, 2005; Wen, Shepherd, & Parchman, 2004). As noted by Scott and Brown (1989, p. 186), “it is at home where day-to-day battles are won or lost”. Kelleher (1988) provides an excellent discussion of this. Family members may provide practical help, for example, assisting with blood glucose testing or foot care. They may also learn to identify the signs of an oncoming hypoglycaemic episode, and act to pre-empt further deterioration in blood glucose. Families may also act as a psychological resource, encouraging people with diabetes to view themselves as healthy and normal (Kelleher, 1988). Many adults with diabetes identify their spouse as very important in buffering the emotional impact of diabetes, and preventing depression or elevated distress about diabetes (Kelleher, 1988; Scott & Brown, 1989). Earlier in chapter 1 attention was drawn to the impact of diabetes as it seen through the eyes of people who have diabetes, this underlined the important connections between the individual with diabetes and their familial environment. Narratives from people with diabetes clearly illustrate that family context can shape diabetes self-care in important ways, and that both positive and negative interactions occur.

Multivariate analyses have revealed that family support accounts for variation in self-care behaviour (glucose testing, insulin injecting, and diet), even when statistical control for demographic characteristics is applied (Skinner & Hampson, 1998). Albright, Parchman and Burge (2001) used a single item ‘my family understands my diabetes’ to measure social context in a cross-sectional study of self-management behaviour among Americans with type 2 diabetes. Social support demonstrated a significant association with three out of the four dimensions of self-care included in this study (exercise patterns, dietary habits, and medication use). Multivariate analyses

suggest that, among the various dimensions of diabetes self-care, family support may show the strongest connection with dietary management. The authors of this study conclude, "social context, specifically the family, is significantly associated with self-care behaviors. Attempts to improve self-care behavior should include the family members of the diabetic patient" (Albright et al., 2001, p. 354). This is consistent with multivariate results reported by Garay-Sevilla et al. (1995), where stepwise regression analyses revealed social support was significantly related to dietary self-care among Mexican people with type 2 diabetes. Social support also showed a significant relationship with medication use in this study. In a more recent study of older Mexican Americans with type 2 diabetes, family support demonstrated a positive correlation with dietary self-care, and exercise patterns (Wen et al., 2004). Similarly, results obtained in an Australian study of adults with diabetes showed family support was associated with better diet and exercise aspects of the self-care routine (Williams & Bond, 2002).

Wang and Fenske (1996) assessed family support in conjunction with other sources of support (friend, and diabetes group). Results showed that support systems accounted for 23% of the variance in universal self-care. Tillotson and Smith (1996) used regression analyses to determine whether social support accounted for differences in diabetes self-management among a relatively large, ethnically varied group of adults with type 2 diabetes. Research findings showed that social support was related to differences in self-care behaviour, but the reported association was small in magnitude ($Beta = .09, p < .05$). Glasgow and Toobert (1988) employed a prospective research design to determine whether social-environment variables could be used to classify people according to differences in self-management and glycaemic control across a six month timeframe. Discriminant-function analyses revealed that regimen-specific family support improved classification of participants in five of the seven analyses used to predict different dimensions of self-management behaviour; family support also contributed to the classification of participants' glycaemic control (low, medium or high). Although the Diabetes Family Behaviour Checklist-II (DFBC-II) includes both a positive and negative subscale, research findings showed the frequency of non-supportive family interaction did not predict self-care behaviour in this study (Glasgow & Toobert, 1988). This contravenes the results of an earlier study using the DFBC among people with type 1 diabetes (Schafer, McCaul, & Glasgow, 1986). Results reported by Toljamo and Hentinen (2001) suggest emotional and instrumental support is associated with good diabetes self-management practices. An interesting finding from

this study was that greater peer support was associated with worse blood glucose control. This suggests support from other people with diabetes may not always have a positive impact on self-care behaviour, although the authors of this study postulate that peer support is important in promoting emotional adjustment to diabetes (Toljamo & Hentinen, 2001). Further, not all studies have shown strong evidence of a connection between family relationships and adherence to the prescribed self-care routine (e.g., McCaul et al., 1987). Clearly, additional research in this area is required before firm conclusions can be made.

It is important to recognise that the family environment may not always have a health-promoting impact on diabetes self-management (Kelleher, 1988; Rubin, 2005). Family members can be both supportive and unsupportive. While family friction has been associated with poor metabolic control among young people, (Edelwich & Brodsky, 1986), diabetes-related familial tension can also arise in adult relationships. At times, one spouse may feel reluctant to assist the other with their diabetes self-management (Fisher et al., 1998). Alternatively, a husband or wife may become over protective of their spouse's health (Kelleher, 1988). In some instances diabetes self-care can become a source of disagreement between family members (Rubin, 2005).

One area that could benefit from greater empirical attention is the possible relationship between diabetes-related family conflict and self-management. Early diabetes research provides some support for the hypothesis that negative diabetes-related family behaviour is associated with poor self-care and worse glycaemic control (Schafer et al., 1986). Further, reported findings suggest these relationships are more likely to be present among adults with type 1 diabetes, compared with adolescents or children. The applicability of these results to people with type 2 diabetes, however, has been questioned (Glasgow & Toobert, 1988). Diabetes-specific family conflict is not necessarily the opposite of family support. It is plausible that these two variables may have quite differential bases, and should not be conceptualised as polar ends of one unified construct. For example, Glasgow and Toobert (1988) report no significant correlation between positive and negative subscales in the DFBC-II. Given that the overwhelming majority of research examining family context in diabetes has focused on children and adolescents with type 1 diabetes (Fisher et al., 1998), there is a need to recognise the importance of family context in diabetes management among adults

(Glasgow, 1994), and to consider the potential impact of both diabetes related support and conflict.

It is plausible that family support and conflict may also be related to individually held views about diabetes. This suggests relationships could exist between variables outlined at the beginning of this section (psychological beliefs and representations concerning diabetes) and family context. Previous research has provided empirical evidence to support this proposition. Skinner and Hampson (1998) present three possible relationships between social support, personal models (psychological variables), and self-care/wellbeing. Both direct relationships, and two types of mediating relationships (total and partial) were modelled. Results revealed direct relationships between family support, and blood glucose monitoring and insulin injections. The direction of these associations implied that greater family support was predictive of active self-management. None of the psychological variables (consequences or perceived control) accounted for variation in glucose monitoring or injecting. However, perceived control was predictive of dietary behaviour.

Hierarchical regression analysis was employed to test for possible mediation. Demographic variables were entered at step 1, followed by socio-economic status and family support at step 2. Perceived control was then entered at step 3 of the analysis. Family support showed a significant association with dietary self-management at step 2 ($Beta = .40, p < .001$); however, the strength of this relationship was attenuated ($Beta = .28, p = .038$) when perceived control ($Beta = .33, p = .017$) was entered into the regression model at the third step (Skinner & Hampson, 1998). The results of this regression analysis suggest the relationship between family support and dietary self-care is largely mediated through perceived control of diabetes. Because the $Beta$ for family support did remain statistically significant at the final step of the model, this does imply a small but statistically significant direct relationship is also present. Other research has suggested self-efficacy may act to mediate the relationship between family support and exercise self-care (Williams & Bond, 2002). Further examination of the relationships between family context and representations of diabetes is recommended. As there has been limited exploration to date of the role *emotional* representations may play in diabetes self-care, it could be useful for future research to determine whether family context variables (support or conflict) may influence the emotional representation of diabetes.

While the impact of family support on health is well documented, a conceptual account that clearly explicates the meanings of 'social support' and 'family support' has been less forthcoming (Fisher, La Greca, Greco, Arfken, & Schneiderman, 1997; Toljamo & Hentinen, 2001). Two main hypotheses have been promulgated regarding the types of relationship between social support and health (Ogden, 2000). The 'stress-buffering hypothesis' suggests the beneficial effect of social support works indirectly through an improved ability to cope with stress. Thus when faced with threats to health, social support improves the individual's ability to cope with this stressful situation by changing the appraisal of the problem (Ogden, 2000) (threat reduction), and this in turn results in an improvement in coping strategies. Previous diabetes research has proposed an interactive relationship between stress and family support; results provide some support for the stress-buffering hypothesis (Glasgow & Toobert, 1988). In contrast, the 'main effect hypothesis' suggests that social support, and its absence (Ogden, 2000), will have a direct impact on health. Empirical evidence has also shown a direct relationship between social support and diabetes self-management, as discussed previously in the current section. Family support has been constructed and measured in many different ways in diabetes literature. In a study of adults living in northern Finland, Toljamo and Hentinen (2001) identified five aspects of diabetes-related support: emotional and instrumental; informational; peer; negative; and financial. It has been suggested that practical support may be more helpful in situations where the problem is acute, and the solution can be clearly identified; conversely, emotional support may be more important in dealing with ongoing problems that are not easy to solve (Fisher et al., 1997).

Research by Lawrence Fisher and colleagues has identified four core components of family context that should be taken into consideration in diabetes research and intervention (Fisher et al., 1998): 'type of family relationship'; 'patient and spouse/partner beliefs and agreement'; 'current and foreseen stresses'; and 'allocation of disease management behaviours'. More recent research has emphasised the importance of family structure/organisation, family world view, and family emotion management in type 2 diabetes (Fisher et al., 2000). Research using this framework suggests the link between family context and diabetes management may vary according to ethnicity. For European-Americans with type 2 diabetes, family world view and family emotion management were related to self-management; for Hispanic-

Americans family structure/organisation was associated with differential self-care patterns (Fisher et al., 2000).

Diabetes researchers have also emphasised the need to distinguish between directive and nondirective social support. Nondirective support appears to be associated with better metabolic control, but directive support may have the opposite effect on diabetes management. Essentially, research findings suggest “cooperative support that does not take over responsibility for tasks appears beneficial” (Fisher et al., 1997, p. 140). The need to distinguish between structural descriptions of the social context (social networks), and the focus on functional descriptions such as social support, is generally well recognised (Toljamo & Hentinen, 2001). While extensive variation in operational definitions and limited conceptual clarity is evident, this should not detract from the importance of the family context in diabetes management. As mentioned previously, there is a dearth of literature examining the role of familial support in diabetes management among adults (Fisher et al., 1998). This can be identified as a pertinent area for future research.

Previous diabetes research has drawn attention to the profound connection between culture and family. Oomen, Owen, and Suggs (1999) provide an excellent discussion of cultural values and diabetes management among Hispanic women. They suggest that current treatment models fail to provide appropriate support for diabetes management for this population, primarily because they privilege individually orientated constructs (e.g., self-efficacy and internal locus of control) that may be inappropriate for collectivist cultures that “emphasize cooperation rather than competition, and family rather than self” (Oomen et al., 1999, p. 221). Fisher and colleagues argue that “many disease-management practices are influenced by culturally based family role behaviours that are a part of family life” (Fisher et al., 1998, p. 604). The authors of this publication go on to propose that important health-related decisions are often made in collaboration with other family members.

Support for this proposition can be found in literature presenting a Māori perspective on health and illness. As discussed earlier, the framework Te Whare Tapa Whā lays out four cornerstones of wellbeing as seen from a Māori world view – te taha whānau, te taha tinana, te taha hinengaro, and te taha wairua (Durie, 1998). In this model, family is presented as one of the four central tenets of what it means to be well. Thus for

many Māori, individual wellbeing is inextricably connected to the wellbeing of one's extended kinship group. Wellbeing is not often defined in an individual manner; *whaiora* (good health) is generally viewed as something that is shared with a collective rather than being located only in the individual.

This de-emphasis of individual ownership of wellbeing filters down to everyday practices in the context of dealing with health threats. When faced with illness, many Māori may express a desire for someone to *tautoko* (support) them in clinical consultations. Most often this will be a *whānau* (extended family) member. Such preferences are also commonly expressed by Pacific peoples living in New Zealand (e.g., people of Tongan, Fijian or Samoan descent). The support person might take an active or passive role in discussions about treatment, and may contribute to decisions about care planning. Many diabetes health services in New Zealand provide opportunity for a 'support person' to accompany the person with diabetes; some actively encourage this (H. Snell, personal communication, July 4, 2006). This practice contrasts in interesting ways with the traditional emphasis on privacy and autonomous decision making that has been a rudimentary principle in medicine. It represents encouraging evidence that contemporary medicine acknowledges the link between culture and health, and implies there is room for the evolution of medical practices in response to the needs of those who seek care.

The pre-eminent point is that family and culture have a strong connection. Fisher et al. (1998) propose that the family unit functions as the central social environment in diabetes, and that the family mediates between culture and health practices. Australian research has emphasised the connection between family and self-care behaviour among Aboriginal people with diabetes, stating "the family and community have a major effect on the individuals' management of their diabetes" (Thompson & Gifford, 2000, p. 1466). A Mexican study of self-management behaviour among people with type 2 diabetes has also highlighted the connection between cultural values and family functioning, and noted that this is a salient area for future research (Garay-Sevilla et al., 1995). Researchers working in diabetes suggest, "the powerful roles that culture, ethnicity, and race play in disease management operate primarily through the family. The family's culture becomes the basis for recognizing, understanding, responding to, and managing chronic disease over time" (Fisher et al., 1998, p. 601). The current research concurs with this position. Thus although culture per se is not a

key variable in the present study, the important connections between culture and family are explicitly acknowledged.

As noted previously, recent health literature has emphasised the benefits of a patient-centred approach to diabetes care. Extensive research by the Picker Institute has identified involvement of family and friends as one of the eight most important dimensions of patient-centred care (Picker Institute, 2003). However, although there is increasing recognition of the impact family members can have on illness management, we have some way to go in determining what this means for clinical practice. Decisions about how best to work with families in medical consultations can be difficult. We need to find clear ways of tapping into patient preferences regarding family involvement. Not every person with diabetes will wish to have his or her family involved in the process of clinical consultation. Alternatively, in some instances, the person with diabetes may want their spouse to join them in making decisions about their diabetes management but the husband or wife does not want to be extensively involved and would not wish to participate in clinical meetings. There is a need for protocols that outline good practice in such situations; these protocols should consider the preferences of the person with diabetes, and their family. Further, it is important to acknowledge that family involvement may not always be health promoting. Families come in all shapes, sizes, and varying functional states. For some people with highly dysfunctional families, family participation in diabetes management may be unhelpful (Durie, 1997).

In summary, individual cognitions and social-environmental context can be identified as two crucial factors impacting on diabetes self-management (Glasgow et al., 1997). Previous literature argues “diabetes research in general has focused too exclusively on personal characteristics (e.g., knowledge, beliefs) and not enough on environmental, social, and cultural factors” (Glasgow et al., 1997, p. 556). Slowly, this is changing. For example, an Australian study considered a number of variables as possible predictors of self-management among adults with insulin-dependent diabetes mellitus. Stepwise regression analysis revealed that, among variables included in this research, family support ($Beta = .31, p < .01$) and patient-provider relationship ($Beta = .26, p < .01$) showed the strongest association with intention to comply with self-care recommendations (Lo, 1999). Very recently, diabetes literature has sought to examine the role sociocultural factors may play in shaping illness representations (e.g.,

regarding controllability of diabetes) (Lange & Piette, 2006). Researchers should be encouraged to use theoretical frameworks that integrate individual and social variables (Glasgow et al., 1997). By including potential determinants of diabetes self-care that sit at different levels in the 'chain of causal association', multivariate analyses may help identify the most important predictors of differential illness outcomes and enable exploration of possible mediating relationships.

All research must have limitations, and it seems important to state these from the outset. As emphasised in this chapter, culture and health are strongly intertwined. Discussion of this issue was included because the author believes it is important to acknowledge the influence of cultural factors on health and illness behaviour. Too often these go unacknowledged, or under-acknowledged, in quantitative health psychology literature. Therefore, this section was included expressly to promote discussion and encourage health psychologists to engage further with these issues. It is, explicitly, not an attempt to set the parameters of the current research. The present study does not focus specifically on cultural differences in diabetes, or cultural predictors of diabetes outcomes – this is beyond the scope of the current research. However, the significant connections between culture, family, and health, have been acknowledged at the start of this study because they are an important part of the contextual backdrop necessary to gain a good understanding of type 2 diabetes, and the complex determinants of self-management behaviour (Anderson et al., 2000; Thompson & Gifford, 2000).

A second caveat deserves mention. The second half of this chapter addressed the issue of 'staying well with type 2 diabetes', and the importance of self-care was emphasised. Although active self-management helps to achieve good glycaemic control, the connection between self-care and illness outcomes is imperfect. It is important both to reiterate that there is 'noise' in diabetes self-management system, and to acknowledge that good self-care does not guarantee good outcomes for people with diabetes. Even with active self-management, the outcomes of diabetes are uncertain (Dunn, 2006). With this caveat accepted, the overall picture suggests good self-care will offer better illness outcomes than no attempt to actively manage one's diabetes.

CHAPTER SUMMARY

Type 2 diabetes is a lifelong condition with serious health consequences. According to the International Diabetes Federation, 194 million people in the world today have type 2 diabetes (International Diabetes Federation, 2006b); among this group, a large proportion have diabetes but do not yet know this. The late 20th century witnessed great technical advancements in treatment; yet many people with diabetes continue to experience poor health as a result of their diabetes. We know good self-care choices are a very important part of ensuring people with diabetes stay well, but concordance with medical advice about self-care is highly variable. The process of self-management is not well understood, partly because there is a lack of empirical evidence in this area. Further research in this area is warranted.

Significant changes in the way researchers frame diabetes self-management may be required if we are to build a better understanding of self-care and ways to promote good self-care. Past perceptions of self-care have often been founded on a medical model that takes an individualized, disease-orientated, view of diabetes. Unintentionally, perhaps, this has isolated individual behaviour from social context. Past perceptions have also viewed medical advice as a primary determinant of diabetes self-care behaviour and could, conversely, be found guilty of failing to acknowledge the contribution other factors make in shaping health-related behaviour. Studies predicated on a medical model of diabetes have tended to view development of (pharmacological) treatments, and practice guidelines as research priorities. This is linked to the idea that wellness is created through adoption of evidence-based guidelines that outline the best way to use available treatments. More often than not, this type of approach glosses over the gap between recommendations from health professionals and actual patient behaviour. As a result, we do not have a good understanding of the self-management process, or an explanation for why some people are masterful at taking care of their diabetes while many others struggle to achieve good self-management.

Although health professionals are important in shaping the health practices of people with diabetes, they are not strongly involved in the day-to-day management of this illness (Fisher et al., 1998). The home and social environment can also play a significant role in guiding self-management practices. This is often where the 'every-

day' battles are lost or won (Scott & Brown, 1989). Further, good self-care is pivotal to staying well with diabetes. Successfully managing diabetes thus becomes an issue of *self*-regulation, with the self-system occupying centre stage in this process. These observations suggest the internal (e.g., beliefs, motivation) and social environments (e.g., family support) may play salient roles in determining self-management behaviour. Individual cognitions and social-environmental context have been identified as two of the most crucial factors impacting on diabetes self-management (Glasgow et al., 1997). Research that seeks to integrate individual and social variables within a clear theoretical framework is recommended. This can be identified as an important challenge for future diabetes research. Fisher et al. (1998) argue that research should seek to incorporate multiple psychosocial variables within a single comprehensive model, making it possible to consider the relationships among these variables, as well as their relative ability to predict diabetes self-management behaviour. The following chapter will examine theoretical frameworks that may provide an appropriate foundation for such research.

CHAPTER 2

**A FRAMEWORK FOR CONCEPTUALISING
THE SELF-MANAGEMENT PROCESS**

CHAPTER OVERVIEW

The previous chapter emphasised that good self-management is the key to staying well with type 2 diabetes. The purpose of this chapter is to examine psychological frameworks that might be applied to study the self-management process. Active engagement in health-promoting behaviour is at the heart of self-management, therefore the current chapter begins by focusing on psychological theories that provide an explanation of health/illness-related behaviour. First, an overview of selected models is presented. This will be arranged under four broad thematic categories: motivational models; action models; process models; and organisational or sociocultural models. The primary purpose of this review is to highlight key features of dominant theoretical frameworks within health psychology and, from this, to identify a model that is suitably matched with the requirements of the present research.

MODELS OF HEALTH-RELATED BEHAVIOUR

Health and illness behaviours have been studied extensively within a number of academic disciplines. In the context of the present study, models of health-related behaviour will be reviewed in reference to the psychology of health and illness. The following section will briefly outline the development of empirical frameworks commonly used in health psychology; key models within health psychology will then be overviewed.

Health psychology is defined succinctly by Marie Johnston as: "the study of psychological and behavioural processes in health, illness and health care" (Johnston, 1994, p. 114). Twenty years ago, as an emerging discipline, health psychology showed little clear empirical focus (Johnston, 2005). Initial attempts to unravel key threads responsible for differences in health behaviour were largely atheoretical, and many intervention studies did not seek to place research within a clear conceptual framework. However, the last 2 decades have witnessed a productive developmental period within health psychology theory. As becomes a youthful discipline, early research often took an exploratory approach, examining core sets of variables in attempts to build an empirical understanding of health and illness behaviour. Key tenets were borrowed from general theories of behaviour, for example Rotter's (1966)

locus of control model, and applied specifically to the health and illness context. New variables were also delineated, such as perceived behavioural control (Ajzen, 1991). A plethora of theories emerged from this exploration. Many share a focus on common constructs, for example, self-efficacy/perceived control and beliefs about outcomes; and most distinguish between motivational and volitional processes (Armitage & Conner, 2000; Conner & Norman, 2005). Empirical attention was then engaged in refinement of proposed theoretical frameworks, and confirmatory studies. In turn, this led to identification of further variables that contribute to explanations of health behaviour. For example, ongoing and systematic investigation by Ajzen and colleagues resulted in extension of the theory of reasoned action, which, with the addition of perceived behavioural control, became the theory of planned behaviour. In more recent years attempts have been made to conceptualise health behaviour as dynamic, using theoretical frameworks that specify temporal unfolding of health behaviour, often over discrete 'stages' (Sutton, 2005). Previous literature has also noted a growing focus on self-regulatory models (Johnston, 2005). Recent discussion (Conner & Norman, 2005) has driven a move towards increased consensus in theory, which may offer greater coherence among the research frameworks employed.

The following section will briefly overview key theoretical models commonly used in health psychology, particularly in the realm of social cognition. In the interests of a concise summary, focus will be on the most extensively used frameworks. These frameworks will be grouped into four general categories: motivational, action, process-orientated, and organisational models. Although there is some degree of overlap between these groupings, this structure does offer a useful taxonomy from which to overview key theoretical frameworks within health psychology (Armitage & Conner, 2000; Michie et al., 2005). This overview has purposely avoided a lengthy and detailed narrative describing models, as such information is readily available within current literature. Rather, the intention of the following section is to provide a summary of some theoretical frameworks commonly used by psychologists to examine health and illness behaviour. The aim is to identify key characteristics among these models, and to reflect on the strengths and weaknesses of different approaches.

Motivational Models

A key characteristic that typifies models fitting this label is an emphasis on attitudes, norms, beliefs (including those about self) that act to generate behavioural intention. Thus research using this approach seeks to identify motivational factors that “underpin individuals’ decisions to perform (or not to perform) health behaviours” (Armitage & Conner, 2000, p. 173). Most motivational studies focus on people who have not yet established a behavioural intention; that is, are not inspired to change their current behaviour (Michie et al., 2005). In essence these models seek insight into how to generate the motivation to change behaviour.

Many motivational models grew out of literature surrounding subjective expected utility and expectancy-value theories (Conner & Norman, 2005), and a number include constructs based on control perceptions and intention. Well-used motivational frameworks include the theories of planned behaviour and reasoned action, the health belief model, protection motivation theory, and social cognitive theory (Armitage & Conner, 2000; Michie et al., 2005). Constructs commonly assessed include health-related attitudes (e.g., theory of planned behaviour), cognitive beliefs (e.g., health belief model), self-efficacy (e.g., social cognitive theory, theory of planned behaviour, and protection motivation theory), threat appraisal (e.g., health belief model and protection motivation theory), and perceived consequences (e.g., social cognitive theory and health belief model).

The selected outcome variable in research using motivational models generally belongs to one of two groups – behavioural intention (e.g., theory of reasoned action and protection motivation theory) or behaviour per se (e.g., health belief model). Many studies focus on intention. One criticism of motivational theories is that such models may imply intention is a sufficient condition for actioned behaviour (Armitage & Conner, 2000). By focusing on variables that predict intention, research may fail to give adequate recognition to the gap between intention and behavioural action. However, the correlation between intentions and actual behaviour is moderate. Previous literature on sexual health practices has quantified this gap, suggesting that on average intention explains around 19% of variance in condom use (Sheeran & Orbell, 1998). Two of the most well-used motivational models are the health belief model, and the theory of planned behaviour. A brief overview of each is provided below.

The health belief model (HBM) defines six constructs of primary research interest in explanatory models of health behaviour (Abraham & Sheeran, 2005), which are conceptualised as cognitive beliefs about health. Perceived susceptibility and perceived severity work alongside perceived benefits and perceived barriers to produce behavioural intentions (Conner & Norman, 2005). Interestingly, these have generally been presented as independent predictors, although the combination of susceptibility/severity and benefits/barriers seems intrinsically logical. Indeed one criticism of the health belief model has been a failure to explicate relationships among these core dimensions (Armitage & Conner, 2000). Two additional constructs are delineated in this model. Health motivation refers to an individual's internal drive to engage in health-promoting behaviour, while cues to action can include information from internal (symptoms) and external sources (such as health professionals or social networks). Reviews suggest variables within the health belief model are only weakly related to health behaviour, with poor construct definition highlighted as one particular limitation (Sheeran & Abraham, 1996) resulting in variable operational definitions, and decreased comparability across studies (Abraham & Sheeran, 2005).

The theory of planned behaviour (TPB) (Ajzen, 1991) grew out of the theory of reasoned action (TRA), an earlier theoretical framework (Ajzen & Fishbein, 1980). This evolution was primarily a response to criticism regarding an inability of the TRA to account for behaviour where volitional control was incomplete (Armitage & Conner, 2000). The TRA postulates that subjective norms and attitudes determine behavioural intention. The TPB, expanding on this, includes perceived behavioural control as a third determinant of intentions (Conner & Sparks, 2005). The theory of planned behaviour posits two constructs as proximal determinants of health related behaviour: intention to engage, and perceived behavioural control. Perceived behavioural control is a central component of the TPB, and functions as an indicator of actual control over behaviour, and a gauge of personal confidence in one's ability to perform the target behaviour. While Ajzen (1991) views perceived behaviour control as synonymous with self-efficacy, this position is not shared by all researchers (Terry & O'Leary, 1995). One feature that distinguishes the TPB from other social cognition models is its explicit attention to normative beliefs (Conner & Norman, 2005).

While the theory of reasoned action focuses on predicting behavioural intention, the theory of planned behaviour explicitly includes both behavioural intention and actual

behavioural engagement as outcome variables. Research evidence has shown some support for the TPB. In a meta analysis of 87 studies using this model, TPB variables were found to account for 41% of the variance in behavioural intentions. The TPB was also shown to explain approximately one third (34%) of differences in health behaviour (Godin & Kok, 1996). A review of social cognition models concluded the TBP offers superior explanation of health behaviour over other motivational type models (Armitage & Conner, 2000). This may reflect better theory or, possibly, more skilful operational definition of core constructs than other competing models (Sheeran & Abraham, 1996). Certainly, the considerable conceptual overlap among social cognitive models (Conner & Norman, 2005) serves as a warning that any apparent pre-eminence should not be overstated. One limitation of the TPB is its view of health behaviour as a rational process, and its focus on cognitive variables (Conner & Sparks, 2005); it provides few avenues for exploring the role of emotion in determining health-related behaviour. There is some evidence for extending the TPB to include self-identity and moral norms.

Action Models

Models fitting this category seek to explain *engagement* in health promoting activities. This can be compared to motivational models, which focus on how to generate the *intention* to change. Action models are predicated on a supposition that people already possess the motivation to change (Michie et al., 2005). These can be divided into two main groups. First, those that focus on what Armitage and Conner (2000) refer to as 'behavioural enaction'. The main research question addressed by such models is how to bridge the gap between intention and action. To this end it may be useful for research to distinguish between goal intentions and implementation intentions. Research has suggested the latter are important for producing active behaviour engagement (Orbell, Hodgkins, & Sheeran, 1997), perhaps because they encourage commitment to a defined course of action.

A second group of theoretical frameworks fitting the action label seek to identify variables that promote engagement in behavioural activities, but do not focus extensively on the intention-behaviour gap. Theoretical frameworks in this group include learning theory, operant theory, self-regulation theory, goal theory, social cognitive theory, and social identity theory (Michie et al., 2005). Most models focus on cognitive representations although some, such as the common sense model of illness

self-regulation, include emotional representations as well. It is worth noting that the distinction between motivational and action models is somewhat blurred, for example, social cognitive theory is listed by Armitage and Conner (2000) as a motivational model, but a more recent review by Michie et al. (2005) places social cognitive theory in both motivational and action model categories. Certain models may contain elements fitting both categories, for example, the theory of planned behaviour focuses on identifying factors responsible for generating behavioural intention, and on variables that promote behavioural action. It is, of course, possible to provide models that attempt to explain behaviour among people with and without behaviour intention – these goals are not incompatible. However, a distinction in the primary focus of different research frameworks is useful. In keeping with their pre-eminent emphasis on explaining engagement in behaviour action, rather than an account of behavioural intention, both self-regulation theory and social cognitive theory are listed by Michie et al. (2005) as belonging to the family of action models. A brief description of each follows below.

Albert Bandura's publication of the *Social Foundations of Thought and Action: A Social Cognitive Theory* (1986) was a seminal event in psychology, and has stimulated much health-related research. Models using social cognitive theory (SCT) as their foundation focus on motivational and self-regulatory skills as 'enabling' factors that encourage healthful lifestyle choices (Bandura, 2005, September). This framework highlights two central determinants of health behaviour: self-efficacy and outcome expectancies (Luszczynska & Schwarzer, 2005). Self-efficacy has often functioned as the main explanatory variable in previous studies using SCT (Armitage & Conner, 2000; Walker et al., 2003). Social cognitive theory postulates that self-efficacy has both a direct impact on behaviour, and an indirect relationship mediated by goal setting and motivational processes that prepare for action (Luszczynska & Schwarzer, 2005). Diabetes research has shown self-efficacy is associated with healthful self-management behaviours (blood glucose testing, diet, and exercise) (Allen, 2004; Griva et al., 2000; Wen et al., 2004; Williams & Bond, 2002).

The notion of agency is central to the social cognitive approach, as social cognitive models view health as a collective asset. A focus on building community capacity, rather than changing individual behaviour per se, is present (Bandura, 2005, September). This implies the effort to improve health will require social, political and

environmental change. Such views contrast with the approach promoted by many other models in health psychology, which often place priority on individual behavioural change. The self-efficacy construct has also received considerable interest from the wider health psychology literature, and has been incorporated in a number of other behavioural models, for example, the theory of planned behaviour, the health action process, and protection motivation theory. Self-efficacy can thus be identified as a key variable across the social cognition literature.

The self-regulatory framework was designed as a “generic model of motivated action” (Scheier & Carver, 2003, p. 26). Proponents of this approach have suggested illness episodes are no different from many other adversities that may block personal goals (Scheier & Carver, 2003). This view is not shared by the present author, who would suggest serious health threats have more salient outcomes than most other adverse experiences, due to the level of their threat to personal safety, even to continued existence. This is a unique characteristic shared with few other types of adversity; thus episodes of serious illness may best be viewed as qualitatively distinct from many other adverse experiences. However cogent arguments suggest the self-regulatory model can be usefully applied to the health domain, where indeed it has been used extensively.

Carver and Scheier (2003) propose that health behaviour is best understood as a process of self-regulation. Central to this is the notion of goal-directed behaviour. It is suggested that goals give a sense of purpose to life; they may act as both a target to strive towards, and a reference for appraisal of progress. Because goals function as a mechanism for steering action, they are essential to a good understanding of health and illness behaviour. Two factors are highlighted as central to encouragement of goal pursuit: an ability to identify valued goals, and a sense that these are attainable (Scheier & Carver, 2003). Feedback loops are another salient feature of the self-regulative processes. These comprise of four key elements: input function, reference value, comparator, and output function (Scheier & Carver, 2003). Goals and behaviour are positioned in the place of reference values and outputs, respectively. Two types of feedback loops are distinguished: those that aim to decrease the gap between status quo and set goal, termed discrepancy reducing; and feedback loops that aim to increase the gap between input and reference value, termed discrepancy enlarging. In

terms of goal-directed behaviour, these could be framed as approach- and avoidance-based strategies.

Scheier and Carver (2003) draw on the notion of outcome expectancies as part of the ongoing feedback process. Specifically, they hypothesise that generalised expectancies – essentially tied to an optimistic or pessimistic disposition – are predictors of commitment to goal attainment. These expectancies will determine whether an individual gives up or continues, when faced with significant challenges to their goal. This decision, to continue or quit, is presented as ‘watershed’ in the self-regulatory process. Scheier and Carver (2003) suggest that people who experience difficulties in obtaining specified goals may ‘take time out’ to evaluate the likelihood of success before returning to, or disengaging from, pursuit of their goal. While disengagement is sometimes an adaptive response, this depends mostly on whether it leads to pursuit of new goals. If this is not the case, disengagement may lead to development of serious psychological distress, and has been implicated in suicide (Scheier & Carver, 2003). Thus disengagement, and subsequent reengagement, is presented as an important positive process in self-regulation.

Health psychologists have applied Carver and Scheier’s general self-regulatory model of behaviour to the specific context of illness-related behaviour. One example of this is the common sense model (CSM) of illness self-regulation (Leventhal et al., 1980; Leventhal et al., 1984). The CSM has been used extensively in research examining self-management across a range of chronic illnesses. According to the common sense model, a number of underlying principles govern the way illness self-regulation occurs. The principle of ‘active processing’ construes individuals as active problem-solvers (Leventhal, Brissette, & Leventhal, 2003; Leventhal et al., 1980). Thus the CSM appears to assume people are motivated to address health threats. This perspective contrasts with motivational models that explicitly recognise people may not always be inspired to change their current behaviour, as described earlier in the current chapter. A second assumption is that illness self-regulation consists of three key stages that influence each other; this has been referred to as ‘stages in processing’ (Leventhal et al., 1984). The three central components are referred to as illness representation, coping, and appraisal. A third assumption relates to hierarchical processing. Self-regulatory theory suggests that goals are positioned in a hierarchical manner according to their level of abstraction (Scheier & Carver, 2003). The CSM proposes that people

process illness experiences at both concrete/perceptual, and abstract levels (Hagger & Orbell, 2003; Leventhal, 2005).

The recursive nature of illness self-regulation is another important assumption in the CSM. As will be seen in chapter 3, the common sense model is endowed with the capacity to represent bidirectional relationships. Self-regulatory literature intimates that illness representations shape coping strategies and that, in turn, coping choices guide physical and emotional illness outcomes. This suggests a degree of forward flow in the CSM. However, feedback loops are also present, and appraisal processes may shape illness representations, and steer future coping strategies. In the context of illness, people are often motivated to make use of feedback systems. Patients may self-monitor their symptoms, and use this information to make medical decisions (Scheier & Carver, 2003). For example, a newly diagnosed diabetic may be placed on medication they have not used before. Personal decisions about whether to take the prescribed medication, or continue taking the recommended dose, could be influenced by feedback from symptoms defined by the patient as diabetes related. If these symptoms are seen to improve with medication use, then medication may be viewed as a helpful part of the discrepancy reducing strategy (aimed at reducing negative symptoms associated with uncontrolled diabetes). In this example, self-regulatory systems may encourage health-promoting behaviour.

However, there is considerable potential for inaccurate interpretation within this system. Scheier and Carver (2003) use hypertension, as an example of an illness with unreliable symptoms, to illustrate how conclusions based on symptom feedback can be misleading. In diabetes, the connection between symptoms and self-management is less than watertight, as discussed in chapter 1. Thus rigid medication adherence may not always show a clear positive connection with diabetes symptoms on a day-to-day basis, or a strong relationship with important indicators of diabetes-related wellbeing like HbA_{1c}. A loose connection between symptoms and behaviour may undermine motivation for active self-management. For example, newly diagnosed diabetics may start taking their medication, but find they do not feel any better after a week (appraisal of progress towards goal is negative), conclude the medication is not working, and therefore stop taking it. In this case, behavioural action towards a goal has been taken, but subsequent reappraisal of symptoms has been inconsistent with the expected outcome (reduction of perceived diabetes symptoms). In this instance, feedback from

the self-regulatory system may act to *undermine* positive behavioural management of illness. Thus self-regulatory systems can act to encourage, or weaken, health-promoting behaviour.

Two parallel pathways are explicated in the CSM. The dual representation of illness (cognitive and emotional) is an important underlying assumption in this framework (Leventhal et al., 1992; Leventhal et al., 1984). An identifiable strength of the self-regulatory approach is its interest in the role of affect in health behaviour. As outlined in chapter 1, the emotional consequences of having diabetes are often significant, and many people find the demands of an ongoing, complex, self-management regimen a serious challenge. The CSM also acknowledges the impact that social context may have on individual beliefs and behaviour. For example, the significant role social communication can play in determining individual perceptions of an illness has been discussed in self-regulatory literature (Leventhal et al., 2003; Leventhal et al., 1984). This model was “intended to provide an overall framework to integrate social and contextual factors with individual cognition and affect” (Leventhal et al., 1992, p. 146); however, the potential to integrate interpersonal and individual aspects has not been a strong feature in empirical research using the CSM to date. A more extensive description of the common sense model will be provided in chapter 3.

To summarise, action-orientated models share a focus on the psychology of health and illness *behaviour*. Commonalities among predictor variables can also be observed, for example, evaluation of outcome expectancies can be found in both self-regulatory and social cognitive theories. In comparison with motivational models, action models do not focus on predicting behaviour intentions. Many do not include intention as a key variable or stage in the behavioural framework although it is often implied as present. For example; the ‘action plans’ discussed in CSM literature (Leventhal, 2005) represent a firm commitment to a specific future behaviour, and provide detail about the process (e.g., where, when) needed to put this plan into action. Previous diabetes research using action models has demonstrated predictive power, that is, identification of variables that explain a significant portion of differences in health behaviour (Griva et al., 2000). But it has been less successful in generating either comprehensive explanations of illness-related behaviour, (i.e., why some people are good at taking care of their diabetes while others struggle), or logical accounts of the process of behaviour decision making over time. In contrast, process models explicitly focus on

the temporal dynamics of health and illness behaviour. These are reviewed briefly below.

Process-Orientated Models

Process-orientated models share a belief that behaviour should be viewed as dynamic, implying models must be endowed with the capacity to represent temporal change. While a common belief in the need to represent temporal dynamics is present, process models do vary in the way they conceptualise behaviour, and the predictors of behavioural change. Certain frameworks assume health behaviour can be grouped into discrete stages, Prochaska and DiClemente's (1984) transtheoretical model is one example. Such models propose that behaviour will be qualitatively different across stages, and that predictors of health-related behaviour will vary depending on the current behavioural phase (Sutton, 2005). This implies the variables that influence adoption of health behaviour may be very different from those that predict sustained behavioural activity over a longer period.

Other empirical frameworks include representation of temporal dynamics within the model, but suggest a core set of variables that is responsible for shaping behaviour, and that this set of variables is applicable to health-promoting behaviour across time. For example, in the health action process approach (Schwarzer, 1999), self-efficacy is hypothesised to influence both motivational and volitional processes across the planning, adoption and maintenance of health behaviours. The common sense model (CSM) of self-regulation (Leventhal et al., 2003; Leventhal et al., 1984) also presents core variables, and assumes these are applicable across the behavioural spectrum. Contrary to the transtheoretical model of change (TCM), the CSM does not present a trajectory of specific behavioural phases, thus key variables are assumed to apply to the behaviour in question per se regardless of whether the behaviour is newly adopted, or part of a well-established routine. For example, illness representations are expected to influence self-care activities among people with diabetes, whether research focuses on those newly diagnosed, or people who have already had diabetes for a lengthy period. Although proponents of the CSM suggest the exact nature of these relationships may be moderated by variables such as illness duration or severity (Hagger & Orbell, 2003), this is not a central tenet of the theoretical framework, unlike the TMC, where qualitative differences in behaviour and behavioural predictors across

stages are a core theme. However, the CSM warrants inclusion under the process model label, as temporal dynamics are clearly an important feature of the framework, both in terms of forward flow between the three core stages (illness representations, coping, appraisal) and recursive feedback loops. Although the CSM has considerable potential as a framework for mapping determinants of behaviour over time, to date this attribute has rarely been utilized in research.

One of the most well used process-orientated models in health psychology is the transtheoretical model of change (DiClemente et al., 1991; Prochaska & DiClemente, 1984), which takes a multi-stage approach to exploring health behaviour. As such, it seeks to demarcate processes that encourage adoption of behaviour, as well as sustaining it over time. Five distinct stages have been outlined (DiClemente et al., 1991): no intention to change behaviour in the next 6 months (precontemplation); thinking about making a change in the next 6 months (contemplation); preparing to make changes with firm intention (preparation); active engagement in behaviour change (action); and stabilising behaviour so that it can be sustained over time (maintenance) (Sutton, 2005). The transtheoretical model of change assumes people will vary in the speed with which they move through the five stages. Some may become entrenched in an early stage; others may regress backwards over time. Many will move through a single stage multiple times. Other variables specified in this model include decisional balance (pros versus cons), confidence and temptation.

The TMC suggests predictors of behaviour will vary depending on stage. By identifying core variables that appear to be particularly important for specific stages, and highlighting those variables that promote movement across stages, research could make a useful contribution to intervention studies. Such information may help generate health-promoting behaviour at both an individual, and population or public health level. Thus the TMC raises the possibility that research data could help target interventions to individual stages and, through this, increase the efficacy of such interventions. But research explicating what variables determine behaviour at what stage has been slow to emerge (Armitage & Conner, 2000). Furthermore, it is difficult to get a clear idea of which variables are most important to promote *movement across* stages. To date, the TMC has told us little about variables that facilitate successful behaviour change, and the best way to target interventions to individual stages remains unclear. Progress has been hampered by a lack of conceptual clarity, and detailed specification of

hypothesised relationships, and their underlying mechanisms, is missing (Schwarzer, 1999). Thus although the TMC offers considerable utility as a research vehicle to generate insight into important behavioural questions, this potential has not been realised to its fullest extent.

The optimal number of distinct phases is another important research question. Although the TMC explicates five behavioural stages, other models propose fewer. For example, Schwarzer's (1999) health action process approach outlines two stages: a motivational phase followed by a volitional phase that incorporates planning, action and maintenance of health behaviour. Although the appropriate number of stages may partially depend on the targeted behaviour (Armitage & Conner, 2000), general consensus is towards thrift rather than excess. It has been suggested some phases are not clearly distinguishable and do not warrant separate theoretical structures. Some researchers have taken this criticism even further, and questioned whether the term 'stages' is actually useful. A good discussion of these issues is provided by Schwarzer (1999). Such criticisms should be given due consideration, but should not detract from the significant contribution the TMC has made to health psychology. Semantics aside, the TMC reminds health psychology that human behaviour is on going, and best understood as a process rather than a one-off event. This is particularly true in the context of chronic illness.

In motivational and action models, effect size, that is explained variance, is the primary criterion used to assess the efficacy of the models. In contrast, multi-stage models such as the TMC are judged on their ability to "advance clear predictions for transition between stages and for the design of interventions" (Armitage & Conner, 2000, p. 174). This stated criterion is somewhat vague and therefore difficult to quantify numerically. While motivational and action models are typically designed to predict behaviour at a single time point, process orientated models view temporal change as important. This has implications for the type of data collection employed. Motivational models are often associated with cross-sectional methods; longitudinal designs fit well with process-orientated models. However multi-stage models have too often relied on cross-sectional data collection (Sutton, 2005). This, along with poor operational definition of key constructs, constitute two of the most substantive criticisms that have been levelled at multi-stage models (Armitage & Conner, 2000). Nonetheless, the suggestion that health behaviour change is best viewed as series of discrete

behavioural phases is intuitively attractive. It can be concluded that multi-stage models do offer a useful umbrella framework for investigating health behaviour and, in particular, behavioural change over time. Multi-stage models may also form a base for integrating findings from a number of models targeting specific parts of the behavioural trajectory, which could include both motivational and action orientated approaches. Further research in this area is needed. Interventions based on the TMC are a useful test of theoretical utility. For example, interventions that are matched to individual stages need to demonstrate greater benefit than unmatched interventions (Conner & Norman, 2005).

Organisational and Sociocultural Models

The models described previously in this chapter primarily explain behavioural differences in terms of individual factors. Commonalities include a view that health behaviour is the product of reasoned action, that is, a largely volitional process of cognitive character. In contrast, models positioned at the organisational or community level place a much stronger emphasis on group membership and social systems as explanations for personal behaviour. Commonly assessed constructs include social identity, power, group values, normative behaviour, community empowerment, social networks, and more recently, social capital (Campbell, 2001; Ferrence, 2001; McDonald, 2004; Plumridge & Chetwynd, 1999; Young, 2004). Examples of models drawing on this type of approach in explaining of health behaviour include decision making theory, social influence group theory, social network theory, diffusion theory, and social organisation strategy (Ferrence, 2001; Michie et al., 2005; Pescosolido, 1992). Social action theories, adaptation theory, and risk theories also emphasise the interactional, socially negotiated nature of health behaviours (e.g., condom use) (Davis, Hart, Bolding, Sherr, & Elford, 2006; Plumridge & Chetwynd, 1999; Rhodes, 1997; Young, 2004).

One significant point of divergence between organisational models and motivational, action and process-orientated models, is therefore their relative focus on groups rather than individuals. Some models, such as the social organisation strategy (Pescosolido, 1992), position interactional events as the core unit of analysis, replacing the interest in individual behaviour. In comparison with the three preceding groups of models, organisational frameworks also view behaviour as less volitional. Thus individual

actions may be subject to constraints forced on them by external sources. These constitute up-stream determinants of health behaviour – an approach that contrasts with the focus on more proximal variables in many motivational, action, and process-orientated models. However, there are some links between organisational models of health behaviour, and the three preceding groups. For example, social cognitive theory views health as a collective asset, and suggests the path to improved population wellbeing requires social, political and environmental change. As stated previously, SCT emphasises the need to build community capacity, which is similar to the approach embodied in many organisational models of health behaviour.

Organisational models tend to explain behavioural change in terms of higher order interventions, which has implications for the types of research design selected. For example, use of organisational frameworks is associated with a tendency toward systems level intervention that is efficacious in promoting change at a population level. This can be contrasted with the focus on intervention at the individual level, often through cognitive-based persuasion, that characterises interventions common among the three preceding model groups. In general, health psychology has not made extensive use of organisational theories as explanations for behaviour, or as the basis for interventions to encourage behavioural change. It is possible that explanations of behaviour might benefit from combining organisational models with motivational and action theories. In this way mediating relationships could be examined, which would allow researchers to investigate hypotheses that specify a causal chain linking variables belonging to individual, interpersonal and societal domains.

Organisational models are predicated on the value of a macro-environmental approach to understanding human behaviour. Sociocultural models take a similar wide lens perspective. As discussed previously, there is a profound connection between culture and health. For example, chapter 1 provided detailed illustrations of how cultural beliefs and social practices might influence health-related (dietary) behaviour among Māori with diabetes. Cultural beliefs could also influence illness-related behaviour. For example, among Māori, transgression of tapu is held as a cause of ill health (Stewart, 1997). If this is identified as the cause of a sudden deterioration in health, it is probable that a tohunga (cultural expert in health) will be consulted for guidance, and advice on treatment. Thus inferences about the cause of an illness, as well as prescribed treatments, can be influenced by cultural beliefs. As noted by Cameron and Moss-

Morris (2004, p. 100) "research exploring illness beliefs in cultures around the globe reveals a diverse array of beliefs about health and illness". These differences serve to illustrate that health-related cognitions are imbued with cultural meaning, and operate within a social context. They may also produce divergent experiences of illness. Differences in worldviews can influence the interpretation of physical symptoms, expectations regarding likely causes of observed illnesses, and beliefs about the most appropriate form of treatment. Greater appreciation of the multiplicity of views about illness and its impact on behaviour, is needed within health psychology. Recent publications in the realm of self-regulatory research provide some encouraging evidence of progress in this regard (Baumann, 2003; Cameron & Moss-Morris, 2004).

Chapter 1 presented social and cultural variables as part of a 'chain of association' that connects determinants located at different points along the causal pathway. It emphasised that different viewpoints (cultural, psychological, biomedical) are not incompatible. Each can make a useful contribution to explaining variation in health behaviour. Future diabetes research should be encouraged to integrate these viewpoints to generate a more comprehensive account of diabetes self-management (Jack et al., 1999). Conceptual models that are consistent with this proposition include the ecological model explicated by Fisher et al. (2005), and the 'pyramid of psychosocial factors' presented by Glasgow (2005). In both models, constructs are arranged in a hierarchical manner, moving from the wider macro-environment to the micro-environment. These frameworks serve to remind us that it is possible to look at the determinants of diabetes self-care from many angles.

Together, chapters 1 and 2 emphasise that there are multiple layers within the determinants of health behaviour (Young, 2004). Some variables, for example attitudes and cognitions, have a proximal impact on behaviour; others, such as sociocultural environment, may sit upstream (Jack et al., 1999). Both can have an important impact on personal health habits. Social cognition models are premised on the assumption that health-related behaviour is a social phenomenon. However, in practice our attention to, and understanding of, this 'social' dimension is very limited. Although some excellent overviews of social-cognition research have been presented, the accompanying description of theoretical frameworks is usually limited to motivation, action and process models; it does not often include models with a significant sociocultural or organisational component (e.g., see Armitage and Conner (2000)).

With some notable exceptions (e.g., Michie et al. (2005)), this is the emergent overall picture. It could be argued that the dominant focus on proximal, cognitive, determinants of health behaviour is appropriate; befitting the label 'social cognition research'. However, this is contested by the present author on the basis that there are clearly demonstrated connections between individual cognitions, and social and cultural context. One way social cognition models could incorporate greater social focus, is to include variables such as family support, and patient-provider relationship in models of health and illness behaviour. This proposition is consistent with the importance of family context and clinical partnership in diabetes management as described in chapter 1. Family interactions are a prime place to observe social context 'in action' in the everyday interpersonal environment. In the same way, patient-provider relationship is an example of organisational health culture at work. Research that seeks to gain insight into the way sociocultural and organisational factors may influence health behaviour could use such interactions as variables of research interest. In this way, it may be possible to weave variables from organisational and sociocultural models into research using a social cognitive approach to study illness behaviour.

SELECTION OF THEORETICAL FRAMEWORK FOR USE IN THE CURRENT STUDY

When deliberating on the most appropriate theoretical framework to employ, researchers should pay close attention to the character of the illness of interest. Type 2 diabetes has a number of salient features, including chronic duration, and serious physical health consequences. At present, there is no cure for type 2 diabetes. For many people, staying well with diabetes relies on a demanding self-care regimen. Active behavioural management is the cornerstone, the single most important factor on which wellbeing for people with diabetes rests. Thus, although health professionals have a role to play in helping people with diabetes stay well, the lion's share of the work is ultimately placed on the shoulders of the individual. As such, self-regulatory processes become a seminal element in successful management of diabetes. Emerging evidence suggests diabetes exerts a considerable emotional burden. Thus affective processes, as well as cognitive processes, are of interest in the present study. Together these features imply the need for a model that: (1) provides an account of

both emotional and cognitive processes; (2) enables examination of behavioural aspects within illness management; and (3) is process orientated, placing *self-regulation* of illness as a central tenet. Ideally, this model should be endowed with the capacity to represent changes in behaviour over time (befitting a chronic illness typology).

One final feature is recommended, namely, conceptual presentation that provides scope for examining the links between individual cognitions, and social context. Traditionally, psychology has taken an individualistic view of behaviour. However, for many people with type 2 diabetes, self-management is inextricably intertwined with their everyday social environment (Glasgow et al., 1997). For example, dietary management is often contextualised within the everyday experience of shared family meals. Insulin injections may be required at socially inconvenient times (e.g., before a sports game, or at a restaurant). Thus diabetes-related behaviour is often embedded within a social context. As discussed in the first chapter, and reiterated in the second, there is growing evidence that social communication can have a pertinent impact on individual health behaviour. In particular, the roles of family context and patient-provider relationship have been highlighted. To date, few diabetes studies have sought to examine the role of individual cognitions and social context within a unified theory (Fisher et al., 1998; Glasgow et al., 1997).

The preceding review provides a useful basis for identifying key features of theoretical frameworks prevalent in health psychology; it is then possible to consider how well these features match the requirements of the present research as outlined above. Among these frameworks, the common sense model of illness self-regulation (Leventhal et al., 1980; Leventhal et al., 1984) stands out as potentially useful. This model explicitly focuses on self-regulation of illness, and has been identified previously as a good framework from which to conceptualise and examine self-management in chronic illness (Petrie et al., 2003; Skinner et al., 2002). There is a reasonable match between key features of the CSM and the most salient requirements of the current research, as described in the following paragraphs.

Active self-care behaviour is an essential ingredient for good diabetes management, as outlined in chapter 1. The CSM provides a useful framework for investigation of illness-related behaviour; 'coping behaviours' and 'coping strategies' have been used

interchangeably in a review of the common sense model (Hagger & Orbell, 2003), and active behavioural coping (termed 'problem-focused coping-specific') was presented as a subcategory within the illness coping typology. Adherence to self-care activities has been measured in a number of self-regulatory studies, including those focusing on people with diabetes (Barnes, 2000; Griva et al., 2000). Hagger and Orbell (2003), encourage researchers using the CSM to employ behavioural measures of coping, explicitly highlighting behavioural coping as a useful direction for future research. This fits with the needs of the current research; where investigation of self-care behaviour is an area of key interest.

Because medical literature positions diabetes as a 'physical' illness, there has been limited attention paid to the emotional burden of this chronic condition in previous research. As has been described in chapter 1, recently emergent studies suggest diabetes can have a substantial emotional impact. However, research to date (e.g., in the DAWN programme) has primarily focused on *description* of levels of distress; there has been little investigation of the factors that may generate distress about diabetes, or attempts to explain differences in affective responses to diabetes. Further research is necessary to unpack the cognitive, emotional, and behavioural patterns that may contribute to elevated distress about diabetes. Over time, this could build explanatory theory that enables a better understanding of the factors responsible for producing high levels of diabetes-related distress. Because emotional representation of diabetes is a core area of exploratory interest in the present study, inclusion of both cognitive and emotional dimensions is considered a strong positive feature of the CSM. Other social cognitive theories, such as the health belief model, lack an emotional component. This has been explicitly highlighted as one reason for choosing the CSM over the HBM as a theoretical framework suitable for studies of diabetes self-management (Hampson et al., 1995).

As emphasised in this chapter, there is currently a dearth of theoretical frameworks that integrate individual and interpersonal variables in a coherent manner. Empirical research that contributes to this can be identified as a pertinent goal for contemporary health psychology. As noted by Steptoe and Wardle (2004, p. 46) "health behaviours are determined by a range of personal and sociocultural factors, and need to be understood within the broad context of people's lives". The present author concurs with this proposition. Psychological researchers must bear in mind that "humans are

social beings – we are born, live and are enmeshed in a social world” (Murray, 2005, p. 9). A first step in recognising the interpersonal milieu that surrounds health-related behaviour is employment of research frameworks that take into account both individual variables, and social factors. Proponents of the CSM state that “the framework allows one to integrate factors at the level of the individual and the social system” (Leventhal et al., 1992, p. 160). The opportunity to combine individual variables and sociocultural context within a single umbrella framework is viewed as attractive, given the importance of social context in diabetes management as outlined in chapter 1. This is a significant and recommendable feature of the common sense model in relation to the needs of the current research.

The dynamic nature of the CSM is another positive feature. This provides conceptual recognition of the need for ongoing adjustment of the treatment regimen, represented by recursive movement between cognition, coping, and appraisal. For example, cognitive and behavioural changes can indicate the presence of emerging hypoglycaemia, blood glucose testing may be used to confirm this and affirmative action is then taken (e.g., consumption of food containing glucose). The process of testing-feedback-adjustment-retesting is a core component of the self-care regimen for many people with diabetes, particularly those using insulin treatment. Blood glucose testing may be used to assess whether there is a need for adjustment in insulin levels; if hyperglycaemia is present, the insulin regimen can then be amended in accordance with this feedback. Subsequent retesting then confirms whether actions taken have brought blood glucose levels back within an acceptable range. This illustrates the salient roles appraisal and feedback play in successful diabetes management. Visual presentation of CSM incorporates feedback loops, and explicative theory specifies a ‘temporal unfolding’ (Leventhal et al., 1992) within illness self-regulation. Thus key features of the CSM are consistent with the process-orientated nature of diabetes management.

The common sense model is often positioned within the action model category. However, close inspection shows the CSM contains elements that are associated with each of the four theory groups outlined in the preceding sections of this chapter (motivational, action, process, and organisational). For example, self-regulatory theory focuses on goal directed motivational behaviour, and specifies the use of action plans (Leventhal, 2005) that are akin to intention formation. The CSM incorporates feedback

loops illustrating the presence of temporal dynamics, and visual presentation of the CSM shows a connection between the broader sociocultural environment and individual self-regulatory processes (Hagger & Orbell, 2003; Leventhal et al., 1992). These features fit with motivational models, process-orientated models, and organisational models, respectively. It appears that the CSM transverses model categories, including useful explanatory aspects of each. This can be identified as a strength of the CSM: essentially it demonstrates an ability to weave together salient features of different social cognition models. By integrating these approaches, the common sense model may provide a heuristic that can be used to develop a broader picture of illness behaviour – a platform on which researchers may stand to gain a more overall view of the factors that shape illness behaviour.

However, the common sense model does not provide a perfect fit with the interests and preferences of the present study. One limitation is particularly evident, and this warrants further discussion. The inclusion of social context variables is a pertinent consideration in the current research, given that the social network has been identified as the “least-studied group of predictors of self-management behavior in type 2 diabetes” (Fisher et al., 1998, p. 600). While the CSM suggests there are connections between the sociocultural environment and individual self-regulatory processes, there is very little theory *explicating* the nature of these connections. Although a general link is proposed, a detailed, coherent explanation of the precise mechanisms connecting the broader interpersonal context to individual representations is largely absent. In early self-regulatory literature, social communication, for example information from familial and medical sources, was hypothesised to play an important role in the formation of cognitive and emotional representations (Leventhal et al., 1984). However, sociocultural variables do not constitute a core area of interest in the CSM, and as a consequence there has been very little empirical examination of potential associations between social communication and illness representations to date. Thus the CSM provides scope for examining the role of social communication but, arguably, this is not a central aspect of illness self-regulation.

In summary, although the CSM has the potential to unite individual variables and sociocultural context within a single theoretical framework (and this is a recommendable feature of the CSM as described previously), the lack of explanatory theory to provide a detailed exposé of how these connections operate is problematic.

The connections specified between sociocultural variables and central CSM constructs are best described as nebulous.

While this limitation is explicitly acknowledged, it should be considered alongside the strengths of the common sense model. In balance, although the CSM is not a perfect lock-and-key match with the interests of the present study, it does provide an acceptable match. Previous literature has described successful diabetes management as a classic example of the self-regulatory process in action (Petrie et al., 2003). The CSM affords a conceptual framework on which to hang key constructs of research interest (e.g., emotional and cognitive representations of diabetes, self-management behaviour), and delineates relationships between these variables in a way that is suitable for hypothesis testing. The CSM also provides an opportunity to coalesce individual variables with sociocultural context in a single umbrella framework. Thus, for current purposes, the CSM of illness self-regulation is selected as the theory of choice.

CHAPTER SUMMARY

The current chapter began by examining psychological theories that provide an explanation of health-related behaviour. This review focused on social cognition models. After careful consideration, the common sense model (CSM) of health and illness behaviour was selected for use in the present study. The third chapter will build on the theoretical groundwork laid in chapter 2 by explicating key CSM constructs in further detail, and providing a summary of findings from previous research employing this model.

CHAPTER 3
THE COMMON SENSE MODEL OF
ILLNESS SELF-REGULATION

CHAPTER OVERVIEW

The previous chapter gave an overview of social cognition models that explain variation in health-related behaviour. After considering the features of various frameworks, the common sense model (CSM) of self-regulation was selected for use in the present study. The third chapter is comprised of three main components. It begins by explicating key characteristics and assumptions of the CSM, and providing a comprehensive description of core constructs. The second segment of chapter 3 aims to provide a synopsis of empirical findings from research using the CSM. A detailed examination of key relationship pathways in the common sense model is undertaken. This includes the associations between (a) illness/treatment representations and coping, (b) illness/treatment representations and illness outcomes, and (c) coping and outcomes. Emerging evidence of relationships among representation variables is also discussed. The third, and final, section of this chapter provides an overview of diabetes research based on self-regulatory theory. This describes relationships among illness/treatment representations, coping, and outcomes, as they pertain to diabetes mellitus. Inconsistencies and gaps in the research literature are highlighted; salient directions for future research can then be identified.

THE COMMON SENSE MODEL OF ILLNESS SELF-REGULATION

Originally developed by Leventhal and colleagues (Leventhal et al., 1980; Leventhal et al., 1984), the common sense model has been used extensively in psychological research focusing on health and illness. Chapter 2 offered a brief introduction to the CSM; chapter 3 will extend this by providing a comprehensive description of theoretical assumptions and core constructs within this model.

Conceptual Presentation

Figure 1 illustrates key features of the common sense model (CSM). Early self-regulatory literature outlined three core structures within the self-regulatory system: representation, coping, and appraisal (Leventhal et al., 1992; Leventhal et al., 1984). These constructs are presented within red boxes in Figure 1, to highlight their seminal importance in the CSM.

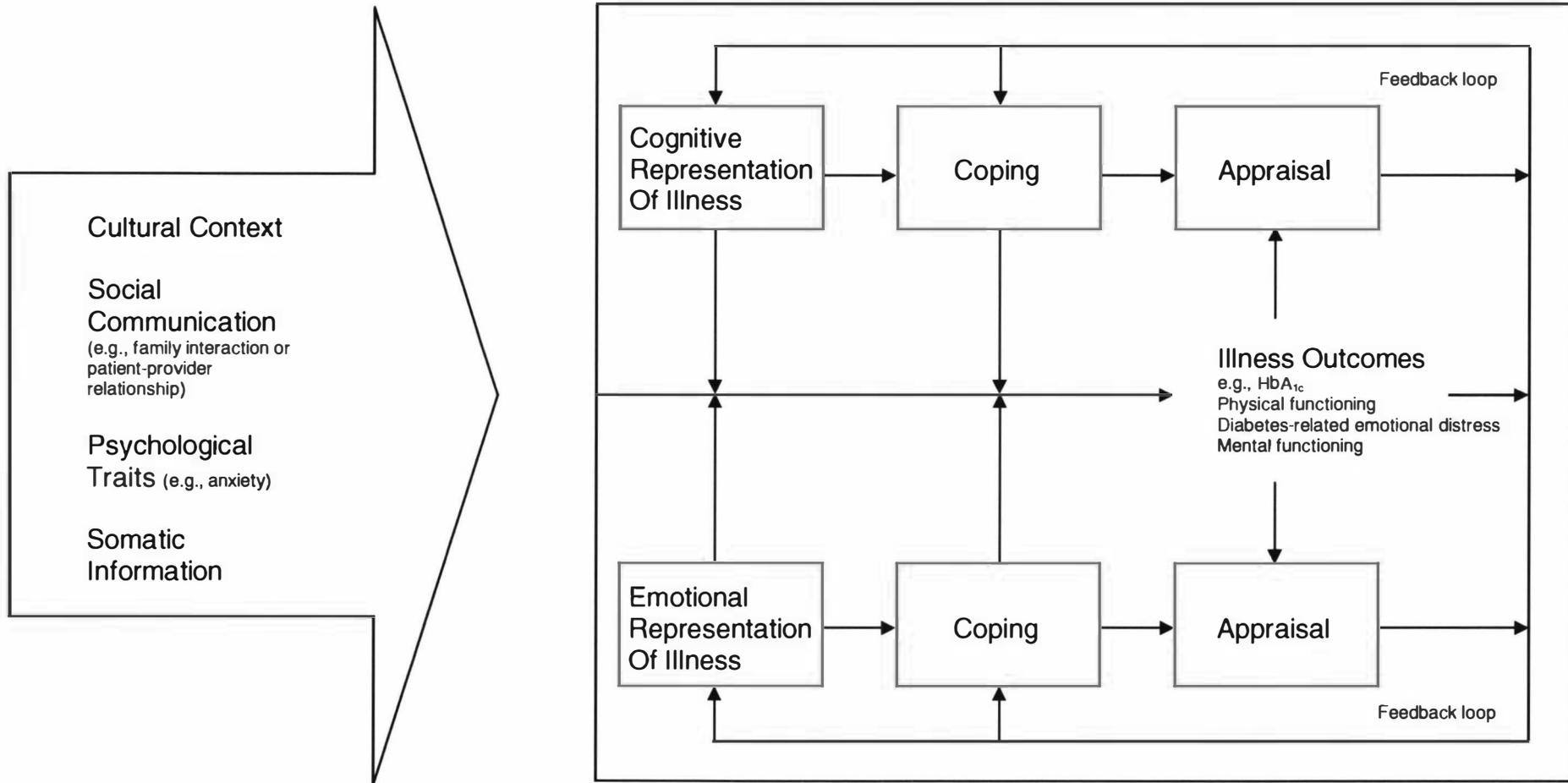


Figure 1. The Common Sense Model of illness self-regulation. Adapted from Leventhal, Nerenz, and Steele (1984); Leventhal, Diefenbach, and Leventhal (1992) and Hagger and Orbell (2003).

The process of self-regulation is predicted to influence both physical wellbeing, and emotional outcomes such as illness-related distress. Recent schematic representation of the common sense model has included illness outcomes within this conceptual framework (Hagger & Orbell, 2003). Examples of physical and emotional illness outcomes are shown in Figure 1. As the common sense model is process-orientated, illness representations steer coping efforts, providing goals and evaluative criteria against which the success of self-regulatory efforts can be appraised (Leventhal et al., 1992). In turn, coping strategies serve to guide illness outcomes. This suggests some degree of forward flow in the process of self-regulation, with each core stage (illness representations, coping, appraisal) guided by the outcome of the previous stage. However feedback loops imply that relationships are bi-directional, with information from appraisal and illness outcomes integrated into early stages of the model in a continual manner. Thus the process is recursive, as demonstrated in Figure 1. The elaboration of illness representations may continue over time, with integration of new information and according adjustment. Self-appraisal is also ongoing, new coping strategies may be employed if previous efforts are deemed unsuccessful. In this way the self-regulatory system is constantly updated (Leventhal et al., 1992).

Two parallel paths are shown in Figure 1. These represent emotional and cognitive streams within the self-regulatory process. Proponents of the common sense model suggest these are largely independent, though interactive to some degree (Leventhal, 2005; Leventhal et al., 1992). The CSM aims to provide a comprehensive “framework to integrate social and contextual factors with individual cognition and affect” (Leventhal et al., 1992, p. 146). As shown in Figure 1, a range of factors may feed into the self-regulatory process. These can include shared cultural schema, social communication, past and present somatic experience, and personality traits (Cameron, 2003; Hagger & Orbell, 2003; Leventhal et al., 2003; Leventhal et al., 1992; Leventhal et al., 1984).

Underlying Assumptions

Self-regulatory theory is premised on a number of assumptions. Individuals are construed as active problem-solvers (Leventhal et al., 1980; Petrie et al., 2003), or ‘common sense scientists’ (Leventhal et al., 2003). The principle of ‘active processing’ is the first of four basic assumptions outlined by Leventhal, Nerenz and Steele (1984). The common sense model presents two interacting but largely independent pathways

(Leventhal et al., 1992). The first has been labelled 'cognitive' or 'objective'; the second 'emotional' or 'subjective'. Both are expected to guide coping goals (Leventhal et al., 1980). This parallel processing is the second assumption outlined by Leventhal, Nerenz and Steele (1984). Breakdowns in either path are assumed to entail negative consequences. Numerous forms of interaction between cognition and emotion are possible (Leventhal et al., 1992). It is suggested that interactions occurring between these two pathways are both conscious and preconscious (Leventhal, 2005; Leventhal et al., 1984).

The common sense model has three core stages: illness representation, coping and appraisal. This is the third principle outlined by Leventhal and colleagues, who refer to this assumption as 'stages in processing' (Leventhal et al., 1984). The common sense model also has an element of 'forward flow'. This begins with an initial exercise in information gathering and interpretation (Hagger & Orbell, 2003), during which symptoms are integrated with abstract information. The emerging illness schema undergoes a process of elaboration and refinement, leading to the formation of illness representations. Sources of information for the construction process may include culture, social communication, past and present somatic experience (Leventhal et al., 1984). Cognitive and emotional representations are created in the first stage, as described above, and serve to 'steer' the second stage comprised of coping responses (Kaptein & Broadbent, in press; Leventhal et al., 1992). The third stage, appraisal, represents an evaluation of the success/failure of coping strategies employed. This information is then fed back into the earlier stages of the model in a recursive manner (Leventhal et al., 1984). Causality may be implied in relationship patterns; Hagger and Orbell (2003) certainly suggest this is the case. Many studies appear to operate on this largely unstated assumption. Both 'prediction' and 'association' have been used to describe relationships observed between, for example, illness representations and treatment adherence among people with diabetes (e.g., Barnes, 2000 (prediction); Griva et al., 2000 (association)). However, the latter is more prevalent within self-regulatory literature as a whole. Few longitudinal studies have been employed to examine causal inferences implied in the CSM – this remains something of a grey area in the self-regulatory literature.

Feedback loops are presented in Figure 1. These provide visual representation of the dynamic nature implicit in the common sense model, and encourage researchers to

conceptualise self-regulation as a *process*. This “temporal unfolding of the self-regulative system” (Leventhal et al., 1992, p. 149) is a key ingredient that makes the CSM different from many others in the health behaviour literature (Leventhal et al., 1980). An individual part in the model can act as outcome, or determinant, at different points in the self-regulatory time sequence. For example, coping appraisal is an outcome of current coping strategies, is also likely to guide future coping efforts, and may shape illness perceptions (e.g., self-appraisal ‘I am not coping well’ could lead to greater concern about illness, and stronger belief in the seriousness of consequences). This maps well onto the nature of chronic illness, where feedback is a central part of ongoing management (Petrie et al., 2003). Diabetes is a good example: monitoring blood glucose and incremental adjustment of insulin is important in avoiding incidents of hypoglycaemia or hyperglycaemia (very low/high blood glucose levels). While the dynamic nature of the CSM fits with processes of self-management across time, there is incongruence between such bi-directional relationships and the implied causality of relationships sometimes presented in research literature (e.g., Barnes, 2000).

‘Hierarchical processing’, the fourth assumption of the CSM as presented by Leventhal, Nerenz and Steele (1984), suggests people process illness experiences at both concrete/perceptual and abstract/propositional levels (Hagger & Orbell, 2003; Leventhal, 2005). The first dimension is represented by physically oriented perception (e.g., exposure to symptoms). The second is conceptual, involving representation using semantic labels and heuristic frameworks. These are interlinked: heuristics are essentially the sociocultural ‘rules of thumb’ used in every day experience to assign meaning to physical symptoms such as lumps, rashes, or headaches (Leventhal, 2005). Previous literature presents a link between symptoms and diagnostic labels: the discovery of one appears to prompt an active search for the matching counterpart. The process may be largely intuitive. This bi-level connection has been referred to as the ‘symmetry rule’ (Hagger & Orbell, 2003). A lack of symmetry may be related to poor illness adjustment. For example, coping problems could arise from inconsistencies between concrete experience and conceptual information provided by medical staff (Leventhal et al., 1984).

The centrality of ‘self’ is a key feature of the common sense model. Proponents of the CSM suggest it is necessary to consider health threats from the patients’ point of view, in order to learn how people successfully adapt to illness (Leventhal et al., 1992;

Weinman & Petrie, 1997). The centrality of the patients' viewpoint has been identified as a strength of the model (Leventhal et al., 1980). This may offer particular advantage when designing interventions (Petrie et al., 2003). It also mirrors trends within health service management showing a vigorous interest in health care through the patients' eyes (Picker Institute, 2003). Self-regulatory theory presents illness as an individual experience (Leventhal et al., 1980). This often takes place in a social environment – that of everyday living – but the experience of illness is essentially a personal one. The impact of the 'self system' on core components of self-regulation (representation, coping, appraisal) has been outlined. This may include, for example, the influences of biological characteristics and psychological traits (Leventhal et al., 1992).

The importance of 'coherence' has been emphasised in self-regulatory literature (Leventhal et al., 1992). For example, people appear to strive to obtain symmetry between symptoms and disease labels in their quest to make sense of illness (Leventhal et al., 1992). Sustained behavioural change may require components of the self-regulatory system to fit together smoothly in a cogent, common sense manner. It is predicted that inconsistencies within this system will undermine the process of self-management and disable attempts to maintain behaviour change. In addition to coherence within the self-system, a good match between self-regulation and the cultural and medical systems with which the individual must interact may also be important (Leventhal et al., 1992). It has been suggested that treatment adherence will be greater when patient and provider share common views about the illness, appropriate treatment, and indicators of successful outcome (Leventhal et al., 1992). Although previous research has often searched for the 'critical ingredient' necessary to create behavioural change, the CSM suggests this may be misguided. The integration and coherence between different parts of the self-regulatory system may instead be what underpins adaptive management of illness (Leventhal et al., 1992).

The impact of interpersonal milieu on individual self-regulatory processes was clearly outlined in early CSM literature (Leventhal et al., 1980; Leventhal et al., 1984). As stated by Leventhal et al. (1992, p. 146), "The model we will propose is intended to provide an overall framework to integrate social and contextual factors with individual cognition and affect". Links between sociocultural sources and the self-regulatory system have been explicated in visual presentations of the CSM (Leventhal et al., 1992). Social communication, for example information from familial and medical

sources, is hypothesised to play an important role in the formation of cognitive and emotional representations (Leventhal et al., 2003; Leventhal et al., 1984). The importance of sociocultural factors in self-regulation has been highlighted in recent self-regulatory theory (Baumann, 2003). However, this area has received comparatively little attention in empirical research practice to date. Inattention to such processes may impair our ability to understand how self-regulation occurs in the real world, where social-cultural context is ever present (Murray, 2005).

CORE CONSTRUCTS IN THE COMMON SENSE MODEL

There are a small number of key constructs frequently used by researchers taking a self-regulatory approach to the study of chronic illness. The purpose of this section is to introduce constructs within each main dimension (illness/treatment representations, coping, appraisal, outcomes) along with common operational definitions for each. A detailed examination of research findings from studies using the common sense model is undertaken in the following sections.

Illness and Treatment Representations

Illness representations are described as cognitive models that provide “an organized set of beliefs regarding how the illness affects the body, its likely impact on life activities and experiences, whether it can be cured, and so on” (Cameron & Moss-Morris, 2004, p. 85). They are also referred to as illness cognitions, beliefs, schemata and personal models (Cameron & Moss-Morris, 2004; Glasgow et al., 1997; Kaptein & Broadbent, in press; Skinner & Hampson, 2001). Illness representations function to define goals for coping, and coping success is then measured against these targets (Leventhal et al., 1992; Leventhal et al., 1984). Research suggests patterns of illness representation differ across illness group (Leventhal et al., 1992). Both cognitive and emotional representations are presented in the research literature. In initial presentation of the CSM, four dimensions of illness representation were delineated: identity, cause, consequences and timeline (Leventhal et al., 1984). Cure/control was subsequently added (Leventhal et al., 1992). Together, these are presented as the five foundation elements in research using the CSM to examine views about illness (Cameron & Moss-Morris, 2004; Hagger & Orbell, 2003, 2006); this includes diabetes research (Griva et

al., 2000). Publication of the Illness Perception Questionnaire (IPQ) stimulated further research. This measure includes five core dimensions: identity, cause, time-line, consequences, and cure control (Weinman, Petrie, Moss-Morris, & Horne, 1996). An excellent review of the CSM in research practice was published by Hagger and Orbell (2003). Exploration of illness representations focused on four cognitive dimensions: consequences, control/cure, identity, and timeline. Results from the meta-analyses provide some evidence of construct validity. Logical relationships were observed between illness representation dimensions, and comparison of data across illness type suggests discriminant validity was present.

Publication of the Illness Representation Questionnaire-Revised (IPQ-R) has extended the core set of illness representations commonly assessed. The revised measure includes emotional illness perceptions, and a scale assessing illness coherence. In the IPQ-R timeline has been separated into two dimensions – acute/chronic and cyclical – and the scale originally labelled cure/control has been divided to differentiate perceptions of personal control from treatment control. The identity scale has also been modified to separate somatisation from illness identity (Moss-Morris et al., 2002). These changes are compatible with wider self-regulatory literature. For example, the inclusion of cyclical timeline fits with the findings of early self-regulatory research that outlined three basic illness timeframes: acute, cyclic, and chronic (Leventhal et al., 1980). A condensed version of the Illness Perception Questionnaire has recently been published. The Brief IPQ includes single items to assess each of the eight primary constructs measured in the IPQ-R (identity, timeline acute/chronic, timeline cyclical, consequences, personal control, treatment control, emotional representation, and illness coherence); an open-ended question on causes of the illness is also provided (Broadbent, Petrie, Main, & Weinman, 2006). In recent years, the importance of treatment representations has been explicated (Horne, 1997; Horne & Weinman, 1999). Publication of the Beliefs about Medication Questionnaire has encouraged empirical investigation in this area (Horne, Weinman, & Hankins, 1999). Succinct descriptions of key illness/treatment representation constructs are provided below.

The *cause* dimension refers to beliefs about the origin of disease. In research using CSM, this identifies the factors responsible for ill health (Gentili et al., 2001). A wide variety of causal explanations have been generated in previous research (Leventhal et al., 1984), including, for example, heredity, environment, and one's own behaviour.

Stress has been widely implicated as a causal factor by people in a variety of illness groups (Cameron & Moss-Morris, 2004). The tendency to identify causes may vary across illness groups. People with breast cancer, for example, appear motivated to identify causes of their illness; this is less common among people with diabetes (Cameron & Moss-Morris, 2004). Emergent consensus from self-regulatory studies suggests there are three main causal categories – psychological, behavioural, and biological (Hagger & Orbell, 2006).

Illness *identity* refers to the “process of matching symptoms to an illness label” (Moss-Morris et al., 2002). When forming illness identity beliefs, people are likely to draw on prototypes of what a particular illness should look like, and such prototypes provide a symptom profile against which to compare current symptoms (Broadbent & Petrie, in press; Cameron & Moss-Morris, 2004). This implies a process of matching illness-related symptoms to a given illness label. This process is likely to be a common experience, occurring across a variety of illness groups. Measured using the IPQ-R, illness identity is the extent to which participants link a given illness label (e.g., diabetes) to a list of frequently experienced symptoms, for example, pain, nausea, breathlessness, fatigue and headaches. The majority of symptoms on this list are common, general health complaints. They are not diabetes specific, and most are not even linked to type 2 diabetes. Although researchers can add additional illness specific symptoms, these will constitute a minority among items in the identity scale. Thus, in essence, high scores on the IPQ-R identity subscale represent a tendency to connect general health complaints to a specific illness label (e.g., diabetes). This suggests common operational definitions of the illness identity construct may reflect a tendency to connect *general* symptoms of ill health to a specific illness label, rather than the process of matching *illness-related* symptoms to a specific illness label. The difference, though subtle, may be important. On this basis it is possible to question whether commonly used operational definitions of illness identity map accurately on to descriptions of the identity construct given in self-regulatory literature. Previous researchers have emphasised the need to distinguish between somatisation (the tendency to report symptoms) and illness identity (connecting symptoms to illness labels); this generated robust discussion and improved operation definition of the illness identity construct (Cameron & Moss-Morris, 2004). However, further conceptual development and clarification is needed in this area.

One alternative proposition is that illness identity, as measured using the IPQ-R, may represent *identification with diabetes*. Essentially, this is the extent of connections between a given illness label, and definitions of self. The strength of such connections is hypothesised to influence attributions about symptoms, such that people who view diabetes as a central part of their self-identity are more likely to draw on a diabetes illness label when interpreting new and/or ambiguous somatic experiences and therefore attribute a greater number of symptoms to their diabetes. In this instance, higher scores on the IPQ-R illness identity subscale could indicate a tendency to see an illness (e.g., diabetes) as 'part of who I am'. It is suggested that people who view their diabetes as a substantial component of their personal identity, are more likely to link ambiguous, commonly experienced symptoms of ill health (e.g., headaches, fatigue) to their diabetes illness label. Conversely, people who view their diabetes as distal from their definition of self, and do not position diabetes as 'part of who I am', are less likely draw on the diabetes illness label when interpreting new somatic experiences, and therefore less liable to attribute such vague symptoms to diabetes. Thus people with a strong diabetes identity link ambiguous symptoms to the diabetes label, while people with a weak diabetes identity do not, or do so to a lesser extent. Whether it is useful to conceptualise illness identity as the extent to which illness labels are linked to a definition of self, remains uncertain. However, this discussion serves to underscore the need for greater conceptual clarity in the area of illness identity.

Illness *consequences* tap into the personal impact of disease. This can include functional capacity, for example, reduced participation in everyday activities. Or physical changes such as lower limb amputation as a possible consequence of diabetes. It may also include non-physical implications of illness. For example, compromise in quality of life, or psychological wellbeing (Gentili et al., 2001).

Timeline has been used to describe the temporal unfolding of illness experience. This includes both expected duration, and symptom frequency (sustained versus spasmodic). Three categories have been identified: chronic, acute, and cyclical (Cameron & Moss-Morris, 2004). The first two terms refer to an ongoing, possibly indefinite condition and an illness with short, well-defined duration, respectively. Variable symptoms that 'come and go in cycles' are hallmarks of conditions with a cyclical timeline.

The extent to which an illness is perceived as responsive to a treatment regime (self-management or medical prescription) constitutes the *cure/control* representation. This has been separated into two dimensions in the IPQ-R (Moss-Morris et al., 2002). The first refers primarily to the expected efficacy of recommended medical regimes: this is termed *treatment control*. The second focuses on personal activity as 'making a difference' to illness outcomes; high *personal control* suggests individual self-care behaviour is effective in providing cure or control of illness symptoms. Diabetes research has suggested there is a close connection between perceived control, and diabetes specific self-efficacy constructs (Griva et al., 2000).

Recent self-regulatory literature has sought to explore whether people vary in the extent to which their illness makes sense to them personally. This is termed 'illness coherence'. As Cameron and Moss-Morris (2004) explain, some people with diabetes may feel they have a clear, logical grasp of what diabetes is and how it develops; others may be mystified about why they have diabetes, and confused about what can be done to control it. This illustrates how people can differ in their degree of illness coherence. In the IPQ-R, illness coherence is presented as a form of meta-cognition that enables people make sense of, or evaluate the usefulness of, the illness representation schema they have developed (Moss-Morris et al., 2002).

The illness representation constructs delineated thus far have been cognitively based. Recent literature has highlighted the importance of affective responses to health threats (Hagger & Orbell, 2006). These constitute the *emotional* dimension of illness representation (Moss-Morris et al., 2002). Previous research suggests episodes of ill health may have positive or negative emotional impact (Paterson et al., 2001). However, operational definitions of the emotional representation construct within self-regulatory literature have focused strongly on negative aspects of affect, for example, illness-related worry or concern. Emotional responses to illness can take the form of abstract 'feelings'. However, concrete emotional experiences may also be very important, for example, vivid images and emotion-infused memories can be created in response to witnessing the adverse health experiences of a significant other (for example, the death of a friend or family member). Cameron and Moss-Morris (2004) provide an excellent example of this in their description of watching a friend struggling with AIDS. Such emotional experiences may have a pertinent impact on future behaviour. Interestingly, self-regulatory research among patients with multiple

sclerosis suggests emotional representation is not strongly related to biomedical measures of severity of illness (Moss-Morris et al., 2002).

Because illness is often inextricably linked to participation in forms of 'treatment', it may be important to consider treatment representations as a core structure in the cognitive schema that is produced in response to a perceived health threat (Horne, 1997). In reference to a specific illness experience, two core dimensions have been identified that focus on views about need and concern (Horne & Weinman, 1999; Horne et al., 1999). *Medication necessity* indicates the extent to which treatment is needed. Although the prescription of a medical regime suggests treatment is warranted, subjective views about how much wellbeing depends on the prescribed treatment may vary. *Medication concern* refers to the degree of worry and anxiety provoked by the use of prescribed treatments. For example, concern about dependency or dangers resulting from toxicity. These are primarily affective representations of treatment. In contrast, medication necessity is more cognitively based.

Ongoing theoretical development in this area is required to ensure clear delineation of research constructs. There is a need to consider evidence of discriminant validity among constructs within the illness representation typology. Control beliefs provide one such example. In the original Illness Perception Questionnaire, the operational definition for this construct was a single subscale labelled 'cure/control' (Weinman et al., 1996). However, recent self-regulatory literature has distinguished between perceptions of (a) prescribed treatment, and (b) personal action, as efficacious in producing desired health outcomes. These are represented by two distinct subscales in the revised Illness Perception Questionnaire: 'treatment control' and 'personal control' (Moss-Morris et al., 2002). While research has shown a moderate positive relationship ($r = .61$) between the two dimensions (Moss-Morris et al., 2002), it is plausible that personal control and treatment control may have different relationships with health behaviour. For example, among people with diabetes, perceptions of high personal control may have a positive impact on self-management behaviours like exercise and dietary choices. Conversely, high treatment control may not show strong relationships with lifestyle behaviours. Instead it makes better sense to predict that strong belief in treatment efficacy will be related to adherence to a prescribed pharmaceutical regime. Such hypotheses are consistent with suggestions made in previous self-regulatory literature (Cameron & Moss-Morris, 2004). Recent research

using the Brief IPQ suggests different forms of perceived control will show divergent relationships with blood glucose control among people with diabetes. Specifically, high personal control was associated with better metabolic control; conversely, high treatment control was correlated with poor metabolic control (Broadbent et al., 2006).

Operational Definition of Representations

In research practice, operational definitions of illness/treatment representations have been dominated by use of the Illness Perception Questionnaire (IPQ, IPQ-R) and Beliefs about Medication Questionnaire (BMQ). A detailed description of both measures is provided in chapter 5. The IPQ-R has been used extensively among a range of illness groups including cancer, chronic fatigue syndrome, heart disease, rheumatoid arthritis, psoriasis and type 2 diabetes (Byrne, Walsh, & Murphy, 2005; Fortune, Richards, Griffiths, & Main, 2002; Scharloo et al., 1998; Steed, Newman, & Hardman, 1999). It has also been used as the basis of a personalised intervention for myocardial infarction patients (Petrie, Cameron, Ellis, Buick, & Weinman, 2002). The IPQ-R has shown good evidence of internal reliability, reliability over time, and an ability to discriminate between illness groups (Moss-Morris et al., 2002). Recently, a condensed version of this measure has been published under the label 'Brief IPQ' (Broadbent et al., 2006). Other instruments have been used to assess illness representations, for example, the Implicit Models of Illness Questionnaire (IMIQ), Personal Models of Diabetes Interview (PMDI), and Diabetes Illness Representations Questionnaire (DIRQ). For an extensive overview of illness cognition assessment, see Kaptein and Broadbent (in press) The Beliefs about Medication Questionnaire (BMQ) has also been well utilised in self-regulatory research. The BMQ-Specific has demonstrated good internal consistency when used among people with diabetes, and evidence of criterion-related validity and discriminant validity (Horne et al., 1999). Recent literature has also highlighted the potential utility of visual representation (drawings) to communicate personal perceptions of illness (Kaptein & Broadbent, in press). This is a useful alternative to traditional questionnaire-based assessment because it does not rely so heavily on linguistic comprehension skills, and may tap into aspects of the illness that are not easily expressed in words. Research with myocardial infarction patients has shown personal drawings of heart damage was a better predictor of recovery than physiological indicators (peak troponin-T) (Broadbent, Petrie, Ellis, Ying, & Gamble, 2004). In summary, much literature has used the common

sense model to examine self-regulatory processes. A review of previous research provides corroboration for both dimensions of illness representation explicated, and the instruments employed as operational definitions of these constructs (Hagger & Orbell, 2003).

Symptom Appraisal

Symptom appraisal is a key feature of the CSM. The specific interest in interpretative processes between stimuli and illness representation, is one characteristic that differentiates it from other models (Leventhal et al., 1992). Recent empirical investigation has focused on the emergence of illness representations, particularly the role of symptom appraisal (Moss-Morris, 2005). Symptom perception may be influenced by many factors. The degree of personal attention to internal (somatic) versus external cues, interpretive styles, and the presence of negative affect, for example, have been highlighted by Broadbent and Petrie (in press). The process of elaboration that forms a substantive illness representation usually begins with somatic experience of symptoms (Leventhal et al., 1992). Symptoms are presented as a precursor – the trigger that ignites the self-regulatory fuse for a particular illness (Leventhal et al., 1980). Symptom perception may also serve as a guide to direct the nature of illness representations. Views about personal control or cyclical nature of illness could, for example, be influenced by appraisal of previous symptom experiences. Thus symptoms may act as both driver of, and guide to direct, cognitive and emotional illness representations. Treatment representations may also be influenced by personal styles of symptom appraisal; for example, research using the Sensitive Soma Assessment Scale (SSAS) suggests people who believe they have a high (adverse) personal sensitivity to medication report greater treatment concern, and lower perceived treatment necessity (Horne et al., 2004).

Previous research has shown people often have a high level of confidence in their ability to read symptom changes (Leventhal et al., 1992). In a study of people with non-insulin dependent diabetes, Hampson, Glasgow, and Toobert (1990) found 80% of participants believed they knew when their diabetes was not under good control, without the use of a blood glucose meter test. Yet greater confidence does not appear to be linked to greater accuracy in symptom perception – in fact the reverse may be true (Leventhal et al., 1984). Though many research participants acknowledge that

other people are not good at accurately monitoring illness changes, they often do not believe this is true for them personally (Leventhal et al., 1980). Evidence from an early self-regulatory study suggests self-prediction of blood pressure is not strongly related to actual blood pressure (Baumann & Leventhal, 1985). This proposition is supported by a recent summary of literature pertaining to symptom perception (Broadbent & Petrie, in press). Although the accuracy of symptom perceptions is questionable, there is evidence of an association between symptom appraisal and cognitive/emotional representation of illness (Moss-Morris, 2005).

Alongside the critical role of symptom appraisal, self-regulatory literature has highlighted the contribution of abstract disease labels in the formation of illness representations (Leventhal et al., 1980). The process of meaning making in chronic illness draws heavily on the abstract disease labels that are a dominant feature of medical discourse. Although some level of cognitive representation and coping may be activated by symptoms, a second layer of meaning develops when a person is informed these symptoms mean they have 'diabetes' or 'heart disease'. Thus both concrete symptoms and abstract labels may play a role in guiding illness-related perceptions (Leventhal et al., 1984). This bi-level processing was identified as an important principle in early literature explicating the common sense model (Leventhal et al., 1984).

Coping

In the CSM, coping and appraisal are presented as two-thirds of an iterative system that cycles repeatedly through three core stages – illness representation, coping, appraisal (Leventhal et al., 1984). The regulatory system acts to "guide coping efforts and to set goals through which coping efforts are evaluated" (Leventhal et al., 1980, p. 26). Two stages of appraisal are explicated in the common sense model: 'primary appraisal' of the threat to health, and 'secondary appraisal' of coping effort (Leventhal et al., 1980). Coping is described as the process of actioning a response to appraisal of threat information (Carver, Scheier, & Weintraub, 1989). Hagger and Orbell (2003) identified seven distinct coping categories in their meta-analytic review of self-regulatory literature: avoidance/denial, cognitive reappraisal, expressing emotion, problem-focused coping (generic), seeking social support, problem-focused coping (specific), and doctors visits.

Common operational definitions of coping used in research include the COPE inventory, Ways of Coping Checklist (WCCL), and the Utrecht Coping List (UCL). Collectively, these cover a broad range of generic coping strategies, for example, avoidance, emotional expression, seeking social support and cognitive reappraisal. Illness-specific measures of coping have been employed in a number of studies. Recent literature has highlighted the importance of active behavioural coping strategies (Hagger & Orbell, 2003). Illness-specific self-care activities can be considered a subset of coping strategies (Griva et al., 2000), and have been described as 'problem-focused, coping-specific' (Hagger & Orbell, 2003). Core features include *active* attempts to ameliorate *illness-specific* symptoms using *behavioural* techniques. These can be targeted at diet, exercise, adherence to prescribed medication, or illness-specific regimes such as insulin injections or blood glucose testing among people with diabetes. Measures of behavioural coping often feature in research where self-management is a core component of the treatment regime: for example diabetes (Barnes, 2000; Griva et al., 2000). The Summary of Diabetes Self-Care Activities (Toobert, Hampson, & Glasgow, 2000) and Medication Adherence Report Scale (Horne & Weinman, 2002) have been used frequently in this area.

Illness Outcomes

Initial research into the self-regulatory process was stimulated by an interest in non-compliance among hypertension patients, and distress among people undergoing chemotherapy as a treatment for cancer (Leventhal et al., 1984). This has spawned a large number of studies, assessing physical and emotional aspects of self-regulation among a wide variety of illnesses including diabetes (Barnes, 2000; Griva et al., 2000; Hampson, 1997), cancer (Antoni et al., 2001; Cameron & Reeve, 2006; Hagger & Orbell, 2006; Horne & Weinman, 1999), chronic fatigue syndrome (Heijmans, 1998; Moss-Morris, 2005), asthma (Horne & Weinman, 2002; Jessop & Rutter, 2003), rheumatoid arthritis (Groarke, Curtis, Coughlan, & Gsel, 2005; Scharloo et al., 1998), Huntington's disease (Kaptein et al., 2006), epilepsy (Kemp, Morley, & Anderson, 1999), and coronary heart disease (Byrne et al., 2005; Petrie et al., 2002; Petrie, Weinman, Sharpe, & Buckley, 1996). Most research using the CSM has selected illness outcomes from one or more of seven main categories (Hagger & Orbell, 2003). These include physical functioning, psychological distress, psychological wellbeing, role functioning, social functioning, vitality, and disease state. Variants from the

Medical Outcomes Study, e.g., SF-36/20/12, have been well used in self-regulatory research (e.g., Heijmans, 1998; Lange & Piette, 2006; Paschalides et al., 2004; Scharloo et al., 1998). Other common outcome measures used across a range of illness conditions include the Hospital Anxiety and Depression scale, Well-Being Questionnaire, and Sickness Impact Profile (e.g., Fortune et al., 2002; Moss-Morris et al., 2002; Skinner & Hampson, 1998; Wearden et al.).

The majority of studies in this area have focused on chronic illness groups. Within a particular field of self-regulatory research (e.g., diabetes,) it is common to find measurement of both physical and emotional aspects of wellbeing. Diabetes studies frequently include physiological assessments, for example HbA_{1c}, self-reported physical wellbeing, and behavioural self-care activities such as dietary and exercise habits (e.g., Barnes, 2000; Griva et al., 2000; Hampson et al., 1990; Skinner et al., 2002; Wearden et al.). However, diabetes research founded upon the self-regulatory model has also included measures emotional wellbeing, and quality of life (e.g., Eiser et al., 2001; Hampson et al., 1995; Hampson et al., 2000; Skinner & Hampson, 1998; Watkins et al., 2000). Assessment of multiple illness outcomes constitutes robust research practice. Many chronic illnesses have a substantial impact on both physical and non-physical wellbeing, and such illnesses can include those primarily conceptualised as a 'physical' disease, such as diabetes mellitus. The emotional burden of diabetes is substantial. In some cases, this may equal the physical burden of this condition as discussed in chapter 1. Where possible, inclusion of psychological (e.g., diabetes distress), clinical (e.g., complications) and physiological (e.g., HbA_{1c}) outcomes is recommended.

KEY RELATIONSHIP PATHWAYS IN THE COMMON SENSE MODEL

A synopsis of empirical findings from research using the CSM constitutes the second main component in this chapter. Self-regulatory research has examined the relationships between representations, coping and outcomes – in varied combinations. Multiple paths of association are embedded within the common sense model (CSM). Thus key variables may connect in many different ways, as shown in Figure 1. Research using the CSM among people with a chronic illness has tended to focus on two main outcome variables: coping and wellbeing (Hagger & Orbell, 2003). Cognitive/emotional representations are often treated as independent variables. The following section presents an overview of major strands in the research literature.

Attention is first given to studies examining coping in the context of chronic illness, and results from research focusing on the link between illness representations and coping will be described. This will lead into a discussion of cognitive and emotional representations as they pertain to active behavioural coping. The focus on behavioural coping is consistent with the need for a better understanding of self-management practices among people with diabetes, as identified in chapter 1.

Second, interest will focus on research positioning wellbeing (health outcomes and/or illness outcomes) as the dependent variable. The pathway of association between illness representations and illness outcomes constitutes one of most thoroughly examined in self-regulatory research to date. However, grey areas remain. Relationships between representations and objective measures of disease state such as HbA_{1c}, for example, are not well understood. Studies are also required to clarify the type of associations that may connect representations to illness outcomes. While most research based on the CSM appears to treat these as direct, the possibility of mediating and moderating relationships with coping variables warrants further attention. A summary of literature pertaining to the coping-outcome association is provided, although a paucity of consistent findings is noted. The subsection following concentrates on emerging evidence of relationships among illness representations, and the implications of this for interpretation of bivariate associations between representations, coping and outcomes. This section closes with a brief reflection on the key strengths and limitations of empirical research employing a self-regulatory approach.

The Relationship between Illness/Treatment Perceptions and Coping Strategies

Leventhal, Nerenz and Steele (1984) suggest that illness representations guide coping behaviours, and a number of empirical studies support this assertion. Identity and cure/control have both shown significant relationships with coping strategies in chronic fatigue syndrome (Moss-Morris, Petrie, & Weinman, 1996). Perceptions of low control over the course of one's illness are correlated with use of passive coping strategies, for example, avoidance. In contrast, greater perceived personal control has been associated with the use of problem-focused coping among people with epilepsy (Kemp et al., 1999).

A meta-analytic review of self-regulatory literature suggests reliable relationships exist between illness representations and coping. Hagger and Orbell (2003) predicted that a strong belief in the controllability of illness symptoms would be associated with active behavioural, and problem-focused coping strategies. Results provide some support for this hypothesis, showing a significant relationships between cure/control and problem-focused coping-generic ($r_c = .27, p < .05$), problem-focused coping-specific ($r_c = .12, p < .05$), cognitive reappraisal ($r_c = .20, p < .05$), and seeking social support ($r_c = .08, p < .05$). In this meta-analytic review, Hagger and Orbell also predicted that greater perceived illness consequences, stronger illness identity, and belief in a chronic timeframe, would each be associated with use of avoidance and emotion-based coping. Results were consistent with this hypothesis. Consequences, timeline and identity each showed a significant positive association with avoidant coping. Identity and consequences both showed a significant positive relationship with emotional expression as a coping strategy. No significant correlation was observed between cure/control and either avoidance or emotion-based coping in this review.

The Role of Illness/Treatment Representations in Promoting Active Behavioural Coping

Hagger and Orbell open their meta-analytic review of the common sense model by stating "an important task for psychological research in health is to understand the factors that influence an individual's adherence to a medical regime or health behaviour for the management of illness and to identify appropriate targets for intervention" (Hagger & Orbell, 2003, p. 141). Previous diabetes literature postulates that "treatment

adherence could be conceptualised as a coping behaviour or a set of coping behaviours” (Griva et al., 2000, p. 735). Thus illness-specific self-care activities are presented as an important dimension within the self-regulatory coping typology and have been described ‘problem-focused, coping-specific’ (Hagger & Orbell, 2003). Among people with diabetes, self-care activities are a primary determinant of wellbeing, as outlined in chapter 1. Active behavioural coping can also benefit many other illness groups (Cameron, 2003). Behavioural activities may take a number of forms, for example, self-management through diet and exercise, or medication adherence. In the context of the present study, which focuses on type 2 diabetes, the potential impact of illness/treatment representations on self-management behaviour is of particular interest. An overview of self-regulatory research pertaining to behavioural coping is provided in the following section.

Self-regulatory literature provides some evidence of reliable relationships between cognitive illness representations and active behavioural coping. In a study of people with asthma, Horne and Weinman (2002) report illness representations were found to account for 13% of variation in self-reported adherence. Jessop and Rutter (2003) also examined the explanatory power of illness representations in regard to adherence to asthma medication. A two-step hierarchical linear regression was employed for this purpose. After controlling for age, gender, and duration of asthma, illness representations were found to account for 10% of variability in current adherence, and 9% of variation in intention to adhere in the future. Inspection of standardised beta coefficients revealed cure/control was a significant associate of both current adherence and intention to adhere in the future. In each instance, greater perceived control was correlated with better adherence to prescribed medication. Perceptions of control over one’s illness have also been linked to active behavioural coping in other illness groups. For example, people who have experienced a cardiac event are more adherent to recommended follow-up treatment if they have a sense of control over their illness (Petrie et al., 1996). Significant bivariate correlations suggest a positive relationship between perceptions of high personal control, treatment control, and illness coherence, and participation in physical activity among people with coronary heart disease (Byrne et al., 2005). Perceived illness consequences have been identified as a predictor of health-related behaviour (Cameron & Moss-Morris, 2004). Chronic timeline has also been linked with greater intention to adhere to medication among people with asthma (Jessop & Rutter, 2003). There is evidence to suggest differential causal attributions

may influence subsequent dietary changes in myocardial infarction (MI) patients. The direction of the observed relationship indicates a greater belief in poor health behaviour as the cause MI is linked to a propensity to improve dietary patterns in the following 6 months (Weinman, Petrie, Sharpe, & Walker, 2000).

However, enthusiastic articulation of relationships connecting cognitive illness representations to behavioural coping must be tempered by a lack of consistent evidence within self-regulatory literature. In a recent study focusing on coronary heart disease, the authors conclude that, "illness representations appeared to be only weak predictors of smoking, exercise, diet, alcohol consumption and medication adherence, accounting for about 2% of the variance in these behaviours" (Byrne et al., 2005, p. 403). Hagger and Orbell (2003) examined the relationship between illness representations and active behavioural coping (termed 'problem focused coping-specific' by authors of this publication,) using average corrected correlation coefficients. Thirteen studies were included in this meta-analysis. Results showed a significant association between cure/control and problem-focused coping-specific. Consequences, identity and timeline did not show significant relationships with active behavioural coping. However, evidence suggests cognitive illness representations may influence the use of emotional coping strategies. For example, significant positive associations have been reported between consequences, identity, timeline; and emotional expression, avoidance, and denial (Hagger & Orbell, 2003). Additional research is required to investigate relationships between cognitive illness representations and behavioural coping in detail.

Self-regulatory research suggests a connection between emotional illness/treatment representations and behavioural coping strategies. Emotion-infused memories may have a potent impact on personal behaviour (Cameron & Moss-Morris, 2004). Vivid images from past experiences may motivate health protective behaviour in a way that is much more efficacious than advice from a doctor presented in a clinical environment devoid of emotional overtones. In relation to diabetes, there is some evidence to suggest that witnessing a close friend or family member experience adverse health outcomes as a consequence of diabetes may focus attention on the need to manage one's own diabetes (Samuel-Hodge et al., 2000). Conversely, there is evidence to suggest greater emotional representation is linked to less healthful coping choices. Among cardiac patients, multivariate analyses showed emotional illness representation

was a significant predictor of exercise behaviour (Byrne et al., 2005). The direction of the relationship implies greater emotional representation is linked to less frequent exercise. Emotional representation was also predictive of alcohol consumption in this study. *Betas* suggest lower emotional representation is associated with greater consumption of alcoholic beverages. Emotional illness representation was not a significant predictor of smoking, dietary habits, or medication adherence in this study. Jessop and Rutter (2003) tested for two possible forms of association between emotional representation and medication adherence among people with asthma – a linear association, and a possible quadratic relationship. They reported no significant associations were found. Further research in this area is needed to clarify the role of emotional representations in behavioural coping choices among people with a chronic illness.

Self-regulatory literature identifies treatment representations as potential predictors of behavioural coping. Both treatment necessity and treatment concern have shown a significant relationship with self-reported medication adherence among people with asthma. Greater concern about the harmful effects of pharmaceutical treatments was negatively associated with adherence, and strong belief in the necessity of recommended medications was positively correlated with adherence. After controlling for demographic and clinical variables, treatment representations were found to account for 17% of variance in self-reported medication adherence (Horne & Weinman, 2002). Treatment representations have also been identified as significant predictors of reported medication adherence among people with coronary heart disease, explaining approximately 7% of the variance in adherence scores (Byrne et al., 2005). In both these studies, treatment representations provided greater explanatory power than illness representations when regressed on to self-reported medication adherence. This suggests that (at least among people with heart disease and asthma) when explaining differences in adherence to prescribed pharmaceutical regimens, beliefs about medication may be more important than views about the illness per se.

In a study that incorporated data from four chronic illness groups (asthma, renal dialysis, cardiac, and oncology) Horne and Weinman (1999) report evidence of consistent associations between treatment representations, and self-reported treatment adherence. These revealed that greater belief in the necessity of prescribed medication is associated with higher reported adherence; conversely, greater concern

about using medication was correlated with lower adherence. The possible utility of calculating a necessity-concerns differential score was also demonstrated by research findings. A stepwise linear regression procedure was employed, with reported adherence as the dependent variable. Among variables included in this model, the necessity-concerns differential score showed the strongest relationship with reported adherence, accounting for 19% of differences in reported adherence (Horne & Weinman, 1999). Emerging research has also highlighted significant associations between treatment perceptions and medication adherence among people with type 2 diabetes (Clark, Avery, & Hampson, 2006).

To summarise, self-regulatory research provides some evidence of reliable relationships between illness/treatment representations and coping. However, the magnitude of correlations between illness representations and coping have, on the whole, been low compared with those between representations and illness outcomes (Hagger & Orbell, 2003). One explanation may be problematic measures. Poor operational definitions of the coping construct could lead to an underestimation of the connection between representations and coping. Employment of generic measures of coping may contribute to this. Often such instruments do not provide adequate assessment of active behavioural strategies, or seek to acknowledge illness-specific needs. Thus, one weakness in the representation-coping literature could be a reliance on generic measures of coping style. It has been suggested that future research may benefit from the use of “problem-focused behavioural coping measures such as diabetes management techniques and drug regimen adherence” (Hagger & Orbell, 2003, p. 180).

The Relationship between Illness/Treatment Perceptions and Wellbeing

Research has shown a relationship between illness/treatment representations and physical wellbeing. Higher perceived illness consequences, stronger illness identity, and chronic duration have been associated with poor physical outcomes (Heijmans & de Ridder, 1998; Scharloo et al., 1998). In contrast, greater perceived control over health threats has shown a positive relationship with indicators of physical health among people with rheumatoid arthritis (Scharloo et al., 1998). In a recent study of Irish women with rheumatoid arthritis, illness representations were found to explain 23% of the variation in concurrent physical functioning, after controlling for the impact

of demographic variables and disease status (Groarke et al., 2005). Inspection of *Betas* revealed identity and control/cure both showed a significant relationship with physical functioning at baseline. However, these relationships were not present at the 12-month follow up. Using the same hierarchical regression procedure used for the baseline analysis, a significant relationship between perceived consequences and physical function emerged ($Beta = .47, p < .01$) at this time point (12 months). The same regression analysis strategy was applied to data collected at 24-month follow up. At this time point, none of the four illness representation subscales showed evidence of a significant relationship with physical functioning. A series of longitudinal regression analyses were also undertaken to determine whether illness perceptions could account for variance in physical function across time. The authors of this study conclude that “overall, the longitudinal analyses showed that the illness perception set did not predict variance in adjustment over time” (Groarke et al., 2005, p. 609). Further research is required to clarify the associations between illness representations and physical functioning across time.

Previous research has demonstrated a significant association between illness representations and role function. Among first-time myocardial infarction patients, beliefs about illness timeframes may influence decisions about when to return to work. Patients were more likely to return to work within 6 weeks of a heart attack if they believed their illness had an acute timeline (Petrie et al., 1996). Perceived illness consequences were also found to predict differences in time to return to work in this study. Empirical studies have provided evidence that illness/treatment representations are associated with psychological and social wellbeing.

Among people with multiple sclerosis, illness representations have accounted for more than one quarter of the variability in self-reported physical fatigue, and 20% of differences in mental fatigue (Moss-Morris et al., 2002). In the same study, illness representations were found to explain 15% of sickness-related dysfunction, with illness identity highlighted as the most important predictor among the illness representations included in this multivariate analysis. Hagger and Orbell (2006) used hierarchical regression analysis to examine the relationship between illness representations and psychological adjustment among people with abnormal cervical or colorectal screening results. Reported findings suggest that illness identity plays an important role in explaining differences in psychological outcomes (e.g., anxiety, anger, embarrassment,

and depression). Illness identity demonstrated a significant relationship with measures of psychological adjustment, even when controlling for demographic characteristics, disease severity, and cognitive and emotional illness representations. In a study of people with epilepsy, Kemp, Morley and Anderson (1999) also reported a significant association between illness identity and psychological distress. Unsurprisingly, the IPQ-R variable labelled 'emotional representation' has demonstrated a strong connection with measures of psychological adjustment (e.g., depression, anxiety, anger, relief) (Hagger & Orbell, 2006).

Perceived illness consequences may influence illness-related adjustment. Expectations of adverse consequences have been linked to greater tiredness and higher anxiety among people with rheumatoid arthritis (Scharloo et al., 1999). Illness identity and perceived consequences have shown a significant relationship with psychological adjustment among people with atrial fibrillation (Steed et al., 1999), and rheumatoid arthritis (Groarke et al., 2005). Hagger and Orbell (2006) have also highlighted the salience of perceived consequences in explaining psychological outcomes after an abnormal screening result. Other illness representations have shown a less reliable association with psychological outcomes. For example, research focused on people with psoriasis has shown perceptions of chronic timeline (a belief that psoriasis is a life-long condition) are associated with poor psychological adjustment to this illness (Scharloo et al., 1998). Other studies have failed to find any association between timeline and physical or psychological adjustment among people with rheumatoid arthritis (e.g., Groarke et al., 2005) or abnormal cervical screening results (Hagger & Orbell, 2006). Control beliefs may play a role in determining adjustment to life with a chronic illness. Low control perceptions have been associated with higher disability among patients with Addison's disease (Heijmans, 1999). Perceived control has also demonstrated a significant negative association with depression and anxiety among women with rheumatoid arthritis (Groarke et al., 2005). However, Hagger and Orbell (2006) found no evidence of a relationship between perceived control and psychological outcomes (anxiety, anger, guilt, embarrassment, sadness, or relief) in a study of emotional adjustment among people who had received an abnormal cervical screening result. Treatment control also failed to show any relationship with anxiety, anger, or depression among a colorectal screening sample in this research. The authors of this study did report evidence of an association between personal control, and both anxiety and depression, among the colorectal screening

sample (Hagger & Orbell, 2006). Overall, it appears that *both* cognitive and emotional illness representations contribute to the explanation of variance in emotional adjustment when facing serious health threats.

Hagger and Orbell (2003) conducted a meta-analytic review of self-regulatory research using data from 45 studies across 23 illness groups. They predicted that perceptions of control over illness symptoms would be associated with adaptive health outcomes. Conversely, it was expected that perceptions of chronic illness duration, serious consequences, and stronger illness identity, would be associated with maladaptive health outcomes such as psychological distress. Average correlation coefficients, corrected for sampling and measurement error, were used to evaluate these predicted relationships. Results indicate a positive association between cure/control and three outcome variables: psychological wellbeing, social functioning, and vitality. A negative association was observed between cure/control and both psychological distress, and disease state. These relationships are consistent with a priori hypotheses. However, the absence of a significant correlation between cure/control and physical functioning is notable.

Results from this review also provided some support for predicted links between consequences, timeline, identity, and health outcomes. Both illness consequences and identity showed significant negative relationships with each of the five adaptive physical and psychological health outcomes. The relationship between timeline and adaptive outcomes was less clear. Significant associations were observed between timeline and role functioning, social functioning, and vitality; but no significant relationship with physical functioning or psychological wellbeing was present. Predicted associations between representation domains and maladaptive health outcomes were partially supported. Consequences, identity and timeline each showed a significant positive relationship with psychological distress. However the correlations between each of these three variables, and disease state, were not significantly different from zero (Hagger & Orbell, 2003). This suggests some inconsistency may be present in the relationships between illness representations and illness outcomes.

Specifically; timeline does not appear to show a significant association with some adaptive health outcomes, and only one of the four representation domains assessed in this study (cure/control) was significantly correlated with objective disease status.

With regard to the relationship between illness representations and disease state, it was concluded that “statistical artefacts corrected for in the meta-analysis accounted for the majority of the variance in these relationships” (Hagger & Orbell, 2003, p. 174). The relationship between illness representations and objective disease state remains an important research question. Previous diabetes research has failed to show an association between key self-regulatory structures and objective measures of disease such as HbA_{1c} (Eiser et al., 2001). At present this remains a grey area in research literature.

It is interesting to reflect on the match between discussion of research findings and structural relationships presented in the common sense model. Potentially, the effect of feedback loops specified within the common sense model (Hagger & Orbell, 2003) may confound a clear causal interpretation, for example, proposing that illness representations impact on illness outcomes. Illness outcomes in diabetes may include changes in perceived symptoms (due to elevated blood sugars), diabetes related-complications (blindness, limb amputation), and as a proportional result of these physical and physiological changes compromise to social and psychological functioning (e.g., illness-related distress, and deterioration in quality of life). These factors may be incorporated into the appraisal process that precedes the formation of illness representations. In this way, illness outcomes may in fact serve to influence illness/treatment representations. It is difficult for cross-sectional research to disentangle such relationships; longitudinal research is needed to provide greater clarity in this area.

Links between illness representations and illness outcomes are often presented in self-regulatory literature, as outlined above. However, few studies explicitly discuss whether research findings represent a direct or mediated relationship. The CSM suggests both are possible, as shown in Figure 1. Mediating relationships have rarely been the focus of empirical research using the CSM. Such lack of attention may suggest researchers operate on the presumption that coping mediates the relationship between illness representation and outcome, i.e., an implicit expectation that does not warrant further discussion. Alternatively it may indicate the reverse: researchers may assume that the relationship they are presenting is direct, and therefore discussion of mediation is not warranted. Either way, such assumptions require robust investigation.

Particular coping strategies may function to regulate (down or up) the extent to which the self-regulatory system becomes activated. In this way, the type of coping strategy employed may strengthen, or weaken, the association between illness representations and illness outcomes. Coping mechanisms, such as denial or avoidance, may encourage the self-regulatory system to 'shut down' – as these coping strategies essentially attempt to ignore the illness and its implications. They may, for example, result in purposeful efforts to decrease any attention to illness symptoms, while also dissuading engagement in cognitive processes that 'make sense' of illness. Such coping strategies may effectively deactivate cognitive processing in the self-regulatory system. This, in turn, is likely to weaken links between self-regulatory structures, including the relationship between illness representations and illness outcomes. In this sense, coping may function to moderate the relationship between illness representations and illness outcomes, as implied previously by Hagger and Orbell (2003).

The Relationship between Coping and Wellbeing

Leventhal and colleagues suggest clear, concrete coping goals can facilitate successful self-regulation. Conversely, ill-defined coping goals may generate uncertainty and distress (Leventhal et al., 1980). Self-regulatory literature has shown significant associations between coping and health outcomes. For example, in an intervention study targeted at patients with malignant melanoma, Fawzy et al. (1993) showed a link between coping strategies and wellbeing. Compared with controls, intervention participants showed greater use of active behavioural and cognitive coping strategies, positive emotional adjustment, and increased survival rate. However, self-regulatory literature has not always shown significant associations between coping and health outcomes. For example, in a study of people with atrial fibrillation by Steed et al. (1999), results showed illness representations explained variation in psychological adjustment, but scores on the COPE accounted for very little of the variance in illness-related adjustment. Illness perceptions have also demonstrated greater explanatory power than coping variables in research examining health outcomes among people with psoriasis (Fortune et al., 2002).

Among people with diabetes, active self-management is a central determinant of long-term illness outcomes, as discussed in chapter 1. Published diabetes literature

suggests positive self-care behaviour is associated with improved glycaemic control, and fewer long-term complications (The Diabetes Prevention Program Research Group, 2002; UK Prospective Diabetes Study (UKPDS) Group, 1998b). Empirical evidence from smaller studies also supports this assertion. Research among young adults with insulin dependent diabetes, for example, demonstrated a significant relationship between adherence to self-care regimen, and HbA_{1c} (Griva et al., 2000). Self-reported adherence accounted for 15% ($p < .01$) of variation in HbA_{1c} in this study. These results illustrate the relationship between active behavioural coping and positive clinical outcomes among people with diabetes.

There is, however, a dearth of consistent findings in the coping literature more broadly defined (Johnston, 1994). There is limited consensus regarding “how to conceptualize or measure the central constructs in the field, namely, ways of coping” (Skinner, Edge, Altman, & Sherwood, 2003, p. 216). Although research by Edgar and Skinner (2003) predicted that coping mediates the relationship between illness representations and emotional wellbeing, research findings did not support this proposition. Recent research hypothesized that coping would mediate the relationship between illness representations and wellbeing among people with Huntington’s disease. Reported findings did not support this hypothesis (Kaptein et al., 2006). The relationship between coping and outcomes has not always been a key focal point in self-regulatory literature. It is absent, for example, from Hagger and Orbell’s (2003) review. Further research in this area is required. Greater use of explanatory theory and clarity of research questions are needed. A priori hypotheses should map accurately onto the self-regulatory framework and test clearly identified pathways within this model. The use of generic versus illness-specific coping measures is worth careful consideration. Illness-specific behavioural self-care activities are presented as an important dimension within the self-regulatory coping typology. Recent diabetes literature has emphasised the importance of behavioural coping, and the need to identify predictors of differential coping (Griva et al., 2000). As noted by Steptoe and Wardle (2004), research that identifies salient determinants of health behaviour, and provides insight into effective means through which to change health behaviour, is of central importance to health psychology.

Areas of Emerging Exploration: Relationships among Representations

Illness and treatment representations constitute two core dimensions within self-regulatory research; empirical evidence suggests there are links between these. The BMQ-specific necessity subscale, for example, has shown a significant relationship with scores on the IPQ timeline and identity scales among people with asthma, and those with diabetes (Horne, 1997; Horne et al., 1999). A study of people with coronary heart disease demonstrated a large number of significant associations between illness and treatment representations (Byrne et al., 2005). In this study, while medication necessity showed a significant positive relationship with illness identity, timeline acute/chronic, consequences, timeline cyclical, and emotional representation, a significant negative association was observed between medication necessity and treatment control. Of the eight illness representations included in the study only two, personal control and illness coherence, did not show a significant bivariate correlation with medication necessity. All eight illness representation subscales demonstrated a significant association with medication concern. Additional research in this area is warranted, as some findings require replication to ensure they are indeed robust. For example, the absence of a significant relationship between cure/control beliefs and treatment necessity among people with asthma is somewhat puzzling (Horne & Weinman, 2002). Variation in the relationships between illness and treatment representations can be observed across chronic conditions. This suggests illness type may moderate the nature of such relationships, perhaps constituting a useful hypothesis for future research.

Horne (2003) refers to a symbiotic relationship between illness and treatment representations. Certainly, there is evidence of a close association. In the interests of maximised explanatory power, Horne proposes that both dimensions should be included in self-regulatory research models. This proposition is endorsed by findings from recent studies, in which results show both illness and treatment representations make a significant contribution to explaining differences in adherence to preventive medication among people with asthma (Horne & Weinman, 2002). After controlling for demographic and clinical variables, illness perceptions and treatment representations accounted for 13% and 17% of differences in adherence, respectively, in this study.

Evidence of mediating relationships between IPQ and BMQ subscales was also present. Specifically, structural equation modelling suggests the relationship between illness timeline and adherence is mediated by beliefs about medication necessity. In addition to this, results suggest that medication necessity may mediate the relationship between illness consequences and reported adherence, although a significant direct relationship between these latter variables was also observed. Further research is required to determine the extent to which mediation is present. Collectively, self-regulatory literature shows considerable evidence of relationships between illness and treatment representations. As Horne remarks, adherence to medical advice is “likely to be the result of dynamic interaction between beliefs about the illness and treatment and perceptions of outcome” (Horne, 1999, pp. 492-493).

In addition to research showing a connection between illness and treatment representations, it is plausible there may be reliable associations among variables included *within* each dimension. Horne, Weinman, and colleagues have suggested personal choices about medication adherence may involve a decisional balance process, whereby an individual weighs up the perceived need for medication against any expected costs (Horne & Weinman, 1999). This has been referred to as the necessity-concerns dilemma (Horne, 2003). At a conceptual level, such ideas stimulate consideration of possible interactive relationships between medication concern and medication necessity (Horne, 2003), implying some effort will be needed to disentangle the relationships between medication concern, necessity, and adherence. As stated by previous researchers, we can “expect this relationship to be complex and to vary between and within individuals” (Horne & Weinman, 1999, p. 164).

Collective findings to date are difficult to interpret, and it is hard to find convincing explanations for observed inconsistencies. For example, a recent study examining secondary prevention of coronary heart disease (CHD) demonstrated a significant association between views about necessity of, and concerns regarding recommended treatments. Results showed belief in medication necessity is positively correlated with concerns about medications among people with CHD (Byrne et al., 2005). An alternative body of research promulgates the idea that necessity beliefs and concerns are separate constructs, which relate to adherence and illness representations in notably different ways (Horne & Weinman, 2002). Studies where there was an absence of any significant correlation between medication necessity and medication

concerns can be cited as supportive evidence for this line of argument (Horne & Weinman, 2002). Further research is required to provide clarity in this area.

A number of key relationship pathways in the common sense model involve illness representations. Recent research suggests complex hierarchical webs of association may exist *among* illness representations. It is necessary to understand these in order to gain an accurate picture of the relationships between illness representations, coping and illness outcomes. This can be considered a salient area of recent investigation among researchers using the common sense model. Some emerging themes are discussed below.

Research has demonstrated systematic connections among illness representations. In their meta-analysis Hagger and Orbell (2003) observed a significant positive association between timeline and consequences ($r_c = 0.43, p < .05$). This suggests people who view their illness as chronic are likely to believe it will have a serious impact on their life. This finding is supported by research across a range of chronic illness, for example, diabetes, asthma, multiple sclerosis, myocardial infarction, and coronary heart disease (Barnes, 2000; Byrne et al., 2005; Moss-Morris et al., 2002). Meta-analytic results also showed negative correlations between cure/control and consequences ($r_c = -.18, p < .05$), and cure/control and timeline ($r_c = -.34, p < .05$) (Hagger & Orbell, 2003). Findings imply those who believe a health threat can be treated effectively are also liable to see this illness as a temporary condition with minimal life consequences. These results are consistent with associations suggested as typical in other self-regulatory literature (Cameron & Moss-Morris, 2004). They are also in keeping with bivariate associations shown in initial publication of the IPQ-R; personal control and treatment control both showed significant negative correlations with timeline acute/chronic and illness consequences (Moss-Morris et al., 2002).

In recent research among people with coronary heart disease both personal control and treatment control demonstrated a significant negative relationship with illness consequences (Byrne et al., 2005). A significant negative association between timeline acute/chronic and treatment control was also evident. Studies using the IPQ-R allow for exploration of any differences between perceptions of personal versus treatment control. On the whole, results suggest treatment control shows stronger relationships with timeline and consequences, than personal control does. Hagger and Orbell

(2005) undertook a confirmatory factor analysis of the IPQ-R in a cervical screening context. The authors of this study proposed that there are predictable relationships between illness representations. Specifically, it was suggested that control based constructs (treatment control, and personal control), and illness coherence, would show a negative association with other illness representations. Positive inter-relationships were hypothesised to exist between consequences, emotional representation, and perceived timeline (timeline acute/chronic, and timeline cyclical). Reported research findings show support for the predicted associations. Hagger and Orbell (2005) conclude that “this arrangement lends support to the validity of the hypothesis that the organisation of the illness representations is similar across illness and may be schematic in nature” (p. 171).

However, researchers need to bear in mind there may be notable differences between chronic illness conditions (Heijmans & de Ridder, 1998; Kaptein & Broadbent, in press). For example, a New Zealand study focusing on people with type 2 diabetes reported no significant relationships between treatment control and timeline acute/chronic, treatment control and consequences, or personal control and consequences (Barnes, 2000). A significant positive relationship was observed between personal control and timeline in this study, ($r = .48, p < 0.01$), such that greater perceived personal control over diabetes was associated with a belief that diabetes is a long-term condition. Previous self-regulatory literature suggests it may be beneficial for people to view their illness as having a short time frame. For example, first-time myocardial infarction patients are likely to return to work earlier if they believe their illness will last a short time (Petrie et al., 1996). However, for people with type 2 diabetes, a belief that diabetes is temporary represents an inaccurate understanding of the nature of this disease. It may also represent an unwillingness to accept that one has diabetes, or that diabetes is a life-long condition. Thus, for people with type 2 diabetes, a belief that the illness is chronic may be beneficial because it indicates an accurate understanding of diabetes. It is important that interpretation of research findings take into account such illness-specific factors. Further empirical attention should be directed toward examining whether relationships among illness representations vary depending on the chronic condition.

Another area that has received particular interest is illness identity. In their meta-analysis, Hagger and Orbell (2003) predicted that illness identity would show a positive

relationship with chronic timeline and illness consequences, and a negative association with perceived cure/control. Averaged intercorrelation coefficients were corrected for sampling and measurement error. These showed positive associations between identity and consequences ($r_c = 0.37, p < .05$), identity and timeline ($r_c = 0.16, p < .05$), and a significant negative correlation between identity and cure/control ($r_c = -0.11, p < .05$). Thus results provided support for all three predicted relationships (Hagger & Orbell, 2003), suggesting stronger illness identity is related to views that this health threat will last a long time, have serious life consequences, and be difficult to cure or control. It is interesting to compare these results with findings presented in subsequent research. For example, authors of the IPQ-R computed Pearson's correlation coefficients to examine relationships among subscales. These showed a positive association between identity and personal control ($r = 0.14, p < 0.001$), and identity and treatment control ($r = 0.13, p < 0.01$) (Moss-Morris et al., 2002). This is not consistent with meta-analytic results presented by Hagger and Orbell (2003). Further, the absence of significant associations between identity and consequences, or identity and timeline acute/chronic reported by Moss-Morris et al. (2002) can only add to concerns about the reliability of reported relationships between identity and other illness representations.

One explanation is that Hagger and Orbell's meta-analysis uses literature published before the IPQ-R was available. Early self-regulatory literature used a simple count of symptoms endorsed as an operational definition of illness identity (Weinman et al., 1996). In an attempt to differentiate illness identity from somatisation, authors of the IPQ-R formulated a new operational definition (Moss-Morris et al., 2002). Namely, the number of symptoms linked to the specified illness label (for example, diabetes). A simplistic explanation for the inconsistencies noted above could then be different ways of measuring illness identity. However, perusal of more recent literature indicates this is unlikely. A recent study using the IPQ-R to examine health behaviour among people with coronary heart disease (Byrne et al., 2005), reports results similar to the original hypotheses presented by Hagger and Orbell (2003). Byrne et al. found significant positive correlations between illness identity and timeline acute/chronic ($r = 0.16, p < 0.001$), and between identity and consequences ($r = 0.31, p < 0.001$). Negative relationships were also reported between identity and both personal control ($r = 0.13, p < 0.01$), and treatment control ($r = 0.15, p < 0.001$). A New Zealand study using the IPQ-R among people with diabetes found significant positive relationships between

identity and timeline acute/chronic ($r = 0.25, p < 0.05$), and identity and consequences ($r = 0.29, p < 0.01$) (Barnes, 2000). However, no reliable relationships were observed between identity and personal control or treatment control in this latter study.

Multi-collinearity among illness representations provides potential for a hierarchy of embedded relationships. In this, one illness representation may act as a mediator between two other representation variables. For example, the observed relationship between cure/control and consequences may be mediated by views about illness duration. In fact, evidence suggests this is the case. Hagger and Orbell (2003) calculated semi-partial correlation coefficients from a correlation matrix produced by a meta-analytical review of self-regulatory literature. Two previously significant relationships were attenuated to zero. The magnitude of a third correlation was significantly reduced. Post hoc analyses were then used to investigate the associations among illness representations in detail. These showed that the relationship between low cure/control and high consequences is explained by perceptions of chronic illness duration. Results reveal that the relationship between strong illness identity and chronic timeline can be explained by a perception of serious illness consequences. A third relationship, that between cure/control and identity, also showed significant, though not total, attenuation. Post hoc analyses indicated consequences and timeline mediated this final relationship. Findings suggest that an observed relationship between two illness representations may hinge on the presence of a third variable (Hagger & Orbell, 2003).

Baron and Kenny (1986) provide an excellent overview of mediating relationships. This shows that, in a statistical sense, demonstration of the observed interrelationship between identity and timeline relies on the maintenance of a relationship pathway between the mediator (consequences) and the two original variables. This mediational pathway can be controlled through calculation of semi-partial correlation coefficients. Once the statistical impact of the mediator has been removed, the magnitude of the previously observed interrelationship may reduce as discussed above. The extent of this attenuation depends on whether total or partial mediation is present. Such results illustrate that the interpretation of relationships among illness representations is far from straightforward. As noted in previous literature, zero-order correlations may "not account for the organizational complexity of people's illness representations. This suggests that some of the illness representation dimensions are not orthogonal but

inter-dependent” (Hagger & Orbell, 2003, p. 177). Similar sentiments have been articulated in recent diabetes literature. For example, Skinner et al. (in press) agree with this proposition, suggesting that “illness beliefs do not act in isolation, but it is the interaction between various beliefs that will be predictive of subsequent active self-management.”

A recent study of illness representations and emotion among women with abnormal cervical screening results also adds to speculation about possible mediating relationships among illness representations. In this study, Hagger and Orbell (2006) used a series of three-step hierarchical regressions to examine the contribution of demographics and disease severity (entered at step 1), cognitive illness representations (entered at step 2), and emotional illness representation (entered at step 3), to measures of emotional adjustment (anxiety, anger, guilt, embarrassment, sadness, and relief). Results suggest that identity is related to emotional adjustment, and that this relationship is independent of emotional representation. In each of the six hierarchical regressions, perceived consequences showed a significant association with the dependent variable (a form of emotion). However, when emotional representation was entered at step 3 of each regression, the previously observed relationships between consequences and embarrassment ($Beta = .23$ $p < .01$), and consequences and sadness ($Beta = .31$ $p < .01$) were substantially attenuated ($Betas$ at step 3 = $.11$, $p < .05$, and $.06$, $p < .05$, respectively). Further, the relationships between consequences and anxiety, anger, guilt, and relief, were each reduced to non-significance when emotional illness representation was entered at step 3 of the analyses. Inspection of $Betas$ at step 2 of each regression revealed that illness coherence also demonstrated a significant association with anxiety, anger, sadness, and relief. However, at step 3 of these regressions, illness coherence no longer showed evidence of a significant relationship with the dependent variable (anxiety, anger, sadness, or relief). The authors of this publication state “the attenuation of these relationships were confirmed as mediation effects in accordance with Baron and Kenny’s (1986) criteria” (Hagger & Orbell, 2006, p. 197). Collectively, such research findings imply emotional illness representation may act to mediate the relationship between certain cognitive illness representations (e.g., coherence and consequences), and emotional outcomes.

Other variables such as illness type or severity may also influence the relationship observed between two illness representations. Data from Hagger and Orbell's (2003) meta-analytic review were used to examine the error variance in interrelationships among six illness representation dyads: cure/control-consequences; identity-cure/control; identity-consequences; identity-timeline; timeline-cure/control; timeline-consequences. The difference between total error variance in each corrected correlation coefficient, and that accounted for by statistical artefacts corrected for in the meta-analysis, was used as an indicator of moderating relationships. This difference was formally evaluated using χ^2 tests ($p < .05$). Each of the six corrected coefficients was associated with a significant χ^2 value: evidence of a significant difference between total error and artifactual error (Hagger & Orbell, 2003). In each case, the percentage of total error variance accounted for by statistical artefacts was less than 30%. Values greater than 75% are required to give reasonable assurance that moderator variables are not affecting the specified relationship. Results provide fuel for speculation about moderating relationships, suggesting these may affect interrelationships among illness representation variables.

An overview of emerging research, as provided above, suggests there are patterns of association among representation domains. However, the interpretation of such patterns is challenging. Replication is necessary before firm conclusions can be drawn about the robustness of any observed relationships among illness representations. This should not dissuade researchers from including hypotheses specifying relationships among illness/treatment representations. Nor should it lead to an assumption that relationships among illness representations are unimportant, or imply these are not needed to further our understandings of the self-regulatory process. The opposite may be true. If self-regulatory research aims to create a platform of knowledge that can be used to develop efficacious interventions promoting positive health behaviour, it is essential to acknowledge and seek to deconstruct the hierarchy of potential relationships among illness representations.

Connections among illness representations may affect the interpretation of observed links between representations and coping or illness outcomes. Hierarchical webs of collinearity among illness representations could mean that one dimension may act as a mediator in the relationship between a second dimension and a stated illness outcome. It certainly implies the need for care when considering such relationships. For

example, a significant bivariate relationship between variable 'a' and behavioural coping may lead to the suggestion that 'a' has a positive influence on coping. However, this observed correlation could be an artefact of the relationship *among* illness representations. If a second variable, for example, 'b', is added to the predictive equation we may find the relationship between 'a' and coping is no longer statistically significant. Such attenuation suggests the presence of a mediating relationship. In this case, there may be no direct relationship between variable 'a' and behavioural coping. Rather, the observed relationship between these variables could be the result of a correlation between variables 'a' and 'b'. In this instance, the relationship between 'a' and coping may be better understood as being 'by association only': it is indirect, i.e., dependent on 'b' as a mediator. Such intricacies may have useful real world applications. For example, initial findings could have suggested an intervention programme should target 'a' as an effective mechanism through which to influence coping behaviour. However, after identification of a mediating relationship, it may make better sense to focus any intervention on 'b'. Researchers using the CSM could be well advised to employ caution in their interpretation of bivariate relationships between single illness representation constructs and other structures of interest within the CSM; replacing these with multivariate analyses where possible.

Overall, research suggests reliable patterns of association do exist among illness representation domains. However, these are complex. At present empirical research using the CSM has not often made this a core investigative aim. Few studies have deliberately sought to examine such interrelationships using hypotheses stated a priori. Further research in this area is warranted. Particular attention should be given to scientific testing of mediating and moderating relationships among illness representations. Such research will help build a better understanding of the interconnections between representation domains. This may, importantly, help to ensure an accurate insight into the relationship between illness representations and coping/illness outcomes is formed.

REFLECTIONS ON SELF-REGULATORY RESEARCH

Health psychology has made frequent use of the self-regulatory approach in empirical research (Hagger & Orbell, 2003); however, critical reflection reveals both strengths

and limitations of this approach. Chapter 2 discussed the strengths and weaknesses of the CSM as they pertain to the needs of the present research (focused on diabetes). The following section elucidates broader considerations that relate more widely to self-regulatory literature.

This begins by focusing on positive elements. The common sense model's focus on *self-regulation* is an important recommending factor, because personal self-care activities are often a primary determinant of long-term wellbeing among people with chronic conditions (for example, coronary heart disease (Byrne et al., 2005)). Other strengths of self-regulatory theory include its process-orientated nature (enabling representation of change in behaviour over time), and inclusion of both cognitive and emotional components within illness self-regulation, as emphasised in chapter 2. Broader reflection implies self-regulatory research is able to contribute to explanatory theory regarding health behaviour and, potentially, assist in the development of efficacious interventions.

Social cognition theories, such as the common sense model, provide a useful framework from which to begin examining health related behaviour. First, because they enable close examination of the proximal determinants of behaviour (Skinner et al., 2002). This generates opportunities for researchers to develop a strong conceptual understanding of how people with diabetes manage their illness; most importantly, it allows for identification of specific variables that may impinge, or act to promote, healthy behavioural choices. Second, social-cognitive variables are useful from an intervention perspective because, hypothetically, such variables should be amenable to change in a way that, for example, socio-demographic status, ethnicity, and physical location are not. The ability of such proximal variables to mediate between health behaviour and other upstream determinants (e.g., social context) is also a valued characteristic (Conner & Norman, 2005).

However, self-regulatory research has identifiable limitations. As described in chapter 2, in the CSM the link between the wider social environment and self-regulation is tenuous. It is suggested that environmental factors feed into the process of illness self-regulation, but there is little detail available to make clear exactly how. For example, connections between social communication and illness/treatment representations have only been vaguely discussed in self-regulatory literature. To date, studies using the

CSM have tended not to integrate interpersonal and individual aspects of illness regulation. As a result, self-regulatory research does not provide a clear understanding of the potential impact social context may have on individual views of health and illness. Steptoe and Wardle (2004) argue convincingly that research must examine the links between social environment, cognitions, and individual health behaviour, in order to create a more comprehensive account of behavioural differences. This sentiment is echoed within diabetes literature (Fisher et al., 1998; Rose et al., 2002; Wolpert & Anderson, 2001). Thus nebulous specification of the connections between the broader environment and self-regulation is a limitation of the CSM, while failure to integrate interpersonal and individual aspects of illness regulation is a limitation of empirical research founded on a self-regulatory approach. These issues are obviously interlinked.

A second area plagued by vague explanatory theory, inadequate empirical attention and, consequently, limited conceptual clarity is the common sense model's emotional pathway. There has been a strong emphasis on the cognitive dimension in self-regulatory literature to date. In comparison, the emotional dimension has suffered from neglect. This is particularly true for chronic conditions that are strongly positioned as 'physical' illnesses, such as diabetes mellitus. However, as explained in chapter 1, the emotional burden of diabetes is substantive. Theoretical frameworks that provide a clear account of emotional processes in chronic illness management are needed. While explanatory theory within CSM literature has developed detailed understandings of the role cognition plays in shaping illness self-regulation, less is known about the processes that regulate the emotional impact of long-term health threats.

In addition to this, greater attention needs to be focused on *interactions* between the cognitive and emotional pathways in self-regulatory literature. Leventhal and colleagues outline the two pathways and place these side by side, but do not explain how these interact in any detail. Further, after a quarter century of self-regulatory research, there is still little specification of the links between these pathways or identification of how particular variables relate to each path. For example, is it plausible that variables labelled as 'cognitive' representations could also contribute to the regulation of emotion in chronic illness. If so, it would be helpful to know which variables are involved and what types of directional relationships (positive or negative) are present.

Thus some parts of the model, for example the emotional pathway, have been overlooked in empirical research. Other aspects, such as coping and appraisal, have failed to show clear results. More than quarter of a century ago, Taylor provided a pithy description of the coping literature, likening it to a “three-car garage filled to the rafters with junk” (Taylor, 1990, p. 44). Unfortunately, this depiction continues to resonate with some truthfulness. Another problematic, and common, research finding is that only a minority of illness representation variables appear to show a reliable relationship with outcomes of interest. In a number of diabetes studies, multivariate analyses show less than half the illness representation variables entered into a regression model demonstrate a significant relationship with the outcome of interest (e.g., Barnes, 2000; Hampson et al., 1995; Lange & Piette, 2006; Lawson, Bundy, Lyne, & Harvey, 2004; Skinner et al., 2002). Such results imply some variables within the CSM may be superfluous; that is, they are unable to make a unique contribution to the explanatory power of the CSM in relation to key outcome variables. This point also relates to a need for parsimonious models.

The CSM enables researchers to examine a large number of variables that may contribute to differences in health behaviour, and illness outcomes. This can help generate a more comprehensive account of behavioural differences. However, there is a flip side. Synthesis of so many variables (aspects of motivational, action, process and organisation models) may come at a price. There is a risk that the CSM becomes a catchall, a loose collection of variables with vague and tenuous specification of relationships between key constructs. To some extent this criticism is valid. Although the CSM provides a useful overarching framework that identifies many possible determinants of health behaviour, the model can be criticised for loose presentation without clear operational definitions for some key constructs, and a lack of parsimony.

One final criticism of self-regulatory literature relates to the infrequent use of specific directional predictions in hypothesis testing. Although it is important to demonstrate that variables within the CSM are able to account for a significant proportion of variance in outcomes of interest (behaviour, wellbeing), this should be balanced with the need to generate explanatory theory through formulation and testing of predicted associations. In order to build a sound conceptual understanding of illness self-regulation, research needs to specify the nature of relationships between key variables (for example, a prediction that higher personal control will show a positive association

with active behavioural coping). It is this detailed level of knowledge about the relationships between self-regulatory variables that creates the foundation for comprehensive explanatory theory. This is also an essential prerequisite for efficacious intervention.

In the context of behavioural research, the real world utility of research findings is tied to an ability to clearly identify individual variables that show a strong association with the health behaviour of interest (Weinman & Petrie, 1997). This type of detailed information produces effective interventions because it indicates what aspects of the cognitive schema should be targeted, and how best to evaluate the impact of the intervention on cognitive perceptions of diabetes (i.e., key variables that function as the targets for, and markers of, cognitive change). By increasing the specificity of proposed relationships between psychosocial variables and coping, self-regulatory research may be better able to produce interventions that work to improve self-management of chronic illness. This is an important goal for health psychology. To date, published research has not often included a priori directional hypotheses predicting and testing specific relationships between individual representation and coping variables. However, this is not so much an inherent limitation of the CSM, as fallibility in the way researchers make use of it. Future research should ensure hypothesis testing includes specific directional predictions, as well as hypotheses that require demonstration of explanatory power.

To summarise, in their early explication of the self-regulatory model Leventhal and colleagues highlight research showing a concrete representation that provides clear, reality-based expectations is linked adaptive coping and positive health outcomes. In contrast a health threat that appears uncertain or unknowable may create distress, fail to generate clear coping goals and, potentially, compromise wellbeing (Leventhal et al., 1980). Since this research was published, a number of studies have sought to investigate the relationship between illness representations, coping, and health outcomes in greater detail, providing insight into the precise nature of associations, and suggesting some evidence of reliable relationships among these constructs.

Further research is required to unpack the complexity of associations between illness/treatment representations, coping, and health outcomes. There is some evidence that the relationships between illness representations and coping may be

moderated by other variables (Hagger & Orbell, 2003), and that potential mediating relationships may exist. The exploration of both mediating and moderating relationships in the CSM can be identified as a useful area for future study. The possible existence of hierarchical webs of association among illness representations demands greater consideration. Future research should consider the need for specific directional predictions in hypothesis testing. Thus, although much has been learned about the relationships between illness/treatment representations, coping, and health outcomes, significant gaps in our understandings of self-regulation are evident. Further research in this area is warranted.

DIABETES RESEARCH USING SELF-REGULATORY THEORY

Studies focusing on diabetes are well represented in the self-regulatory literature, comprising, for example, the largest illness group in Hagger and Orbell's (2003) meta-analytic review of research using the CSM. An overview of diabetes research founded on self-regulatory theory constitutes the third component in the current chapter. A variety of measures have been used to assess illness perceptions among people with diabetes, including versions of the Illness Perception Questionnaire (IPQ (Weinman et al., 1996), IPQ-R (Moss-Morris et al., 2002), DIRQ (Skinner et al., 2003)) and the Personal Models of Diabetes Interview (PMDI) (Lawson et al., 2004). Particular attention has been given to examining behavioural coping strategies using, for example, the Summary of Diabetes Self-Care Activities (SDSCA) scale, and Medication Adherence Report Scale (MARS). Health and illness outcomes assessed include self-reported physical and mental health using the Medical Outcomes Study SF-36/SF-20, Well-Being Questionnaire (WBQ), or Center for Epidemiologic Studies Depression (CES-D) scale. Objective disease status has also been measured in some studies using glycosylated haemoglobin (HbA_{1c}). In comparison to other chronic conditions, diabetes research is reasonably well represented in self-regulatory literature. However, in absolute numerical terms, the number of studies is quite low (Griva et al., 2000). Considerable opportunity still exists for acquisition of further knowledge, in particular regarding the connections between illness/treatment representations and self-care. Active behavioural self-management is crucial to wellbeing among people with diabetes, and forms a core construct of research interest in the present study. Previous literature has proposed that "treatment adherence could

be conceptualised as a coping behaviour or a set of coping behaviours” (Griva et al., 2000, p. 735). Therefore the CSM, with its focus on illness representations and coping, provides an excellent theoretical framework from which to explore self-regulatory processes among people with type 2 diabetes.

Illness/Treatment Representations Associated with Diabetes

The term chronic illness is applied to a wide range of ongoing health conditions. Yet illness representations may vary substantially between groups (Heijmans & de Ridder, 1998). For example, perceptions of chronicity, curability, and personal control over illness symptoms can vary considerably depending on the illness type (Hampson et al., 2000). Using standardised measures, such as the IPQ-R, it is possible to compare illness and treatment perceptions across chronic conditions. This information can provide an ‘illness profile’; that is a sense of how, on average, people with diabetes see their illness. In a study of people with non-insulin dependent diabetes mellitus, Hampson, Glasgow, and Toobert (1990) reported that approximately 90% of respondents saw diabetes as a chronic condition. Almost all believed there is an important connection between controlling your diabetes now, and avoiding complications in the future.

Research has compared the illness beliefs of people with insulin-dependent diabetes to those of people with rheumatoid arthritis (RA), chronic fatigue syndrome (CFS), and chronic idiopathic pain, using one-way analyses of variance with post hoc Scheffe tests (Weinman et al., 1996). Results showed that, compared with people with CFS, people with diabetes have weaker illness identity and less belief in the presence of serious illness consequences. A significant difference in illness identity scores was also observed between the RA and diabetes groups, such that people with diabetes showed a weaker illness identity. Group differences were also observed in relation to identified causes of the illness. People with diabetes were more likely to attribute this condition to genetic factors, in comparison with the CFS and pain groups. Treatment perceptions may also vary between illness groups. Research using the Beliefs about Medicine questionnaire has shown people with diabetes are more likely to view prescribed treatments as necessary, in comparison to people with asthma, cardiac disease, or psychiatric illness (Horne, 1997; Horne et al., 1999). Empirical findings suggest people with diabetes are likely to see exercise, and low-fat/low-calorie diet as

least effective in controlling diabetes; while use of prescribed medications and avoiding sweet foods are viewed as being most efficacious (Glasgow et al., 1997). Collectively, research into illness and treatment representations suggests people with diabetes view their illness differently to people with other chronic conditions. In addition to observed differences between disease types, variation within an illness group may be present. For example, research suggests illness representations may vary according to perceived severity of diabetes (Hampson et al., 1990). A recent study by Wearden et al. (2005) presents evidence that people using insulin treatment perceive the consequences of diabetes as being more severe, and are more likely to view this as a long-term illness, compared with those who do not use insulin. Results also imply people who have recently been diagnosed with type 2 diabetes may have stronger illness identity than those who have lived with this condition for a considerable length of time.

Relationships among Illness and Treatment Representations

There is some evidence suggesting relationships between illness representation constructs among people with diabetes. A strong correlation between course (timeline) and consequences was reported by Hampson, Glasgow, and Toobert (1990). This is consistent with New Zealand research by Barnes (2000) that showed moderate positive relationships between views about illness timeframe, and other illness representation variables (timeline cyclical-consequences $r = .49, p < .01$; timeline chronic-consequences $r = .54, p < .01$; timeline chronic-personal control $r = .48, p < .01$). A moderate negative association was reported between timeline cyclical and illness coherence ($r = -.47, p < .01$). A significant association was observed between the two dimensions of control beliefs included in this study ($r = .42, p < .01$). Although suggesting a degree of shared variance, the moderate nature of this correlation implies it is useful to separate personal control from treatment control; these are best viewed as distinct self-regulatory constructs. Results from recent diabetes research using the Brief IPQ agrees with this proposition (Broadbent et al., 2006). Diabetes identity has also shown significant associations with other illness representation variables. For example, Griva et al. (2000) report a positive correlation between identity and consequences ($r = .41, p < .001$), and a negative association between identity and cure/control ($r = -.31, p < .01$). This study also provides some evidence that illness representations (identity, consequences, and control) are linked to diabetes-specific

self-efficacy beliefs. Further research is needed to clarify the nature of inconsistent associations. For example, although some diabetes research has shown relationships between timeline and consequences (Barnes, 2000; Hampson et al., 1990), other studies have not (Griva et al., 2000).

Early literature suggested personal models of diabetes are comprised of both emotional and cognitive components (Hampson et al., 1990). This proposition has been supported by recent empirical studies using the IPQ-R. For example, a New Zealand study focusing on type 2 diabetes demonstrated significant bivariate correlations between emotional representation of diabetes and timeline cyclical, coherence, consequences, personal control and diabetes identity (Barnes, 2000). Watkins et al. (2000) used structural equation modelling to assess the relationships between illness representation variables, self-care behaviour, and quality of life. Although not strictly a measure of emotional representation, the variable labelled as 'negative impact' appears to be founded on negative affect-based representation of diabetes. Inspection of item content reveals questions that include "I am afraid of my diabetes" and "I feel unhappy and depressed because of my diabetes" (Watkins et al., 2000, p. 1513). In this study, diabetes understanding and perceived control both showed a significant relationship with negative impact. The direction of these associations suggest that lower perceived coherence of diabetes, and less perceived control over diabetes, are both associated with greater negative emotional representation of this illness. To summarise, there is emerging evidence of relations between cognitive and emotional representation of diabetes. This is identified as a salient area for future study.

Illness and Treatment Representations and Self-Management Behaviour

Previous diabetes research notes that "according to the SRM, illness perceptions should influence adherence behaviours" (Griva et al., 2000, p. 735). Thus one salient area of empirical investigation should be the relations between illness/treatment representations and diabetes self-management. This has concentrated on five core illness representation constructs: identity, consequences, timeline, cause, and controllability (Glasgow et al., 1997; Griva et al., 2000; Skinner & Hampson, 2001; Watkins et al., 2000). There is also emerging interest in emotional representation, and cognitions pertaining to treatment (medication necessity and concern). The following

sections will draw on diabetes research framed as examining 'illness representations' as well as that seeking to investigate 'personal models' of diabetes. These linguistic terms essentially refer to the same constructs and have been used interchangeably in previous diabetes research (e.g., Glasgow et al., 1997; Lange & Piette, 2006).

Illness identity

Research focused on adolescents with insulin dependent diabetes mellitus has demonstrated a significant bivariate relationship between diabetes identity, and overall adherence scores ($r = -.38, p < .01$). The direction of this relationship implies greater identification with diabetes is associated with lower self-care (Griva et al., 2000). Investigation of correlations between identity and four separate dimensions of diabetes regimen adherence reported in this study suggests identity is most strongly connected to dietary adherence ($r = -.41, p < .001$). Research by Skinner et al. (2003) suggests that greater illness identity is associated with higher depression ($r = .34, p < .001$), greater anxiety, ($r = .32, p < .01$), and lower positive wellbeing ($r = -.29, p < .05$). Illness identity is closely connected to symptoms; indeed, identity is created through the process of connecting symptoms to illness labels (Moss-Morris et al., 2002). Further research is needed to clarify the role of identity and symptoms in diabetes behaviours. For example, Lawson et al. (2004) predicted that people who regularly sought professional assistance to care for their diabetes (regular care seekers) would have tighter glycaemic control, leading to increased risk of hypoglycaemia, and therefore greater symptom reporting. Results did not support this hypothesis. Instead, patients receiving regular care were found to report less symptoms than non-attendees. This difference was statistically significant. There is some evidence that rejection of a 'diabetic identity' is linked to poor self-care behaviour (Tilden et al., 2005). Further, as highlighted by Montez and Karner (2005, p. 1087), "diabetes is not necessarily an illness that can be experienced symptomatically through the body". Because people with diabetes may experience few noticeable symptoms (indeed, many people have diabetes but do not know this), the embodied experience of illness is not always present in type 2 diabetes (Montez & Karner, 2005).

Illness coherence

Clear evidence connecting coherence with diabetes self-management is scant. This is largely attributable to the recent nature of keen interest in coherence. It will take time for research to investigate the role coherence plays in self-regulation of chronic illness; a reliable empirical picture is not available at present. However, inclusion of a subscale labelled 'coherence' in the revised Illness Perception Questionnaire has stimulated exploratory diabetes research in this area. It appears that being able to 'make sense' of diabetes is associated with better self-management. For example, in New Zealand research greater perception of diabetes coherence has been associated with health-promoting dietary choices (Barnes, 2000). Watkins et al. (2000) used a comprehensive questionnaire (234 items) to assess diabetes-related attitudes, beliefs and behaviours. Within this, four illness representation constructs were measured – consequences, cause, control, and diabetes understanding. It appears that the variable labelled 'diabetes understanding' may be similar to but not synonymous with, the IPQ-R variable 'coherence'. Structural equation modelling was used to determine relationships among illness representations, self-care behaviour, and quality of life. Results revealed that greater reported understanding of diabetes was associated with better dietary patterns. Thus findings from both New Zealand and international research suggest a personal belief that diabetes 'makes sense' may play a health-promoting role in relation to dietary self-management among people with diabetes. However, further research is needed to establish a clear understanding of the role coherence plays in diabetes self-regulation, particularly its relationship with other aspects of diabetes management (e.g., exercise, medication use). This is an important area for future study.

Timeline (acute/chronic and cyclical)

A negative association between timeline cyclical and dietary habits ($r = -.24, p < .05$) has been reported among people with type 2 diabetes in New Zealand (Barnes, 2000). However, timeline has not shown significant relationships with self-reported adherence in some studies. For example, Griva et al.(2000) assessed adherence across four dimensions of diabetes self-care (insulin, diet, blood glucose monitoring, and exercise). Timeline (measured using the IPQ) did not show a bivariate relationship with any of the

four aspects of adherence, and there was no relationship between timeline and total adherence at the multivariate level.

Control

Previous studies have shown evidence of connections between perceived control and patterns of self-care; the direction of this relationship suggests people who view diabetes as controllable are more likely to engage actively in self-care than those who have low perceptions of diabetes control. In a study of adolescents with type 1 diabetes, perceived control showed a significant positive relationship with dietary patterns (Skinner & Hampson, 1998). A second study of young adults with insulin dependent diabetes found perceived control to be the most consistent associate of reported adherence to self-care activities (Griva et al., 2000). Among the four illness representation variables included, control was the only variable to show significant bivariate relationships with each of the adherence domains assessed (insulin, diet, blood glucose monitoring, and exercise). All correlations were in the same direction: showing greater perceived control was associated with higher self-reported adherence ($r = .30$ to $.69$). Hierarchical forward multiple regression was then employed to identify those variables that offered explanatory power at the multivariate level. Total adherence scores were regressed on age, diabetes duration, identity, perceived control, diabetes self-efficacy, and generalised self-efficacy. Results identify perceived control as the only variable that made a statistically significant contribution to explained variance in this analysis. The authors of this study conclude that perceived control accounted for 39% of differences in total adherence (Griva et al., 2000).

Watkins et al. (2000) used structural equation modelling to map the relationships between illness representations, self-management, and quality of life. Research findings indicate that greater perceived control is associated with positive dietary management. This model appears applicable across a heterogeneous sample consisting of people with type 1 diabetes, type 2 diabetes, those using insulin, and those whose treatment consists of oral medication and/or lifestyle recommendations. Research founded on a personal models approach has frequently used a variable labelled 'treatment effectiveness' to assess the relationship between perceived control and diabetes self-management. Treatment effectiveness is considered similar to the IPQ variable labelled 'cure/control' (Hampson et al., 2000). This proposition is

consistent with conceptual analysis presented by Lange and Piette (2006). In a study by Glasgow et al. (1997), treatment effectiveness showed a significant relationship with diet, physical activity, and glucose testing, even when controlling for medical and demographic characteristics. Prospective analysis has also identified perceived treatment efficacy as a significant predictor of dietary adherence among older adults with diabetes (Hampson et al., 1995).

Skinner, Hampson, and Fife-Schaw (2002) used structural equation modelling to investigate the relationships between emotional stability, conscientiousness, illness/treatment representations, and four aspects of diabetes self-management (insulin injections, blood glucose testing, exercise, and diet). Treatment control was split into two dimensions: a belief that prescribed treatments are effective in controlling diabetes, and a perception that treatments are effective in preventing diabetes complications. Results showed that cognitive representations of treatment as a control for diabetes was the more important predictor of diabetes self-management behaviour; as this variable showed a significant relationship with each of the four aspects of self-care included in the study. In contrast, perceived effectiveness of treatment to prevent diabetes complications was only related to blood glucose testing. This is in keeping with other diabetes studies, suggesting the perception of treatment as a control for diabetes complications has minimal influence on diabetes self-care (Skinner & Hampson, 1998).

In the IPQ-R perceived control is separated into two components. As discussed in chapter 2, these are labelled treatment control and personal control. New Zealand research has reported a significant relationship between perceived control and diabetes-self management. A study of people with type 2 diabetes showed greater personal control of diabetes is associated with more frequent blood glucose testing (Barnes, 2000). It is interesting to note that treatment control did not show any statistically significant relationships with self-reported diet, exercise, glucose testing, or medication adherence in this study. However, other studies have shown perceptions of treatment control may have an impact on diabetes self-care. For example, perceived treatment efficacy has been shown to predict dietary and exercise behaviour (Glasgow et al., 1997; Hampson et al., 1995; Hampson et al., 2000; Hampson et al., 1990). Emerging research suggests perceived control may act to mediate the observed relationship between family support and dietary self-management (Skinner &

Hampson, 1998). There is some evidence that the impact of perceived treatment control on health behaviour may be greater for dietary aspects of self-management (Hampson et al., 1995; Hampson et al., 2000; Hampson et al., 1990; Skinner & Hampson, 1998; Watkins et al., 2000). Previous literature has identified perceived control as one of two personal model components that show “consistent and replicable associations with dietary self-management” (Hampson et al., 2000, p. 28).

Prospective research has identified perceived treatment control as a significant predictor of differences in glycosylated haemoglobin (Hampson et al., 2000). However, recent research using the IPQ-R and Brief IPQ leads us to question the relationship between perceived control and HbA_{1c} (Broadbent et al., 2006). Reported findings highlight the need to distinguish between personal control, and perceived treatment control in diabetes research. Broadbent et al. found no significant correlations between HbA_{1c} and perceived personal control ($r = .02, p = .86$), or treatment control ($r = .18, p = .09$), using the IPQ-R. However, different results were evident when the Brief IPQ was employed: higher personal control was related to lower HbA_{1c} ($r = -.30, p < .01$), while higher treatment control was significantly associated with higher HbA_{1c} ($r = .21, p < .05$). This intriguing finding may be the result of connections between high personal control and internal locus of control and, conversely, an association between high treatment control and external locus of control (Broadbent et al., 2006). Further empirical research is necessary to disentangle the relationships between perceived control and HbA_{1c}.

Consequences

Diabetes research has shown a significant association between expected consequences of diabetes and behavioural self-management. For example, Barnes (2000) reports a positive relationship between consequences and frequency of blood glucose testing ($r = .37, p < .01$). An Australian study focusing on adults with diabetes assessed the consequences of performing recommended self-care behaviours, labelled ‘outcome expectancies’ in this study. Results showed that greater outcome expectancies were positively associated with frequency of glucose testing, and levels of exercise (Williams & Bond, 2002). Previous literature has suggested that the IPQ variable ‘consequences’ is comparable with the variable labelled ‘seriousness’ in studies using a personal models approach to self-regulatory processes (Hampson et

al., 2000). Qualitative research has emphasised the importance of acknowledging that diabetes is serious, suggesting this belief plays a key role in enabling people with diabetes to stay well (Campbell et al., 2003). Recent research using a culturally varied sample that included both type 1 and type 2 diabetes has demonstrated that perceived seriousness explains variance in metabolic control (Lange & Piette, 2006). Together with treatment effectiveness, seriousness is predicted to play a pertinent role in determining diabetes self-management, particularly diet and exercise patterns (Glasgow et al., 1997; Hampson et al., 2000).

Multivariate analyses have shown that perceived seriousness of diabetes is related to variation in diet, and physical activity, though these relationships are not always consistent across variations in analyses (Glasgow et al., 1997). The direction of observed associations indicates that greater perceived seriousness is related to less healthful lifestyle choices among people with diabetes. Although the magnitude of these relationships was not strong, it did remain statistically significant even when controlling for other illness representation variables, and medical and demographic characteristics. Eiser et al. (2001) have suggested that the relationship between consequences and wellbeing may be moderated by type of diabetes. Empirical evidence has shown that, in comparison with people with type 1 diabetes, those with type 2 diabetes report diabetes is less serious (Lange & Piette, 2006).

Research using the self-regulatory model in a series of studies focused on adolescents with type 1 diabetes introduced a distinction between 'perceived threat', and 'perceived impact', as two dimensions within the 'consequences' of diabetes (Skinner et al., 2003). Lawson et al. (2004) separated consequences into two components in a study of adults with type 1 diabetes: 'threat' assessed diabetes severity and perceived susceptibility to complications, while 'impact' referred to the consequences for everyday living. This distinction is similar to that made between variables labelled 'perceived seriousness' and 'perceived impact' in recent research by Skinner et al. (in press). Self-regulatory research among young adults with type 1 diabetes has highlighted possible differences between the impact of diabetes on personal life, and the impact of diabetes on one's health (Skinner et al., 2002). Results from the study by Lawson and colleagues (2004) showed greater perceived threat, but not impact, was negatively related to regular diabetes care. Research by Edgar and Skinner (2003) has demonstrated a relationship between perceived impact of diabetes, and negative emotional wellbeing.

Overall, research findings suggest perceived *personal* impact may play an important role in determining emotional adjustment to diabetes, while the perceived *health* impact of diabetes (seriousness of threat to health) is related to self-care behaviour. The IPQ-R does not separate illness consequences into multiple dimensions. However future research should be encouraged to consider this proposition. Consequences may also have important links with other illness representations among people with diabetes, for example, illness identity and symptom appraisal, as discussed in the following section.

The Relationship between Symptoms and Consequences

Self-regulatory literature suggests perceived symptoms act as the yardstick people implicitly use to decide whether an illness is serious or not (Cameron & Moss-Morris, 2004). An illness with a large number of adverse symptoms is likely to be viewed as serious; this is often a good motivator for health protective behavioural action. Conversely, an illness with few symptoms is not likely to be seen as serious, or as having important life consequences. This can create a problem for people with diabetes. As Cameron and Moss-Morris (2004) point out, people with poorly controlled diabetes do not always experience adverse symptoms. This is particularly true in early diabetes, before serious complications (e.g., neuropathy, retinopathy) are noticeable to the person. It is important to note this early symptom-free period may last a number of years, during which time serious and irreversible damage to body systems can occur as a result of poor glycaemic control.

The discussion above highlights the significance of illness representations labelled 'consequences' or 'seriousness' for type 2 diabetes. It also suggests an important connection between symptoms and consequences. As stated by Lange and Piette, (2006, p. 246) "it appears that patients rely heavily on current symptoms . . . in determining the severity of their diabetes". People who are not experiencing significant adverse symptoms may, erroneously, conclude that diabetes is a relatively benign condition which is unlikely to have a serious negative impact on their life (low perceived consequences). This belief could form a barrier to active behavioural self-management. Because people with diabetes may experience few symptoms, they may then see their diabetes as having few serious consequences, and as a result lack the motivation to commence and sustain the level of commitment to self-care activities required to produce good glycaemic control. Self-management of diabetes exhorts a

considerable burden. It demands both time and energy. If there appears to be little at stake (low perceived consequences), why bother? With a better appreciation of the relationship between illness representations and self-management, it becomes easier to understand why so many people with diabetes have poor self-management and comprised glycaemic control as a result. Research evidence provides some support for the proposal that higher perceived consequences (Skinner et al., 2002), and a stronger belief in the seriousness of diabetes (Hampson et al., 1990), are associated with more active diabetes self-management. However, Griva et al. (2000) report a significant association between *lower* diabetes identity (linked to symptom appraisal), and more active dietary self-management. Additional research is required to disentangle the complex relationships between illness identity, consequences, seriousness, and diabetes self-care behaviour.

Emotional representations

Studies have shown illness-related distress, and elevated frustration with the prescribed self-management routine, are common experiences among people with diabetes as discussed previously in chapter 1. Furthermore the CSM suggests self-regulation is comprised of two parallel pathways, one of which is labelled 'emotional'. Previous diabetes research using the CSM has highlighted the importance of examining emotional responses to illness (Hampson et al., 1990; Lawson et al., 2004). It is therefore surprising to find there is a dearth of empirical studies using the CSM to examine affective aspects of self-regulation among people with diabetes (Wearden et al., 2005). Diabetes mellitus is positioned as a 'physical' illness in biomedical and clinical literature. However, it is important to recognise that "psychological factors contribute significantly to the pathogenesis of medical illnesses, affect their course and may be a target for effective intervention" (Schattner, 2003, p. 617).

In the context of a discussion focusing on the role of emotion in diabetes, it may be important to emphasise the difference between clinical depression, and emotional representation of diabetes. There are likely relationships between the two, but also important conceptual distinctions. Although the foundation block for both is negative emotion, the latter is specifically referenced to views about diabetes while the former, clinical depression, is not. Hampson et al. (2000) compared depression and personal models as predictors of multiple outcomes among people with diabetes across a 3-

month period. Depression was measured using a 20-item instrument developed by the centre for Epidemiological Studies in the USA (CES-D). In this study, depression failed to account for differences in dietary or physiological outcomes, and depression scores showed minimal predictive utility in relation to quality of life outcomes. The authors of this study conclude “the failure of depression to predict . . . outcomes in this study suggests that interventions to improve diabetes outcomes may have overemphasized depression at the expense of other, more predictive personal model variables” (Hampson et al., 2000, p. 38). The failure of (general) depression scores to account for variance in diabetes health outcomes should not imply that *diabetes specific* negative emotional representations are unimportant in self-regulative processes. Further research is needed to examine in detail the relationships between emotional representation of diabetes (for example, using the IPQ-R or PMDI), behavioural coping, and physical and psychological health outcomes. This can be identified as a pertinent area for future study. Emerging research has demonstrated that diabetes related worry is linked to both self-care, and utilization of diabetes health services.

For example, Barnes (2000) reports a significant bivariate relationship between emotional representation of diabetes, and dietary patterns ($r = -.25, p < .05$) among people with type 2 diabetes. The direction of this association implies that greater emotional representation is linked to poor dietary self-management. Greater emotional representation has also shown a negative relationship with health-related behaviour among other chronic illness groups; for example, emotional representation was a significant predictor of (lower) exercise in Byrne et al.'s (2005) study of coronary heart disease patients. Along with self-management, access to professional health services can play an important part in helping people with diabetes achieve good glycaemic control. Thus two forms of health-related behaviour can be identified as important in diabetes: active engagement in self-care, and regular contact with health care representatives.

A study by Lawson et al. (2004) examined two emotional cognitions in research predicting regular diabetes care seeking among people with type 1 diabetes, which were labelled diabetes ‘fear’ and ‘worries’. They relate to fear of long-term complications, and worries about day-to-day management (e.g., hypoglycaemia), respectively. Short-term worries were found to predict regular diabetes care seeking behaviour in a multivariate analysis using logistic regression. Fear of complications

was not a significant predictor of diabetes health service use. The authors of this study conclude that “a certain amount of worry is necessary to motivate care-seeking behaviour” (Lawson et al., 2004, p. 250). They observe that people who do not regularly attend diabetes health care services worry less about the short-term consequences of diabetes, and suggest this type of avoidance behaviour may serve as a protective shield to promote mental wellbeing, even though this is likely to have costs to their long-term physical health.

Collectively, these embryonic findings suggest that the impact of emotional representation of diabetes on health-related action might vary across behavioural domains. Specifically, negative emotional representation of diabetes may have a negative impact on dietary self-care behaviour as shown by Barnes (2000), but, conversely, could help promote regular contact with diabetes health care professionals, as demonstrated by Lawson et al. (2004). The exploratory nature of this research precludes firm conclusions – further empirical investigation in this area is warranted.

The Association between Cognitive and Emotional Representations in Diabetes

The relationship between cognitive and emotional representations is another important area for future study. New Zealand research has shown some evidence of connections between emotional and cognitive dimensions within illness schema. Barnes (2000) reports significant correlations that suggest greater emotional representation of diabetes is associated with stronger diabetes identity, lower perceived personal control over one's diabetes, and a belief that symptoms come and go in cycles. Those with high emotional representation of diabetes are also likely to have trouble ‘making sense’ of their illness, and believe diabetes has serious consequences. Of the seven illness representation variables reported by Barnes, only two (timeline chronic and treatment control) failed to show any association with emotional representation of diabetes.

In research focusing on young adults with type 1 diabetes, Skinner et al. (2002) propose a relationship between low emotional stability (presented as a dimension of personality) and increased diabetes related worries, which is in turn linked to avoidance-based coping. The authors of this study hypothesised that emotional stability would influence health behaviour indirectly, through its impact on illness representations. Results indicated that the effect of emotional stability on diabetes self-

care is mediated by perceived consequences of diabetes. In this study two subscales (perceived impact and perceived threat) were used to assess consequences of diabetes. Structural equation modelling revealed that perceived threat acted as a mediator, but perceived impact did not. Together with associations explicated in the New Zealand study outlined above, this provides some detail about possible relationships between emotional factors and cognitive representations. In particular, these studies fuel speculation of a close link between consequences and emotional representation of diabetes; this has been suggested previously by other researchers (Hampson, 1997). This proposition is consistent with demonstration of a strong, positive association ($r = .50$, $p < .001$) between emotional representation and consequences among people with coronary heart disease (Byrne et al., 2005). Intuitively, if one wished to generate emotional representation of diabetes, a simple and efficient method for achieving this would be to spend 5 minutes contemplating the possible consequences of having diabetes. Most people with diabetes are very aware of the negative impact diabetes has on health and longevity. It would be difficult to escape awareness of this. Health promotion campaigns targeting people with diabetes often provide graphic illustration of why good self-care is essential. Health literature, both lay and academic, presents frequent reminders that we are in the midst of diabetes 'epidemic' (Vinicor, 2005).

While self-regulatory literature would argue emotional representations and consequences are conceptually distinct, there appears to be some overlap between the operational definitions of these two constructs in research practice. For example, both Skinner et al. (2002) and Lawson et al. (2004) present two variables designed to measure diabetes consequences, labelled 'impact' and 'threat'. The first relates to the impact of diabetes on everyday life; the second is described as "views about the severity of diabetes and perceived vulnerability to future diabetes complications" (Lawson et al., 2004, p. 244). Lawson et al. also explicate two variables that appear to be positioned as emotional representations in their research. The first, labelled 'fear', is "related predominately to fear of future complications and the long-term outlook" (pp. 244-5). This seems to share some commonality with the description 'threat', seen above. Operational definitions of 'threat' and 'fear', positioned as diabetes consequences and emotional representations respectively, thus appear reasonably analogous. A second emotional representation variable, labelled 'worries', was also included in the study by Lawson et al. This referred to short-term concerns about day-

to-day management of diabetes, for example, concerns about hypoglycaemia. These three variables share a conceptual basis, that is, grounding in negative affect. Although the variable labelled 'threat' was presented as a component of perceived diabetes consequences, both the question content and label have pervasive emotional connotations.

The term 'threat' is not emotionally neutral – it has negative connotations of impending compromise to one's safety or wellbeing. Further, individual items that comprise this subscale represent diabetes in negative emotional terms; questions include "my diabetes is a serious threat to my future health" and "I worry about getting the complications of diabetes" (Skinner et al., 2002, p. 65). In most self-regulatory literature, illness consequences are positioned as a cognitive variable. However, critical reflection suggests variables positioned within the CSM's 'cognitive' pathway may have a substantial emotive content, as described above. This proposition agrees with Hampson et al.'s (1997; 1990) suggestion that emotional responses to diabetes may contribute to the variable labelled 'seriousness' (closely related to the IPQ variable consequences).

Although conceptual and operational commonalities can be observed, it is imperative that future research seeks to understand the nuances that may distinguish between various forms of emotional representation of diabetes. Empirical evidence provides support for this assertion. The three variables discussed above (fear, threat, and worries) did not show parallel relationships with health-related behaviour in the study by Lawson et al. (2004). Greater perceived threat was associated with less regular participation in diabetes health care; fear showed no relationship with health service attendance. Greater worries did show a relationship with health service use but in the opposite direction from that observed between perceived threat and health care use; more worries about diabetes appeared to encourage regular care seeking behaviour. In addition, Barnes (2000) reports that greater emotional representation shows a negative correlation with some diabetes self-management behaviours (diet), but no significant association with other aspects of self-care (exercise, glucose testing, or medication adherence). These findings are intriguing, though somewhat difficult to explain. They hint at the complex associations between illness representations and health-related behaviour.

Together, the results of self-regulatory research to date, as described above, suggest the relationships between emotions, cognitions, and self-care behaviour are complex, and may involve both direct and indirect associations. On reflection, these findings serve to illustrate the need for: greater clarification of research constructs in the CSM; evidence of convergent and divergent validity among cognitive and emotional illness representation variables; better understandings of the impact emotional representations may have on different types of health-related behaviour; and comprehensive assessment of emotional representations. At present, it is premature to make any firm conclusions about the role of negative emotion in diabetes self-regulation. Additional research is needed to explore the emotional pathway presented in the CSM. As a starting point, future research may consider it useful to include assessment of emotional representation of diabetes, and emotional representation of diabetes *treatments*, as discussed in the following section.

Treatment representations

Diabetes research has shown treatment representations are also connected to differences in self-management behaviour. For example, bivariate relationships have been observed between the BMQ subscale 'concern', and reported medication adherence ($r = -.35$ $p < .01$) (Barnes, 2000). This suggests that greater concern about the harmful effects of using diabetes medications is associated with lower adherence to the prescribed pharmaceutical treatment regime. This is consistent with self-regulatory research focused on coronary heart disease (Byrne et al., 2005). There is also a large volume of literature assessing the role of treatment effectiveness in diabetes self-regulation, an overview of which can be found in the present chapter, under the heading 'control'. This is because previous studies have positioned treatment effectiveness as a form of perceived control (Lange & Piette, 2006). However, it is worth noting that questions in this subscale are specifically referenced to treatments (medication and behavioural) recommended for people with diabetes (Skinner et al., 2002). It therefore seems reasonable that treatment effectiveness could be considered as a type of treatment representation, specifically, a cognition that relates to treatment control. The IPQ-R variable treatment control also fits this dual categorisation. In summary, perusal of relevant literature reveals three forms of treatment representations that may play a pertinent role in self-regulation of diabetes: beliefs

about the *need* for medication; *concern* about using medication; and a perception that prescribed treatments are effective in *controlling* diabetes.

Greater exploration of views about treatment has been recommended in recent diabetes literature (Lawson et al., 2004; Skinner et al., 2002). Further research is essential if research is to build an accurate understanding of non-compliance with prescribed treatments. A comprehensive review of adherence to medical advice among people with diabetes has identified representation of medication as one of four elements responsible for differences in adherence (Gentili et al., 2001). This may be particularly salient for people using insulin, or those who are fearful of moving from oral medication to insulin. There is some evidence that people with diabetes may believe prescribed treatments are more necessary than do people with other chronic illnesses such as asthma or heart disease (Horne et al., 1999). Horne (2003) makes a cogent argument for extending the CSM to include treatment perceptions, alongside illness representations. There is some merit in his proposition that this will encourage greater explanatory power. This may be particularly relevant for research that aims to provide an account of variation in adherence to glucose testing, oral medication, or insulin use. It is likely that treatment representations will make a smaller contribution to explanation of dietary or exercise patterns, as these are less medically orientated dimensions of the diabetes treatment regimen. Future research should consider assessing multiple forms of treatment representations, for example, the need for treatment, perceptions that treatment offers control over diabetes, and emotional representation in the form of worries about diabetes medications.

Causes

In addition to illness/treatment representations, there is empirical evidence connecting views about the cause of diabetes to differential patterns of self-care. Findings suggest attribution of diabetes to an external source is associated with suboptimal diet, glucose testing, and medication adherence (Barnes, 2000). Interestingly, a prospective study by Hampson et al. (1995) showed that while attributions of personal responsibility for diabetes were not predictive of self-management behaviour (diet, exercise, or glucose testing), causal beliefs did predict differences in HbA_{1c}. Greater belief in personal responsibility for diabetes was associated with better glycaemic control, and there was also evidence of an interaction between cause and gender such that women showed a

stronger relationship between belief in personal responsibility for 'causing' diabetes, and HbA_{1c} than men. Research among African-Americans with type 2 diabetes suggests a strong belief in chance as the cause of diabetes is associated with higher HbA_{1c} (worse metabolic control), and reduced efficacy of medical attempts to change HbA_{1c} (Hayes et al., 2000).

To summarise, previous diabetes research has demonstrated a number of relationships between illness representation variables and measures of diabetes self-care behaviour. Some, such as perceived control and consequences, have received considerable empirical attention; others, for example coherence, have yet to be examined in detail. The importance of specific illness representations to self-care may be dependent on the behavioural domain (Griva et al., 2000). For example, research by Barnes (2000) showed significant bivariate relationships between diet and coherence, timeline cyclical, and emotional representation. However, glucose testing showed no significant associations with any of these three illness representation variables. Instead significant bivariate correlations were found between glucose testing and three different representation variables – timeline chronic, consequences, and personal control. Conversely, dietary adherence showed no significant relationship with any of these latter three variables. Also noteworthy is the absence of any significant bivariate relationships between self-reported medication adherence and nine out of ten illness/treatment representation variables in this study. Whether this represents a spurious result, or a genuine absence of connection between illness/treatment representations and medication adherence is an important question for future research.

Multivariate Relationships between Representations and Self-Management Behaviour

Multivariate analyses have been used to determine whether illness/treatment variables can account for variance in self-management over and above the contribution made by demographic and clinical factors. Hampson et al. (1995) found personal model variables predicted dietary habits in a prospective study using a sample of older adults with type 2 diabetes. Multivariate analyses identified treatment effectiveness as the most important determinant of dietary patterns at 4-month follow up. Findings reported by Glasgow et al. (1997) agree, suggesting also that treatment effectiveness plays a

key role in diabetes self-management. In this study, hierarchical regression analyses were used to determine whether illness representations could provide explanatory power in regard to dietary patterns, physical activity, and glucose testing. Demographic and medical covariates were entered as controls at step one; three illness representation variables entered the model at step 2. In each of the three multivariate analyses a significant increase in explained variance was observed on entry of illness representation variables (treatment effectiveness, perceived barriers, and seriousness) at step 2 ($p < .001$). This suggests illness representations are able to account for a significant portion of variance in three aspects of diabetes self-management (diet, physical activity, and glucose testing), even when controlling for demographic and medical characteristics. The increase in explained variance at step 2 of each analysis can be estimated by calculating the change in R^2 from step 1 to step 2. Results show that, after controlling for relevant medical and demographic characteristics, illness representations accounted for 20% of the variance in dietary patterns, 19% of differences in exercise frequency, and 18% of variation in blood glucose testing (Glasgow et al., 1997).

In a study of young adults with insulin-dependent diabetes Griva et al. (2000) used hierarchical forward multiple regression to identify the psychological variables that best accounted for overall adherence to diabetes self-management activities, while controlling for age and diabetes duration. Results showed the IPQ variable 'control' accounted for 39% of differences in total adherence (Griva et al., 2000). Other studies have sought to separate aspects of the self-care regimen, and consider the predictors of each adherence dimension in discrete analyses. Barnes (2000) used two-step hierarchical regressions with control variables (for example, education, feet condition, HbA_{1c}, length of diagnosis, and ethnicity) entered at step 1; illness/treatment representation variables were subsequently entered at step 2. Results showed that, after controlling for variables entered in the first step, illness/treatment representations explained 25% of differences in dietary habits, and 23% of variation in self-reported glucose testing. Illness and treatment representations were found to explain 15% of differences in medication use, and 9% of variation in exercise. In these multivariate analyses few individual representation variables showed significant *Betas*, though results suggest medication necessity and medication concern may play an important role in determining adherence to prescribed treatments, both pharmacological and lifestyle.

Further research is needed to examine these associations in detail, and to replicate results that may be somewhat counterintuitive. For example, at the multivariate level medication necessity was a significant predictor of dietary adherence ($Beta = .42, p < .01$), and exercise ($Beta = .27, p < .05$), but not of glucose testing or medication adherence (Barnes, 2000). The absence of a significant association between views about the need for diabetes medication and self-reported use of medication seems puzzling. It is important to acknowledge that some studies have failed to show evidence of a connection between illness representations and self-care behaviour. For example, research among adolescents with diabetes reported that "illness beliefs did not significantly affect diabetes self-management" (Law, Kelly, Huey, & Summerbell, 2002, p. 384). Key representation variables have also shown inconsistent relationships with different aspects of diabetes self-care. For example, findings reported by Skinner and Hampson (2001) suggest that treatment effectiveness plays an important role in dietary self-care, with changes in perceived treatment effectiveness explaining 17% of the variance in dietary patterns across a 12-month period. However, treatment effectiveness did not show any association with other aspects of behavioural self-management assessed in this study (exercise, insulin administration, or blood glucose testing). Further research in this area is warranted.

Good diabetes management is prefaced on good self-care, *and* access to high-quality health care. As emphasised in the first chapter, almost all people with diabetes seek the advice and opinions of 'experts' in health and illness (doctors and nurses); interaction with health care services is a necessary component of successful diabetes management. In the present study, contact with health professionals is viewed as an important element of diabetes-related health behaviour, because, alongside self-care, care-seeking behaviour plays a crucial role in the achievement of good glycaemic control. There is some evidence that illness representations can account for variation in diabetes-related health care behaviour.

Lawson et al. (2004) used a combination of variables from the IPQ and PMDI to assess both cognitive and emotional responses to type 1 diabetes. Logistic regression analyses were used to determine whether illness representations could predict care-seeking behaviour. Results indicated that treatment effectiveness ($p < .001$), and perceived control ($p < .05$) were related to hospital clinic attendance. A second logistic regression was undertaken using a broader outcome variable; regular diabetes care

(hospital or general practice). Again, treatment effectiveness showed a significant relationship ($p < .01$); threat ($p < .05$) and short-term worries about diabetes ($p < .05$) were also associated with differences in care attendance. Results from these multivariate analyses imply perceptions of control, consequences and emotional representation of diabetes may all contribute to the explanation of care seeking behaviour among people with type 1 diabetes. The precise nature of these associations highlights the need for better understandings of the complex role emotion may play in diabetes-related behaviours, as discussed earlier in this chapter. Due to the cross-sectional and exploratory nature of this study, cautious interpretation of findings is warranted. Further examination of the relationship between illness/treatment representations and care-seeking behaviour should be encouraged.

Overall, diabetes research using self-regulatory theory has shown illness/treatment perceptions do contribute explanatory power in models that aim to account for differences in diabetes self-management behaviour. This is more successful for certain behavioural domains. As a general rule, illness/treatment variables appear to be better at predicting differences in diet than, for example, medication adherence or exercise (e.g., Barnes, 2000; Hampson, 1997; Hampson et al., 1995; Hampson et al., 1990; Skinner & Hampson, 1998; Watkins et al., 2000). Previous self-regulatory research has identified two variables that appear to show the most consistent relationships with self-care: seriousness (consequences) and treatment effectiveness (perceived control) (Clark & Asimakopoulou, 2005; Hampson, 1997; Hampson et al., 2000; Lange & Piette, 2006). This may, in part, be because they have been more frequently included in studies of diabetes self-regulation than other illness representation constructs (e.g. Hampson et al., 1995; Skinner et al., 2002). It is recommended that future research seek to provide a comprehensive assessment of illness and treatment representations related to diabetes, incorporating both cognitive and emotional variables. The use of multivariate analyses is encouraged as it enables identification of those illness/treatment variables that are most important in explaining variation in self-care while controlling for associations among predictor variables. Analyses that allow for statistical control of medical and demographic characteristics (e.g., hierarchical multiple regression) are also recommended.

Illness/Treatment Representations and Emotional Wellbeing

Self-regulatory research has demonstrated evidence of a connection between illness representations and diabetes health outcomes. Researchers using the personal models (PM) approach have stated the PM variable labelled 'seriousness' is comparable to the 'consequences' dimension in the common sense model of illness self-regulation (Hampson et al., 2000). A prospective study has shown significant bivariate associations between self-reported mental wellbeing (measured using the Medical Outcomes Study (MOS) Short-Form 20) and perceived seriousness ($r = -.40, p < .05$), and treatment effectiveness ($r = .28, p < .05$) (Hampson et al., 1995). The direction of these relationships suggests expectations that diabetes will have few serious consequences, and higher perceptions of control over diabetes, are both related to better mental health. Multivariate analyses have shown that perceived seriousness is significant predictor of self-reported physical functioning and mental health among a sample of middle-older aged people with diabetes (Hampson et al., 2000).

Bivariate correlations have demonstrated an association between perceived consequences of diabetes and depression scores on the Well-being Questionnaire in two recent studies ($r = .51, p < .001$) (Eiser et al., 2001), ($r = .41, p < .01$) (Paschalides et al., 2004). A positive relationship between consequences and anxiety ($r = .45, p < .001$), and a negative correlation between consequences and positive wellbeing ($r = -.55, p < .001$) were also reported by Eiser et al. (2001). Expected outcomes, specifically regarding one's ability to prevent future complications, were assessed in this study. These were labelled 'representations of control' by authors of the study. Pessimistic views about future complications (representing lower perceived control) showed a moderate positive association with depression and anxiety scores. At the multivariate level, a pessimistic view of diabetes complications was associated with low general wellbeing ($Beta = -.17, p < .05$); an expectation that diabetes will interfere with your life was also related to poor wellbeing ($Beta = -.48, p < .001$). These results suggest low perceived control over future complications, and high expectations of negative consequences, are both related to compromise in psychological wellbeing among people with type 2 diabetes. Paschalides et al. (2004) also report significant associations between greater number of diabetes symptoms and depression ($r = .48, p < .01$), and low perceived control and depression ($r = .28, p < .01$).

Wearden et al. (2005) used the IPQ and Well-being Questionnaire to evaluate the relationship between illness representations and psychological outcomes among people with type 2 diabetes. In combined analyses using the total research sample (those recently diagnosed and those with long-standing diabetes) control and identity variables showed a positive relationship with both depression and anxiety, and negative associations with psychological wellbeing. Greater perceived consequences was associated with higher anxiety and depression; thus providing support for the findings of Eiser et al. (2001) reported previously. Perceived impact and identity were also correlated with depression, and anxiety, in research conducted by Edgar and Skinner (2003). There is some evidence that length of diagnosis may function to moderate the relationship between control and depression; specifically, it is proposed that this association is stronger for those with long-standing diabetes (Wearden et al., 2005).

Skinner and Hampson (1998) report evidence that illness representations account for variance in psychological outcomes among adolescents with type 1 diabetes. Using multiple regression analyses, the perceived impact of diabetes (a form of consequences) was found to explain differences in depression ($Beta = .37, p < .001$), and anxiety ($Beta = .48, p < .001$), highlighting the importance of investigating illness representations in detail. Research suggests it is helpful to separate the perceived consequences of diabetes into two dimensions. As discussed earlier in this chapter, 'impact' appears to predict psychological outcomes, but it does not appear to show reliable relationships with diabetes self-care (Skinner & Hampson, 1998; Skinner et al., 2002). Conversely, 'threat' does show relationships with self-care variables including dietary habits, exercise and glucose testing (Skinner et al., 2002). Emerging research suggests diabetes coherence may be associated with differences in quality of life variables. A study by Watkins et al. (2000) used structural equation modelling to investigate the relationships between illness representations (control, cause, consequences, and understanding), self-care behaviour, and quality of life. Results showed that lower understanding of diabetes, a sense that one had little control over diabetes, and belief that personal behaviour was causing poor diabetes control, were each associated with a belief that diabetes was burdensome (presented as a measure of quality of life in this study).

Illness/Treatment Representations and Physical Wellbeing

Hampson, Glasgow, and Foster (1995) used the Personal Models of Diabetes Interview (PMDI) to examine the relationship between perceptions of diabetes (treatment efficacy, seriousness, and causes) and glycosylated haemoglobin A_{1c} among older adults with diabetes. Hierarchical multiple regressions were employed to control for demographic and medical variables. Results showed a belief in personal responsibility as the cause of diabetes, and perception that prescribed treatments are effective, were both significantly related to HbA_{1c} in this study. On the basis of reported results, it was concluded that personal model constructs (illness/treatment representations) are able to predict differences in HbA_{1c} using prospective analyses based on a 4-month timeframe. This early study provides encouraging evidence that illness/treatment representations are related to clinical indicators such as glycosylated haemoglobin among people with diabetes. The prospective design is a particular strength, although it should also be noted that there are questions regarding generalisability to the diabetes population; the study had a small sample size ($N = 78$), and was limited to older adults (mean age = 70) with a high level of comorbid health problems.

Personal control over diabetes is conceptually similar to diabetes self-efficacy – both are founded on confidence that personal action is effective in managing diabetes. A recent prospective study among Japanese with type 2 diabetes suggests self-efficacy is an important prospective predictor of exercise and dietary self-care behaviour, and HbA_{1c} (Nakahara et al., 2006). Research by Griva et al. (2000) aimed to investigate relationships between illness perceptions and self-efficacy expectations; and to consider the role of these variables in explaining variation in treatment adherence and metabolic control among young adults with insulin-dependent diabetes mellitus. Bivariate correlations showed significant positive associations between blood glucose control and identity, consequences, and diabetes specific self-efficacy ($r = .23$ to $.51$). Results also demonstrated a negative relation between HbA_{1c} and both control ($r = -.35$, $p < .01$) and generalised self-efficacy ($r = -.37$, $p < .01$). These findings suggest that higher perceived control over diabetes is linked to lower HbA_{1c} (better glycaemic control). Conversely, greater identification with diabetes, expectations of serious consequences as a result of diabetes, and lower diabetes self-efficacy, are all related to poor metabolic outcomes.

A three-step multiple regression was used to test for relationships present at a multivariate level. Age and diabetes duration were entered at step 1, total adherence at step 2, and five psychological variables at step 3. Steps 2 and 3 both resulted in a significant increase in R^2 . Self-reported adherence was found to explain 15% ($p < .01$) of variation in HbA_{1c} in this study; illness representation and self-efficacy variables were shown to account for an additional 30.8% ($p < .001$) of differences in HbA_{1c} . Significant *Betas* were diabetes-specific self-efficacy, consequences, and identity ($p < .01$). It is interesting to compare these results with the regression analyses for adherence also reported in this study. While perceived control was a strong predictor of total adherence, it showed no significant relationship with HbA_{1c} at the multivariate level. Also, although consequences showed no relationship with adherence at the bivariate or multivariate level, consequences made a significant contribution to explaining variance in HbA_{1c} . Together, these results imply the variables that best account for differences in self-reported adherence may be different from those that explain variation in HbA_{1c} . Preliminary research findings from the Diabetes Education and Self-Management for Ongoing and Newly Diagnosed (DESMOND) pilot study suggest that illness representations may also be related to changes in metabolic control across time (Skinner et al., in press). In this study, personal control, perceived impact, and perceived seriousness, were each correlated with changes in HbA_{1c} across a 3-month period from baseline to intervention follow-up.

Results from some studies suggest the relationship between illness/treatment representations and HbA_{1c} is less solid. A British study assessed illness representations (control and consequences) and HbA_{1c} among 139 persons with type 2 diabetes (Eiser et al., 2001). Results showed no evidence of significant relationships between illness representations and HbA_{1c} . However, a number of associations between illness representations and psychological outcomes (depression, anxiety, and positive wellbeing) were present. Paschalides and colleagues (2004) used a stepwise regression procedure to examine whether illness representations and psychological wellbeing explained variance in HbA_{1c} . Demographic and medical descriptors were entered at step 1 of the regression. Illness representations (IPQ), anxiety, and depression (from the Well-Being Questionnaire) were entered at step 2 of the analysis. Variables entered at step 2 did not make a significant contribution to explained variation in metabolic control. The authors of this study concluded that "neither IPQ nor WBQ scales were associated with HbA_{1c} after controlling for demographic and medical

illness details" (Paschalides et al., 2004, p. 557). In a recent study, Lange and Piette (2006) utilised a 3-step hierarchical regression to examine variables that accounted for variation in HbA_{1c}. Findings showed that, when controlling for sociocultural variables (entered at step 1) and diabetes severity (entered at step 2), personal model variables explained a very small proportion of the variation in metabolic control at follow-up (R^2 change at step 3 = .02).

There is also some inconsistency regarding the illness/treatment representations that are most important in predicting variation in HbA_{1c}. For example, Hampson et al. (2000) report control was the only illness representation variable to show a significant relationship with HbA_{1c} at multivariate level. Recent research by Wearden et al. (2005) has identified control as an important bivariate associate of HbA_{1c} among people with type 2 diabetes, suggesting that illness duration may moderate the relationship between control and metabolic control. In contrast, Griva et al. (2000) found control did not show a significant association HbA_{1c} in multivariate analysis, instead consequences and identity were identified as the representation variables linked to HbA_{1c}. Research by Lange and Piette (2006) has highlighted a relationship between perceived seriousness and HbA_{1c} ($Beta = .66, p < .05$). Eiser et al. (2001) assessed representations of perceived control, self-efficacy, and consequences in a mixed sample including both type 1 and type 2 diabetes, reporting no evidence of reliable associations between these variables and metabolic control. In contrast, Nakahara and colleagues used structural equation modelling to predict HbA_{1c} at 12-month follow up; in the ensuing causal model "self-efficacy had a consistent relationship with glycemic control and was one of the most important prospective factors in diabetes-treatment research" (Nakahara et al., 2006, p. 244). Four illness representation variables – identity, timeline, consequences and control – were assessed by Wearden et al. (2005). Bivariate correlations revealed only perceived control showed a significant relationship with HbA_{1c}. Recent research using the Brief IPQ has suggested that perceived personal control is *negatively* related to HbA_{1c}, while perceived treatment control has a *positive* association with HbA_{1c} (Broadbent et al., 2006).

It is clear that further research in this area is warranted. In this context, it is useful to note preliminary results from the DESMOND trial, which suggest interventions showing improvement in metabolic control may work *through* modification of illness representations. Skinner and colleagues (in press) present data from the pilot study

showing that participation in the DESMOND programme changes illness representations; furthermore, they demonstrate that “these changes predict quality of life and metabolic control at 3-month follow-up”. Such findings underscore the need for a clear understanding of the relationships between illness representations and illness outcomes among people with diabetes.

Association between Emotional and Physical Wellbeing in Diabetes

Also of interest to self-regulatory researchers has been the relationship between anxiety and depression, and biomedical markers of diabetes control. Prospective research by Hampson et al. (2000) showed that depression (assessed using the CES-D) was not a significant predictor of glycosylated haemoglobin at across a 3-month period. Eiser et al. (2001) also report no significant relationships between general psychological wellbeing (measured using the Well-being Questionnaire) and clinical outcomes including duration of diabetes and HbA_{1c}. This finding was consistent across people with both type 1 and type 2 diabetes. They describe the absence of a relationship between HbA_{1c} and psychological variables as “noteworthy” (Eiser et al., 2001, p. 108). This can certainly be identified as a pertinent area for future research. It is important to appreciate that clinical depression and anxiety are qualitatively distinct from the construct of diabetes-specific emotional distress, as emphasised previously.

While there has been limited empirical investigation of the relationship between metabolic outcomes and diabetes-related distress to date, researchers have proposed such an association is likely. Emotional distress may have a direct physiological influence on the regulation of blood glucose (Griva et al., 2000); alternatively, indications of poor metabolic control (e.g., results of HbA_{1c} feedback at clinical visits) may increase worry about future complications and as a result, elevate diabetes-related psychological distress. Further research will be required to establish the primary direction of causality. Empirical enquiry has demonstrated a connection between distress about diabetes, and metabolic control. A recent study by Keers et al. (2006) reported a weak positive association between HbA_{1c} and scores on the Problem Areas in Diabetes Scale ($Beta = .09, p < .05$). Similar results have been obtained in Japanese research focusing on people with type 2 diabetes. Nakahara and colleagues used structural equation modelling to identify variables that influenced metabolic control across a 12-month period. At baseline, a positive correlation was observed

between HbA_{1c} and diabetes-related distress ($r = .21, p < .05$). In the prospective component of this study, diabetes-related distress (measured using the PAID) was found to have an indirect impact on self-care and metabolic control through self-efficacy (Nakahara et al., 2006). Greater distress about diabetes was associated with lower self-efficacy, and in turn reduced self-efficacy predicted poor self-care and lower metabolic control.

In a study of psychosocial correlates of glycaemic control among people with type 1 diabetes, Weinger and Jacobson (2001) also report a significant relationship between diabetes related emotional distress and HbA_{1c}. Participants in this research took part in an intensive diabetes educational intervention. Results showed that greater emotional distress about diabetes (measured using the PAID) was associated with worse metabolic control both at baseline, and post-intervention assessments. One of the most important findings from this study is that *change* in metabolic control was also associated with change in scores on the PAID ($r = 0.38, p < .02$). The direction of this association implies people who showed an improvement in metabolic control, also showed a reduction in diabetes-related distress.

Weinger and Jacobson (2001) suggest the relationship between diabetes-related distress and glycaemic control might be complex. They postulate that, initially, high emotional distress about diabetes acts to motivate self-management behaviour in an effort to achieve good metabolic control. However, if these efforts are unsuccessful (good metabolic control is not achieved) and emotional distress about diabetes remains high, ongoing diabetes-related distress may act as a barrier to self-care behaviour, and therefore reduce the likelihood of good glycaemic control. To surmise, in the short-term, diabetes-related emotional distress may be beneficial (because it motivates self-care behaviour, and thus encourages good metabolic control); however, chronically elevated distress about diabetes may have a negative impact on self-care behaviour and HbA_{1c}. Bi-directional relationships are likely to be present. It is predicted that difficulty obtaining good metabolic control (especially after active, effortful, investment in self-care) leads to frustration and, possibly, disengagement from behavioural management of diabetes.

Relationships between Reported Self-Care Behaviour and HbA_{1c}

Diabetes literature has also sought to examine connections between self-care behaviour and clinical parameters such as HbA_{1c}. Previous New Zealand research among adults with type 2 diabetes examined the relationships between HbA_{1c} and four dimensions of diabetes self-care. Results revealed no statistically significant associations between HbA_{1c} and self-reported diet, exercise, glucose testing, or medication adherence (Barnes, 2000). Hampson, Glasgow and Toobert (1990) used a two-step hierarchical regression analysis whereby age and insulin status were entered at step 1; diet, exercise, and glucose testing were then entered at step 2. At both step 1 and step 2, variables entered in the regression equation were unable to account for a significant portion of variance in HbA_{1c} in this study. However, the sample was small ($N = 46$) and restricted to women between the ages of 46 and 79. Thus questions of statistical power, and generalisability of results, may arise.

Other research by Griva et al. (2000) has been successful in demonstrating a significant relationship between adherence to self-care regimen, and HbA_{1c}. Results showed that self-reported adherence was able to account for 15% ($p < .01$) of variation in HbA_{1c}. Active behavioural coping was also found to be associated with better metabolic control in a study by Rose et al. (2002). Research among adolescents with diabetes has reported significant bivariate associations between HbA_{1c} and both dietary self-management and insulin administration (Law et al., 2002). Results from this study revealed that self-management behaviours explained 29% of the variation in metabolic control (adjusted $R^2 = .29$, $p < .01$). Longitudinal research among children with type 1 diabetes has suggested the relationship between metabolic control and self-care behaviour may be bi-directional; results demonstrated "an initial worsening of glycaemic control as a result of puberty preceded worsening of adherence behaviours" (Du Pasquier-Fediaevsky, Chwalow, & Tubiana-Rufi, 2005, p. 427).

Directions for Future Research

Further empirical investigation is needed to clarify the exact nature of relationships between illness representations, self-care behaviour, and HbA_{1c}. Research by Griva et al. (2000) tested for mediating and moderating relationships, suggesting that psychological variables may impact on the relationship between adherence and

glycaemic control. Results largely failed to show evidence of interactive relationships. The exception was the demonstration that self-efficacy acts as a mediator of the relationship between adherence and HbA_{1c}. However, the direction of testing was conceptually dissimilar from the general direction of relationships presented in the CSM.

In the CSM, there is an element of forward flow that implies illness representations influence coping behaviour, and coping in turn influences illness outcomes. This conceptual presentation suggests behavioural adherence may act to mediate the relationship between illness representations and illness outcomes. This proposition is different from that tested by Griva et al., and is worthy of further investigation. The possibility of direct relationships between representations and outcomes should also be examined. There is some evidence that psychological variables (such as diabetes self-efficacy and perceived consequences) may have a direct impact on HbA_{1c}. This could occur through the direct impact of cognition on physiological processes, for example those that regulate stress, anxiety, and immune functioning (Griva et al., 2000). Previous research has predicted that coping will act to mediate the relationship between illness representations and emotional wellbeing; results failed to demonstrate support for this hypothesis (Edgar & Skinner, 2003). Further examination of potential mediating relationships between representations, coping, and illness outcomes is necessary.

It is important that future research includes a comprehensive range of self-care and wellbeing outcomes. There is evidence that the predictors of self-care behaviour are different from those variables that account for variation in illness outcomes (Griva et al., 2000). Further, the variables important to each type of outcome may be disparate. For example, in a study using multivariate analyses and longitudinal data collection Hampson et al. (2000) identified links between treatment effectiveness and dietary patterns, control and HbA_{1c}, and seriousness and quality of life. Thus individual illness/treatment representation variables may show a stronger relationship with a particular health outcome (e.g., physical wellbeing), and no association with another outcome (e.g., emotional wellbeing). Such nuances should not be glossed over; they constitute an important area worthy of further examination.

Hagger and Orbell's (2003) meta-analytic review demonstrated a positive relationship between cure/control and problem focused coping strategies; consequences, identity and timeline also showed a positive association with coping strategies based on expression of emotion, avoidance, or denial. While analyses collating information from a wide array of chronic conditions is helpful, it is important to acknowledge chronic illness can be experienced in many different ways, and the salient features of one condition (e.g., chronic fatigue syndrome), may be very different from a those associated with a second (e.g., diabetes). As such, there is merit in collating illness-specific information, and utilising this to create directional hypotheses that pertain to a specific illness, and outcome variable.

For the most part, published diabetes literature describes the relations between illness/treatment representations and behavioural/health outcomes in an ad hoc and incremental manner. For example, in a study of illness perceptions among adolescents, Griva et al. (2000) dichotomised adherence in to 'good adherers' (never or rarely deviated from prescribed treatment regimen) and 'intentional poor adherers' (modified treatment regimen sometimes, often or very often). Twenty-four t-tests were then conducted to determine whether illness representations were related to differences in adherence across four dimensions of diabetes self-care; diet, exercise, blood glucose monitoring, and insulin use. Alpha was set to .01 and, using this criterion, ten of the twenty-four t-tests showed a significant result. This was interpreted as evidence that illness perceptions differ between 'good' and 'poor' adherers. Employment of such analytic strategies is not recommended, as the use of multiple single tests inflates the likelihood of incorrectly rejecting the null hypothesis. Future research should pursue a more rigorous approach, to avoid increasing the odds of making a type 1 error. While bivariate correlations provide one test of predicted relationships, multivariate analyses using blocks of variables can offer advantages (e.g., multiple hierarchical regressions). First, these enable the impact of demographic and medical variables to be removed. Second, they provide control for relationships among predictor variables.

Although relationships between individual representations and individual outcomes have been noted in previous studies, attempts to pull this information together to present a meaningful 'overall picture' have been rare in diabetes literature to date. This makes it harder to identify psychosocial variables that show a consistent directional

relationship with self-management behaviour. In part, progress has been hindered by a lack of critical mass, that is, enough studies to provide a sense of the big picture (Lawson et al., 2004). There is a strong need for research that delineates specific hypotheses to test expected relationships between illness representations and behavioural/health outcomes. This constitutes an important challenge for future research. Previous diabetes research has not often utilised this approach and, to date, few studies in this area have stated directional hypotheses when outlining the research aims. The dearth of previous empirical findings means that it becomes difficult to formulate useful a priori hypotheses. However this does not preclude the use of directional predictions. These constitute robust research practice and, as such, should be encouraged.

As discussed earlier in this chapter, it is important that self-regulatory research incorporates specific directional hypotheses, as well as examining explanatory power. Employment of directional predictions may promote refinement of theory, and assist in producing parsimonious models. For example, specific directional hypotheses could help to identify those individual variables that show the *strongest positive* relationships with self-care behaviour, or metabolic control. In this way, testing of specific predictions may highlight (and assist in weeding out) variables that are not so important in diabetes self-regulatory processes. Over time, this may be useful to refine our understandings of diabetes self-management and encourage parsimonious research models. This is important, as self-regulatory theory could be criticised for a lack of parsimony, as discussed previously.

Previous literature has questioned whether HbA_{1c} is the “most appropriate outcome variable on which to focus in a study of psychological variables” (Hampson et al., 1990, p. 644). However, metabolic parameters such as HbA_{1c} are central determinants of the complications that so often accompany diabetes (for example retinopathy, nephropathy). Through this relationship with complications, poor glycaemic control can have a substantial impact on psychological outcomes such as quality of life. Inclusion of HbA_{1c} in psychological research is warranted, because it is a salient determinant of physical and psychological wellbeing among people with diabetes. At present our understanding of the relationship between psychological variables and HbA_{1c} is murky, which in part may reflect the complexity of connections between these psychological and clinical variables. The association between self-care and HbA_{1c}, for example, may

be moderated by other variables such as patient-provider relationship, or individual differences in physiology and metabolic processing (Hampson et al., 1990). In short, current literature fails to provide a sound understanding of the relationship between illness/treatment representations, self-care, and HbA_{1c}. While the lack of clarity in this area of research should be acknowledged, this does not constitute a valid justification for discounting HbA_{1c} as an important outcome variable in psychosocial diabetes research. In the same breath, clinically orientated diabetes research should not ignore psychosocial outcomes such as illness related adjustment and quality of life. Thus greater examination of the impact of diabetes on social functioning and mental wellbeing is recommended, alongside metabolic outcomes such as HbA_{1c}.

The empirical studies described in this chapter show the self-regulatory model can provide a useful framework for research examining diabetes self-management. However, some inconsistencies are evident in diabetes self-regulatory literature, for example, the relationship between reported self-care behaviour and HbA_{1c} remains contentious. Bivariate relationships reported by Barnes (2000) showed no significant associations between self-care and glycaemic control; multivariate results reported by Hampson et al. (1990) revealed self-care was unable to account for a significant proportion of variance in HbA_{1c}. However, other studies have shown self-reported adherence *does* explain variation in HbA_{1c} (Griva et al., 2000; Rose et al., 2002). The relationship between specific illness/treatment representations and self-care is also ambiguous. For example, Griva et al. (2000) report a negative association between illness identity and dietary self-management ($r = -.41$, $p < .001$), and positive relationships between control and four dimensions of self-care ($r = .30$ to $.69$). In contrast, New Zealand research has reported no significant associations between self-care behaviour (diet, exercise, glucose testing, medication use) and either identity, or treatment control (Barnes, 2000). Other studies report that treatment control shows a significant relationship with certain aspects of self-care, such as diet, but no relationship with other aspects of self-care behaviour (e.g., exercise or insulin administration) (Hampson et al., 1995; Skinner & Hampson, 1998). Further examination of observed inconsistencies is necessary, and empirical attention should also be directed towards areas that have been largely overlooked in diabetes self-regulatory literature to date. There is a dearth of studies examining the relationship between emotional representations and diabetes behaviour. As described previously in reference to self-regulatory literature as a whole, there is a need for greater attention

to the emotional aspects of illness self-regulation. This also constitutes a useful path for future research.

It is important to recognise there are notable differences between research samples, which may provide some explanation of inconsistencies between findings across published diabetes literature. For example, the study conducted by Griva et al. (2000) used data from 64 participants who were young (mean age = 20, range = 15–25), and insulin dependent (implying a diagnosis of type 1 diabetes). There was no ethnic diversity with the sample (100% Caucasian). In contrast, participants in the New Zealand study by Barnes (2000) were ethnically diverse (47% Tongan, 52% New Zealand European), older (mean age = 58), and most had type 2 diabetes. Both studies used relatively small samples (patient $N < 100$). Thus careful analysis of previous research reveals small samples with disparate demographic and medical characteristics, which is likely to account for some of the observed ambiguities in diabetes literature, as described in the preceding paragraph. Variation in the operational definition of key constructs may also have contributed to differences in reported findings. Many studies have used the Summary of Diabetes Self Care Activities scale (Toobert et al., 2000), but some notable exceptions are present (e.g., Griva et al., 2000). The use of larger research samples, with characteristics (e.g., ethnicity) that closely match the regional diabetes population, is strongly encouraged.

One final issue deserves discussion. As emphasised in chapters 1 and 2, comprehensive models are necessary if we are to generate a good understanding of the multiple factors determining diabetes self-management. Diabetes literature postulates that illness/treatment representations, also referred to as personal models of illness, are a proximal determinant of diabetes self-management (Skinner et al., 2002). Empirical literature presented in this chapter demonstrates the importance of such variables. However, as outlined in chapter 1, it is also pertinent to consider the influence of interpersonal interactions (e.g., with medical staff or family). Multiple, complex demands are a common feature of illness experience (Petrie et al., 2003). Successful management often entails interaction with health professionals and social support networks (Hampson et al., 1990). Early self-regulatory literature drew attention to the potential impact of social communication on illness cognitions (Leventhal et al., 1980; Leventhal et al., 1984). It was predicted that information from both familial and medical sources would contribute in important ways to the process of 'making sense' of

illness, but this has received limited attention to in research using the CSM to date. The influence of both individual and interpersonal factors on self-management was recently highlighted by the godfather of self-regulatory literature, who provided a timely reminder that “Information from practitioners, friends, family, and mass media feed into the interpretive processes that create the [illness] representations” (Leventhal, 2005, p. 4).

Future research may benefit from acknowledging the importance of intrapersonal *and* interpersonal factors in determining self-care behaviour, and integrating assessment of both within a coherent theoretical framework. The common sense model of illness self-regulation provides such a model. As shown in Figure 1, the self-regulatory framework explicates a number of upstream determinants of health behaviour. Some, for example anxiety, have received a reasonable amount of empirical attention; others, such as social communication, have been largely overlooked in diabetes self-regulatory literature to date. As discussed previously, this limitation is also more widely applicable to self-regulatory research. It is recommended that studies seek to examine the role of individual illness/treatment representations, and social communication, as potential determinants of diabetes self-management. This is identified as a fruitful direction for future research.

CHAPTER SUMMARY

Chapter 3 provided a detailed description of the CSM; this was accompanied by an overview of previous research employing the common sense model to examine self-regulation in chronic illness. It is suggested that illness/treatment representations and self-care are related to differential illness outcomes, but that there is limited information available to tell us exactly how. As noted by Hampson, Glasgow, and Strycker (2000, p. 38) “the complex reciprocal relations between cognitions and outcomes in the self-regulatory model of health behaviour have yet to be fully explored”. This is certainly evident within diabetes literature, where a number of inconsistencies are apparent.

Collectively, research literature presented in the preceding three chapters implies the determinants of diabetes self-regulation are multifarious. Chapter 1 emphasised the importance of social context, suggesting that interpersonal relationships can be a

salient part of successful diabetes management. In contrast, chapter 3 highlighted the contribution of individual illness/treatment representations in illness self-management. Chapter 2 reminded us that it is possible to look at the determinants of diabetes self-care from many angles, and stressed the need for empirical frameworks that integrate individual variables with sociocultural context, in order to generate a more comprehensive account of diabetes self-management.

It is clear the relationships between social communication, illness/treatment representations, self-management behaviour, and physical and psychological illness outcomes require further examination. There is a strong need to consider how these variables may connect in regard to *specific* illnesses, for example, type 2 diabetes. In conclusion, chapters 1, 2, and 3, provide the rationale for relationships of core interest in the present research. The purpose of chapter 4 is to delineate specific aims and hypotheses within the present research.

CHAPTER 4
RESEARCH OBJECTIVES

CHAPTER OVERVIEW

The purpose of this chapter is to delineate the aims and hypotheses of the present research. The first objective is to provide a descriptive account of observed relations; the parameters of this exploratory investigation are outlined in aims 1 and 2. The second objective is to test a priori hypotheses. Multivariate analyses will be employed for this purpose. Hypotheses 1, 2, and 3 examine variance in key illness outcomes for people with diabetes (metabolic control, diabetes-related psychological distress, and quality of life). Hypothesis 4 focuses on the relationship between support and conflict from family and medical sources, and affective representations of diabetes. Hypotheses 5 and 6 examine diabetes self-management behaviour in detail. These analyses focus on four dimensions of self-care: dietary patterns, exercise habits, blood glucose testing, and medication use. Hypothesis 7 will test a proposed mediating relationship between treatment representations, medication adherence, and HbA_{1c}. A summary of the core aims and hypotheses concludes chapter 4.

AIMS OF THE PRESENT STUDY

A number of relationships are specified in the common sense model, as seen in Figure 1; however, empirical attention has not been evenly distributed. Some aspects of the common sense model have received considerable interest in literature to date (e.g., illness representations). Others have not. As a result, certain relationships hypothesised by the CSM remain largely untested, while evidence for others is inconclusive at present. Chapters 2 and 3 provided an overview of previous research. They highlighted a number of grey areas in the self-regulatory literature. For example, evidence of a relationship between illness representations and objective measures of disease state is equivocal. Emotional dimensions of self-regulation also require further exploration. The CSM originally explicated a link between social communication and illness representations; however, this has received very little empirical testing to date. Associations between cognitive and emotional dimensions of the CSM may be a useful area for future study, as is the relationship between views about illness and prescribed treatments among people with diabetes. While the CSM is applicable to many chronic conditions, exact self-regulatory mechanisms may vary across illness groups. It is therefore important that generic theoretical structures and hypothesised relationships

are tested across a range of illness groups. Research is needed to examine self-regulation as it applies to specific conditions, for example, type 2 diabetes.

Examination of bivariate relationships is a constructive first step. These relationships can be used to overview the 'web of associations' among structures within the CSM, as they apply to diabetes. This is particularly helpful when exploring relationships that have received limited previous empirical attention, or where diabetes research is scant. Examination of bivariate relationships may serve to engender a priori hypotheses that can be tested in future research. In turn, these help generate a better understanding of the self-regulatory process as it relates to diabetes. The first aim of the present study is examine salient bivariate relationships; these are listed at the end of the present section. Particular emphasis is placed on the relationships between (a) cognitive and emotional representations, and (b) illness and treatment perceptions.

The second aim of the current study is to provide a descriptive account of wellbeing among New Zealanders with type 2 diabetes; this will incorporate results from both generic and diabetes specific measures. Attention will be given to examining physical and emotional wellbeing. Explicit comparisons will be made between the results of the present study, and those obtained in previous research using the same or similar instruments. Through these comparisons it will be possible to ascertain whether people in New Zealand experience a similar level of wellbeing to others with type 2 diabetes around the world. Previous research using the SF-36 has shown evidence of significant between group differences (Ministry of Health, 2004). Therefore the possibility of differential wellbeing according to gender or ethnicity will be examined.

Aim 1: To identify bivariate relationships between socio-medical context, illness/treatment representations and illness outcomes.

Within this, attention will be given to associations between:

- (a) Demographic characteristics and illness/treatment representations
- (b) Socio-medical context and illness/treatment representations
- (c) Illness and treatment perceptions

- (d) Cognitive and emotional representations
- (e) Psychosocial variables and health behaviour
- (f) Psychosocial variables and illness outcomes

Aim 2: To examine levels of physical and psychological wellbeing among people with type 2 diabetes in New Zealand

HYPOTHESIS TESTING

Leventhal, Meyer and Nerenz (1980) highlight the need to construct a substantive theory that creates a scientific understanding of psychological processes in health and illness. The common sense model provides the framework for such an endeavour. The first step is to create stable, and empirically tested “fundamental units of meaning” (Leventhal et al., 1980, p. 27). These units form the building blocks of our model. The last quarter of a century has shown huge development in this process. Publication of the Illness Perception Questionnaire has provided psychometrically solid operational definitions of many illness representation constructs (timeline, control, consequences etc.). Once such structures have been identified, it is possible to investigate the relationships between key parts of the common sense model (Leventhal et al., 1980). This enables examination of the *process* of self-regulation. Thus, while description of core components in the CSM is an important goal, this can only provide an understanding of self-regulation as a static body. It is timely, then, to consider the next stage of empirical questioning, the underlying relationships between core dimensions of the CSM as they occur in the context of specific illness experiences.

Hypothesis 1

Total glycosylated haemoglobin A_{1c} is a core clinical outcome for people with type 2 diabetes. HbA_{1c} is a strong predictor of diabetes complications and, through this, loss of physical functioning due to diabetes. Previous research using the common sense model has sought to examine HbA_{1c} as an outcome of the self-regulatory process, with mixed results (Eiser et al., 2001; Griva et al., 2000; Hampson et al., 1995; Hampson et

al., 2000; Hampson et al., 1990; Wearden et al.). At present the relationship between self-regulatory variables and objective disease outcomes remains a grey area in published literature. Additional research is required, and use of multivariate analyses is recommended. As a first step, research should determine whether self-regulatory structures, collectively, account for a significant amount of the variance in HbA_{1c}. If so, this suggests the CSM has explanatory power in regard to the selected outcome variable. It implies a connection between psychological/behavioural processes and disease state is present among people with diabetes. Further examination of specific relationships is then warranted, for example, identification of individual variables that are associated with differential metabolic control. The first hypothesis in the present study aims to investigate the relations between psychosocial variables and glycaemic control. It is stated formally below.

Hypothesis 1. Psychosocial and behavioural factors will explain a significant proportion of the variance in metabolic control among people with type 2 diabetes

Hypothesis 2

Chapter 1 highlighted the emotional impact of type 2 diabetes. Research, particularly that grounded in a patient-centred view of diabetes, indicates the psychological burden of diabetes is substantial. However, we know little about the factors that are most important in determining diabetes-related distress. Or the relative contribution of various categories of variables located at different points along the anticipated causal pathway (e.g., social context, individual cognitions, or health-related behaviour). The self-regulatory framework provides a platform from which to begin examining the psychological impact of diabetes, and determining whether variables from health psychology are able to provide an explanatory account of differences in diabetes-related distress. As noted in chapter 2, limited attention has been paid to the emotional pathway in research using the CSM to date. This constitutes the basis for the second hypothesis in the current study, as stated on the following page.

Hypothesis 2. Psychosocial and behavioural factors will explain a significant proportion of the variance in diabetes-related emotional distress

Hypothesis 3

As suggest in chapter 1, successful management of diabetes should focus on dual outcomes, which includes achievement of (1) good metabolic control, and (2) quality of life. In the present study, each is accorded equal status. Therefore, alongside examination of HbA_{1c} and diabetes-related distress, it is important to establish whether self-regulatory variables are able to provide an explanatory account of differences in quality of life. This constitutes the basis of the third hypothesis, as stated below.

Hypothesis 3. Psychosocial factors, self-care behaviour, and diabetes-related wellbeing will explain a significant proportion of the variance in quality of life

As discussed previously, the analyses used for testing hypotheses 1, 2, and 3 also enable identification of individual variables that account for differences in wellbeing among people with type 2 diabetes. Thus, with the stipulated demonstration of explanatory power, it is possible to identify individual variables that show a significant relationship with HbA_{1c}, diabetes-related distress, and quality of life. This is an important goal in the present study. Attention will be given to ascertaining whether the variables that account for differences in one domain of wellbeing are similar to those explaining variance in the remaining two dimensions.

Hypothesis 4

The importance of examining emotional representation of diabetes was strongly emphasised in the third chapter. To date, very little research has sought to examine the process through which emotional representations of diabetes are generated and/or sustained. This has been highlighted as important goal for future research (Skinner et al., 2002). It is plausible that a relationship exists between the emotional tone expressed in interpersonal relationships (support or conflict), and the degree of negative emotional representation of diabetes and diabetes treatments. Self-regulatory theory suggests social communication may play a significant role in determining the way people view their illness (see Figure 1, chapter 3). As highlighted in chapter 1, clinical partnership and family context may both have a pertinent impact on the process of diabetes self-management. However, little is known about the role of socio-medic

context in emotional responses to diabetes. The CSM provides a framework from which to develop potential hypotheses about the relationship between socio-medic context and emotional representation in diabetes. In the present study it is predicted that differences in support/conflict from family and medical sources (that is, socio-medic relationships) will be related to variation in diabetes concern and treatment concern. Six sub-hypotheses are also stated.

Hypothesis 4. Differences in support/conflict from socio-medic relationships will be related to variation in diabetes concern and treatment concern

Sub-hypotheses

Hypothesis 4a. Higher conflict with family/health professionals over diabetes self-management will be associated with greater concern about diabetes

Hypothesis 4b. Greater support for diabetes self-management from family/health professionals will be associated with lower concern about diabetes

Hypothesis 4c. Higher conflict with family/health professionals over diabetes self-management will be associated with greater concern about prescribed medication

Hypothesis 4d. Greater support for diabetes self-management from family/health professionals will be associated with lower concern about prescribed medication

Hypothesis 4e. Socio-medic context will explain a significant portion of variance in diabetes concern

Hypothesis 4f. Socio-medic context will account for a significant amount of the variation in medication concern

Hypothesis 5

Hypotheses 5 and 6 focus on self-management behaviour. As stated and continually reiterated in the preceding chapters of this thesis, active self-care plays a critical role in maximising long-term wellbeing among people with type 2 diabetes. This is a key research theme. However, collective literature fails to provide a good explanation for the wide variance in self-care practices. As emphasised in chapter 1, despite growing technical advancement in the field of medicine the puzzle of how best to encourage people to take care of themselves remains. Above all, clinicians and researchers struggle to find clear answers to two fundamental questions: (1) why is concordance with medical advice so variable? And (2) how best can we encourage good diabetes self-care? Information from psychological research could make a potentially useful contribution. First, by determining whether psychosocial factors can contribute to the explanation of variance in self-care behaviour; second, by identifying specific variables that are related to differential self-care practices; and third, by using this information to develop interventions that, through targeting key variables, are efficacious in improving self-management. In some studies of diabetes, self-management psychosocial variables have demonstrated explanatory power, that is, an ability to account for variance in diabetes self-management behaviour. However, published findings have largely focused on dietary patterns and, to a lesser extent, exercise (e.g., Hampson et al., 2000; Skinner & Hampson, 1998; Watkins et al., 2000). It is important that future research seeks to include both lifestyle elements of diabetes self-care (e.g., diet and exercise) and medical aspects of self-management (e.g., medication use). This constitutes a fruitful area for empirical enquiry. Hypothesis 5 is comprised of four sub-hypotheses. These examine whether psychosocial variables are able to account for variation in four aspects of diabetes self-care.

Hypothesis 5. Psychosocial factors will explain a significant proportion of the variance in diabetes self-care behaviours

Sub-hypotheses

Hypothesis 5a. Psychosocial factors will explain a significant proportion of the variance in dietary patterns

Hypothesis 5b. Psychosocial factors will explain a significant proportion of the variance in exercise habits

Hypothesis 5c. Psychosocial factors will explain a significant proportion of the variance in medication use

Hypothesis 5d. Psychosocial factors will explain a significant proportion of the variance in blood glucose testing

Hypothesis 6

The core aim of hypothesis 6 is investigation of a priori sub-hypotheses that test for directional associations between self-care behaviour and individual psychosocial variables. As noted in chapter 3, associations between individual representations and individual outcomes have been noted in previous studies, but attempts to combine this information to present a meaningful 'over all picture' are infrequently encountered in diabetes literature at present. This makes it difficult to highlight particular psychosocial variables that do show a consistent directional relationship with diabetes self-management behaviour. However, this is an important goal for self-regulatory research.

The present study therefore sought to examine relationships between psychosocial variables and diabetes self-care using specific directional sub-hypotheses stated a priori. The rationale for selecting the direction of sub-hypotheses focused on two criteria: first, evidence of a reliable relationship within current diabetes literature; and second, emergence of new variables for which little empirical evidence is currently available but for which self-regulatory theory provides an expected direction for the relationship. The exploratory nature of these directional sub-hypotheses should be

emphasised. Specific sub-hypotheses are provided below, accompanied by a brief account of their genesis.

Hypothesis 6. Treatment control, personal control, consequences, chronic timeline, coherence, and treatment necessity, will each show a positive relationship with diabetes self-care behaviour; treatment concern, cyclical timeline, diabetes identity, and negative emotional representation, will each show a negative relationship with self-care behaviour

One theme emerging from both generic and diabetes specific self-regulatory literature is the connection between control and coping. A core hypothesis in Hagger and Orbell's (2003) meta-analytic review was that the cure/control variable would be positively associated with problem-focused coping strategies. Results supported this hypothesis, showing a significant positive bivariate relationship between cure/control and behavioural coping ($r_c = .12, < .05$). Diabetes literature has also demonstrated convincing evidence of a connection between perceived control and active behavioural coping (Barnes, 2000; Griva et al., 2000; Skinner & Hampson, 1998; Skinner et al., 2002). A second key theme is the role of perceived seriousness of diabetes in self-management. Diabetes literature has proposed that these two variables (treatment effectiveness and seriousness) play a pertinent role in determining diabetes related behaviour, particularly diet and exercise patterns (Gentili et al., 2001; Glasgow et al., 1997; Hampson et al., 2000).

These variables emerged from self-regulatory research using a personal models approach to diabetes. However, they are closely related to the constructs of control and consequences used in studies that have employed the IPQ or IPQ-R for assessment of illness representations (Hampson et al., 2000). Therefore, the role of control and consequences in active behavioural coping constitutes a key area of interest in hypothesis 6. It is predicted that (a) greater belief in the efficacy of prescribed treatments as means to control diabetes, (b) a perception that one has a high degree of personal control over diabetes, and (c) a conviction that diabetes is associated with serious life consequences, will each be associated with more active self-care behaviour. These directional relationships are stated more formally in sub-hypotheses 6a, 6b, and 6c.

Hypothesis 6a. Higher treatment control will be associated with active self-care behaviour

Hypothesis 6b. Higher personal control will be associated with active self-care behaviour

Hypothesis 6c. Higher perceived consequences will be associated with active self-care behaviour

Exploratory hypotheses are also valuable, as discussed previously. These allow new research to build upon current literature, examining relationships that have received little or no previous attention in diabetes studies to date. The present study predicted a belief that type 2 diabetes is a lifelong condition would be associated with better self-care. This belief represents an accurate understanding of diabetes. A negative relationship between timeline cyclical and self-care was also hypothesised. This suggests a perception that diabetes symptoms come and go in a cyclical manner (and are, therefore, confusing to interpret) will be associated with lower self-care. Previous New Zealand research has shown a positive correlation between chronic timeline and blood glucose testing ($r = .43, p < .01$), and a negative association between cyclical timeline and dietary self-care ($r = -.24, p < .05$) among adults with type 2 diabetes. A negative relationship between diabetes identity and self-care was also predicted. Previous research suggests differentiation of self from illness might be an important part of adaptive self-management of diabetes (Paterson et al., 1999). These directional relationships form the basis of sub-hypotheses 6d, 6e, and 6f, as stated below.

Hypothesis 6d. Stronger belief in a chronic timeline for diabetes will be associated with active self-care behaviour

Hypothesis 6e. Stronger belief in a cyclical timeline for diabetes will be associated with less active self-care behaviour

Hypothesis 6f. Stronger diabetes identity will be associated with less active self-care behaviour

As noted in previous chapters, the role of affect has received limited attention in many self-regulatory studies; the focus has more often been on cognitive variables. Further, where emotional representation has been of interest, this has usually been referenced to its role in emotion-based coping strategies such as avoidance and denial. Active behavioural coping is crucial to staying well with diabetes; however, there is a dearth of research examining the role of emotion in behavioural self-management. This is a key area of interest in the present study. Alongside inclusion of the emotional representation subscale, the revised Illness Perception Questionnaire also presents a new variable labelled 'coherence'. This is described by Moss-Morris et al. (2002, p. 2) as "a type of meta-cognition reflecting the way in which the patient evaluates the coherence or usefulness of his or her illness representation". Few studies have examined the role of coherence, a personal belief that diabetes makes sense, in self-management of type 2 diabetes. Therefore, it is proposed that greater perceived coherence will be related to better self-care; conversely, greater negative emotional representation of diabetes will be associated with less active self-management behaviour. These relationships constitute the basis of exploratory sub-hypotheses 6g and 6h.

Hypothesis 6g. Greater coherence will be associated with active self-care behaviour

Hypothesis 6h. Stronger emotional representation of diabetes will be associated with less active self-care behaviour

Treatment effectiveness could also be considered a form of treatment representation rather than illness representation per se. Because perceived treatment efficacy appears to play a salient role in diabetes self-care, as discussed in chapter 3, it makes sense to examine the role of other types of treatment representations. Research by Horne and colleagues has demonstrated that perceptions of treatment necessity may be important in the self-regulation of chronic illness. Concerns about taking prescribed medication are also likely to influence self-management choices. Therefore, in the present study it is predicted that (a) greater belief in the need for diabetes medication, and (b) less worry about the use of prescribed pharmaceutical treatments, will each be associated with more active engagement in self-management of diabetes.

Hypothesis 6i. Higher treatment necessity will be associated with active self-care behaviour

Hypothesis 6j. Lower treatment concern will be associated with active self-care behaviour

Hypothesis 7

The fifth and sixth hypotheses focused on accounting for differences in diabetes self-management. Hypothesis 7 centres on one particular aspect of self-management, and its relationship with metabolic control. Specifically, it seeks to examine adherence to prescribed pharmaceuticals, as a potential mediator of the relationship between treatment representations and metabolic control. In a sense this provides close examination of medical aspects within diabetes self-regulation.

Good blood glucose control is the primary aim of therapeutic intervention for people with type 2 diabetes (New Zealand Guidelines Group, 2003); therefore HbA_{1c} is a salient clinical outcome in diabetes research (Griva et al., 2000). At present, the relationships between psychological factors, behavioural management and HbA_{1c} are not well understood. Very few studies have sought to investigate the different types of associations (direct, moderating, mediating) that may be present. Self-regulatory theory suggests the association between illness representations and health outcomes may be mediated by coping (Hagger & Orbell, 2003). However, the mediating model has received limited empirical attention to date. Recent diabetes literature has highlighted the need to “investigate potential mechanisms, such as self-care behaviors, that explain the relationship between personal models of diabetes and glucose control” (Lange & Piette, 2006, p. 251).

Diabetes research has sought to examine possible mediating relationships among illness representations, treatment adherence and HbA_{1c}. Griva et al. (2000) proposed that illness representations may act to moderate the relationship between adherence and metabolic control; however, no evidence of such relationships was observed. Possible mediating relationships were also considered. It was hypothesised that illness representations would function to mediate the relationship between adherence and

HbA_{1c}. Only those illness representation variables that showed a significant bivariate association with HbA_{1c} were examined as potential mediators; these were diabetes self-efficacy, identity and perceived consequences. Two of these variables showed a significant relationship with adherence, and were retained for further examination.

Griva and colleagues employed the analyses strategy outlined by Baron and Kenny (1986) to test for the presence of mediating relationships. Results revealed that self-efficacy appears to mediate the association between adherence and HbA_{1c}, but diabetes identity does not. Conceptually, the relationships examined by Griva et al. (2000) do not match up with those presented in the common sense model. Self-regulatory theory suggests illness representations will influence coping, and, as outlined in chapter 3, previous diabetes literature has identified active behavioural self-care as a form of coping strategy. It therefore makes sense to predict that adherence will act to mediate the relationship between illness representations and metabolic control. However, Griva et al. hypothesised that illness representations will mediate the association between adherence and metabolic control. This latter proposition seems somewhat at odds with the primary direction of association shown in the common sense model of illness self-regulation presented by Leventhal and colleagues (Leventhal et al., 1992; Leventhal et al., 1980; Leventhal et al., 1984).

Further research is needed to examine possible mediating relationships in detail. Previous studies have identified a large number of illness representation domains, and coping strategies. At present, limited information is available to indicate which representation dimensions and types of coping show evidence of connections that may form a mediating relationship, and which do not. As previously emphasised, testing of specific hypotheses is necessary in order to develop a more accurate understanding of the self-regulatory process. In the present study, interest in mediating relationships will be focused on treatment representations, medication adherence, and metabolic control. Two sub-hypotheses are specified, as shown on the following page.

Hypothesis 7. Medication adherence will mediate the relationships between treatment representations and HbA_{1c}

Sub-hypotheses

Hypothesis 7a. Medication adherence will mediate the relationship between medication necessity and HbA_{1c}

Hypothesis 7b. Medication adherence will mediate the relationship between medication concern and HbA_{1c}

SUMMARY OF RESEARCH AIMS AND HYPOTHESES

Aims

Aim 1. To identify bivariate relationships between socio-medical context, illness/treatment representations, and illness outcomes.

Aim 2. To examine levels physical and psychological wellbeing among people with type 2 diabetes in New Zealand

Hypotheses

Hypothesis 1. Psychosocial and behavioural factors will explain a significant proportion of the variance in metabolic control

Hypothesis 2. Psychosocial and behavioural factors will explain a significant proportion of the variance in diabetes-related emotional distress

Hypothesis 3. Psychosocial factors, self-care behaviour, and diabetes-related wellbeing will explain a significant proportion of the variance in quality of life

Hypothesis 4. Differences in support/conflict from socio-medical relationships will be related to variation in diabetes concern and treatment concern

Hypothesis 5. Psychosocial variables will explain a significant proportion of the variance in diabetes self-care behaviours

Hypothesis 6. Treatment control, personal control, consequences, chronic timeline, coherence, and treatment necessity, will each show a positive relationship with diabetes self-care behaviour; treatment concern, cyclical timeline, diabetes identity, and negative emotional representation, will each show a negative relationship with self-care behaviour

Hypothesis 7. Medication adherence will mediate the relationship between treatment representations and HbA_{1c}

SUMMARY OF INTRODUCTORY CHAPTERS

The purpose of this chapter is to outline key objectives in the present study. These objectives emerged from a review of relevant literature as presented in the preceding chapters. Genesis of specific hypotheses can be linked to central themes accentuated in chapters 1, 2, and 3. For example, chapter 1 emphasised the need to consider metabolic control *and* quality of life as important outcomes in diabetes management. The second section of chapter 1 highlighted the pertinent role self-management behaviour plays in determining long-term wellbeing among people with type 2 diabetes. These constructs are strongly represented in hypothesis testing; metabolic control and quality of life constitute the key outcome variables in hypotheses 1 and 3, and diabetes self-care behaviour forms the basis of hypotheses 5 and 6.

Chapter 2 examined theoretical frameworks that might provide a conceptual foundation for the present study, and culminated in selection of the common sense model (CSM) of illness management. Chapter 3 presented an overview of previous research using the CSM, with particular attention to studies focusing on diabetes. This enabled identification of grey areas in the research literature; information that has then been incorporated in development of research aims and hypotheses within the present study. For example, the pre-eminent focus on cognitive variables was observed, and the relative dearth of previous research examining the CSM's emotional pathway noted (particularly in relation to 'physical' illnesses such as diabetes). To date, there has been limited interest in the role of emotion in engagement of active behavioural coping strategies. The need to examine possible connections between intrapersonal (individual representations) and interpersonal (social context) factors was also emphasised. These themes were instrumental in guiding the generation of hypotheses 2 and 4. Arguments for the use of specific directional predictions played a salient role in shaping hypothesis 6. The importance of investigating interactive relationships was accorded recognition; this stimulated presentation of mediating relationships as outlined in hypothesis 7.

In summary, the preceding chapters (1, 2, and 3) shaped the goals of the present study, and specification of hypotheses emerged from a review of relevant literature as presented in earlier chapters. Objectives of the present study incorporate seven hypotheses; these test predicted relationships between key variables included within

the common sense model of chronic illness management, as represented in chapter 3. Thus stated objectives fit with the overarching aim of the current research; namely, to examine the process of diabetes self-management using a self-regulatory approach.

CHAPTER 5
METHOD

CHAPTER OVERVIEW

The purpose of chapter 5 is to explicate research methods employed in the current study. This chapter begins with an overview of the research design, a description of participants, and an account of the data collection procedure. Attention will then focus on measures used in the present study. A detailed description of each main instrument will be given, with information on psychometric properties where this is available. As part of the current research, two new measures were developed that sought to assess the diabetes-specific family context, and patient-provider relationship. Preliminary stages in this developmental process are outlined in Appendix A; chapter 5 expands on this by presenting statistical analyses used to refine item content and identify underlying factor structure for each of the two new measures. A description of the final instruments is provided, with assessment of internal consistency. In the present study, information collected through self-report measures will be supplemented by physician-assessed health status. An overview of clinical descriptors will conclude the Method chapter. Following this, chapter 6 will present results from the current study.

DESIGN

A cross-sectional survey was the primary method of data collection in this study. Psychosocial and self-report information was obtained through a mailed questionnaire survey. A medical database review was undertaken to provide supplementary clinical data. Medical and survey data were merged using a system of unique identifiers; participant confidentiality was maintained throughout the research.

PARTICIPANTS

From a medical database administered by the Wellington Regional Diabetes Trust (WRDT), 1275 potential participants were identified. Of these, 130 were subsequently removed from the study due to inaccuracies in the WRDT database (deceased (4), incorrect mailing address (115), did not believe they had diabetes (11)), which left a sample of 1145. The 629 completed questionnaires that were returned provided a

response rate of 55% for the mailed survey. Permission was given by 615 questionnaire respondents (98%) for clinical records pertaining to their diabetes to be released to the researcher in non-identifiable form. All participants had been diagnosed with type 2 diabetes by a medical practitioner in New Zealand. Detailed demographic and health information for the sample is provided in chapter 6.

DATA COLLECTION PROCEDURE

A Memorandum of Understanding was signed between the Wellington Regional Diabetes Trust (WRDT) and Massey University. Ethical approval was provided by the Massey University Human Ethics Committee. Analysis of database composition showed an under representation of Māori and Pacific groups compared with population-based diabetes estimates (PricewaterhouseCoopers, 2001). Furthermore, previous research using mailed surveys has shown lower response rates for Māori and Pacific peoples, compared with the response rate among New Zealand Europeans in the same study (Zwier & Clarke, 2005). A stratified sampling technique was therefore employed to encourage a representative sample. First, potential participants were identified by the WRDT database manager. Inclusion criteria for this study were: (a) diagnosis of type 2 diabetes by a medical practitioner in New Zealand; (b) aged over 18; and (c) recent clinical data available on WRDT database (within 18 months). All persons had indicated previously they were willing to be contacted by the Wellington Regional Diabetes Trust. The inclusion criteria were met by 4857 people in the WRDT database. Potential participants were then divided into four groups based on their ethnicity as recorded in medical notes (Māori, Pacific, New Zealand European and Other). Third, a computer-generated random number sequence was used to select 1275 individuals who were subsequently invited to take part in the study. Māori and Pacific groups were purposefully over-sampled. In practice this meant the selection process was undertaken separately for each of the four ethnic groupings, though random selection within each ethnic group was maintained. An individual identification number was assigned to each person for the purposes of the research. Printing of postal address labels and collation of mail out materials was done at the WRDT premises in Wellington. All information was sent on behalf of the researcher by the Wellington Regional Diabetes Trust. Clinical and demographic information provided to

the researcher was listed by study identification number only. Patient confidentiality was protected at all times; no personal details were given to the researcher.

Potential participants were sent a letter of introduction from the Wellington Regional Diabetes Trust (Appendix B) informing them of the study and inviting their participation. This was accompanied by an information sheet (Appendix C), questionnaire (Appendix D), pen and freepost reply envelope. The information sheet explained that potential participants were randomly selected, and stated clearly that participation was voluntary. A return address was provided on the back of the envelope to ensure these were returned to the researcher if the address was incorrect. An 0800 number (free phone) was provided on the envelope, pen, questionnaire and information sheet that invited any persons with questions or concerns to contact the researcher at no cost.

A reminder letter (Appendix E) was sent to all persons who had not returned a questionnaire or contacted the researcher 14 days later. The letter thanked those who had already returned the questionnaire, provided a reminder about the study and stated that responses were still welcome. Participants who did not wish to receive any further information about the study were informed how to advise the researcher of this.

Four weeks after the reminder letter a second letter of introduction, information sheet, questionnaire, pen and freepost reply envelope were sent to all potential participants who had not yet returned a questionnaire, or contacted the researcher to indicate they did not wish to take part. Data collection for this study began on 10 May 2004 and was completed on 10 September 2004.

A medical database review was used to collect additional information. Demographic and descriptive clinical data for all persons invited to take part in this study were provided from the WRDT database. This enabled comparison of respondents and non-respondents. Extended clinical data from medical notes held on the WRDT database were provided to the researcher for 615 cases. All medical data was directly relevant to diabetes. This information was released only for those participants who provided written permission at the time of questionnaire completion (98%). All clinical data were listed using the identification number assigned to each participant for the purposes of this research. The data were merged with information collected from the mailed questionnaire survey. All data were screened for inaccurate entry before exploratory

analysis of new measures and computation of summary statistics. At study completion a copy of the research findings in layperson's terms was mailed to all participants who had requested this (90%).

MEASURES

Self-Reported Health Status

Self-rated health was assessed using the Short Form-12 (SF-12®) questionnaire (Ware, Kosinski, & Keller, 1998). This measure contains 12 questions that produce two summary scores: mental health (MCS-12) and physical health (PCS-12). These scores were computed according to instructions provided by authors of the SF-12. This included reversal of item scoring for four items, creation of indicator variables, weighting and aggregation of indicator variables, and transformation of summary scale score to achieve norm-based standardization (Ware et al., 1998). A higher score represents better self-reported health. The Short Form-12 has been used as a measure of functional status in other studies focused on people with type 2 diabetes (Aikens et al., 2005). Previous research has used an extended version of this measure, the SF-36, in a large New Zealand general population study. Evidence of validity and reliability in this population has been provided (Scott, Tobias, Sarfati, & Haslett, 1999). Recent research among people with diabetes in New Zealand utilized three subscales from the SF-36: general health, vitality and mental health. Evidence of good internal consistency among a New Zealand diabetes sample was presented (Barnes, 2000).

Previous research suggests the SF-12 is able to differentiate between people with diabetes and general (non-diabetic) population samples, at least for physical functioning. Using data from the Medical Outcomes Study, Ware et al. (1998) report that, on average, people with type 2 diabetes had a physical health summary score of 44.84. This can be compared to a mean of 50 in the general American population. International research also suggests the SF-12 is responsive to differences in physical health across chronic illness groups. A validation study ($N = 1238$) compared mean physical and mental health summary scores across four chronic conditions: hypertension, congestive heart failure, recent myocardial infarction and type 2 diabetes

(Ware et al., 1998). Results showed significant differences in mean PCS-12 scores between the groups, $F(3,1232) = 14.76, p < .001$. However, no significant differences across the four conditions were shown for MCS-12 scores. Study findings suggest the SF-12 is able to detect differences in mean physical and mental summary scores among people differing in severity of congestive heart failure. However no significant differences were observed among people differing in severity of diabetes – defined by length of diagnosis and complications. Estimates of reliability for the PCS-12 and MCS-12 have primarily focused on correlations between repeated administrations of the SF-12. Test-retest reliability coefficients were calculated across a 2-week period for general population U.S. ($N = 232$) and U.K. ($N = 187$) samples (Ware et al., 1998). Reliability coefficients of .76 (U.S.) and .77 (U.K.) were observed for the mental health summary scale. Test-retest reliability for the PCS was high in both samples ($r = .89$ (U.S.), $r = .86$ (U.K.)). In the present study, both physical and mental health summary scores showed moderate evidence of internal consistency (Cronbach's alphas = .61 and .57 respectively).

The presence of health complications related to diabetes was assessed using a list of five microvascular and macrovascular symptoms. Participants were asked to indicate whether they had experienced specific health problems listed during the last 2 years. Responses were provided as yes or no. Four items assessed microvascular complications (neuropathy, retinopathy and nephropathy). One item assessed macrovascular complications. A second question sought information on diabetes-related operations or procedures experienced by participants. This included cataract surgery, laser treatment, lower-extremity amputation, coronary surgery, dialysis or renal transplantation. Information was collected on co-morbid medical problems. A list of nine serious health problems was presented (e.g., stroke, heart attack, cancer, memory loss, depression). Respondents indicated health problems they had previously been diagnosed with; they could indicate multiple responses.

Diabetes-specific psychological distress was measured using the Problem Areas In Diabetes (PAID) scale. This instrument was developed at the Joslin Diabetes Centre, Boston and has been used extensively to evaluate diabetes-related emotional distress (Welch, Weinger, Anderson, & Polonsky, 2003). Twenty statements are provided, each presenting an emotional problem frequently reported among people with diabetes (e.g., feeling overwhelmed by your diabetes). Participants rate how much each

problem currently affects them on a five-point scale ranging from 1 (*not at all*) to 5 (*serious*). All item responses are summed, and the product was multiplied by 1.25 to provide a final score ranging from 0 to 100. A higher score represents greater emotional distress about diabetes. In a recent review of data from seven diabetes treatment intervention studies, Welch et al. (2003) concluded the PAID is sensitive to change over time. Previous research has also shown evidence of excellent internal reliability, and good test-retest reliability across a 2-month period using a Dutch sample of clinically stable patients ($r(202) = 0.83$) (Snoek, Pouwer, Welch, & Polonsky, 2000). As shown in Table 1, this instrument showed excellent internal consistency in the present study (Cronbach's alpha = .96)

Quality of life was assessed using two items from the Audit of Diabetes-Dependent Quality of Life (ADDQoL) (Bradley et al., 1999). Participants were asked to rate their current quality of life in general, and their quality of life if they did not have diabetes. Responses were provided on a seven-point scale; with responses ranging from 1 (*excellent*) to 7 (*extremely bad*).

Illness and Treatment Representations

Illness representations were assessed using the Illness Perception Questionnaire-Revised (IPQ-R) (Moss-Morris et al., 2002). This instrument provides a comprehensive quantitative measure of illness representations, and includes the five cognitive components presented in the self-regulation model: cause, consequences, control/cure, identity, and timeline (Hagger & Orbell, 2003; Leventhal et al., 2003; Weinman et al., 1996). The Illness Perception Questionnaire has recently been revised to include assessment of emotional illness representations. This instrument has been used extensively among a range of illness groups, including cancer, chronic fatigue syndrome, heart disease, rheumatoid arthritis, psoriasis, and type 2 diabetes (Byrne et al., 2005; Fortune et al., 2002; Scharloo et al., 1998; Steed et al., 1999).

Table 1.

Alpha Coefficients Showing Internal Consistency for Main Measures and Associated Subscales.

	Cronbach's Alpha
<i>Illness Perception Questionnaire-Revised</i>	
Timeline Acute/chronic (N = 6)	.81
Timeline Cyclical (N = 4)	.80
Consequences (N = 6)	.75
Personal Control (N = 6)	.69
Treatment Control (N = 5)	.46
Diabetes Coherence (N = 5)	.82
Diabetes Concern (N = 6)	.87
Diabetes Identity (N = 16)	.83
Cause – Psychosocial (N = 6)	.90
Cause – Risk Factors (N = 5)	.81
Cause – Behaviour (N = 3)	.71
Cause – Ageing/immunity (N = 2)	.58
<i>Beliefs About Medicines Questionnaire-Specific</i>	
Treatment Concern (N = 6)	.94
Treatment Necessity (N = 5)	.97
<i>Summary of Diabetes Self Care Activities</i>	
Diet (N = 4)	.75
Exercise (N = 2)	.61
Blood Glucose Testing (N = 2)	.91
Foot Care (N = 2)	.63
<i>Short Form-12</i>	
MCS (N = 12)	.57
PCS (N = 12)	.61
Problem Areas in Diabetes (N = 20)	.96
Medication Adherence Report Scale (N = 7)	.82

In a recent study, eight illness groups were used to explore psychometric properties of the IPQ-R (Moss-Morris et al., 2002). Seven of these groups, including type 2 diabetes, were recruited in New Zealand. Results showed empirical support for the theoretically derived factor structure used in the IPQ-R. Evidence of internal reliability and stability over time were provided. The IPQ-R also demonstrated good discriminant and predictive validity.

The Illness Perceptions Questionnaire was presented in three sections. First, 19 possible causes of diabetes were listed. Authors of the IPQ-R encourage researchers to adapt the 'causal' dimension of this measure to the specific nature of their project (Moss-Morris et al., 2002). In the present study, two of the original causes were combined into one, 'alcohol or smoking', representing behaviour as a cause of diabetes. Two additional items were included: 'God's will' and 'spiritual or emotional worries'. These have been used in previous New Zealand diabetes research (Barnes, 2000). Participants were asked to indicate how much they believed each factor was a cause of their diabetes. Responses were recorded on a five-point scale: strongly disagree, disagree, neither agree nor disagree, agree, and strongly agree. Participants also specified (in rank order) the three most important causes of their diabetes.

A principal component analysis was conducted to identify underlying factor structure within the causal scale, after confirming the suitability of data for factor analysis (Kaiser-Meyer-Olkin value = .88; Bartlett's Test of Sphericity was significant, $p < .001$). Results from the rotated solution are presented in Table 2. Nineteen items were entered. This produced five factors with eigenvalues exceeding 1, explaining 31.6%, 9.6%, 7.4%, 5.9%, and 4.7% of the variance, respectively. Varimax rotation was used to aid in the interpretation of these five components. Items that loaded 0.50 or greater were interpreted as representing a particular factor. Sixteen items loaded exclusively on to one of the five factors. Both 'God's will' and 'my personality' loaded .49 on to the factor labelled behaviour, and .45 on the ageing/altered immunity factor. These two items were removed from further analyses because they did not load clearly on to a single factor. One item, 'alcohol or smoking', was retained in the behaviour factor although its loading was marginal (.50).

Table 2.

Principal Component Analysis of the IPQ-R Causal Items and Cronbach's Alpha for Each Subscale (N = 432).

	Factor I	Factor II	Factor III	Factor IV	Factor V
<i>Psychosocial attributions ($\alpha=.88$)</i>					
Stress or worry	.79	-.09	.07	.08	-.09
My mental attitude, e.g., thinking about life negatively	.65	.37	.18	.04	.10
Family problems or worries	.83	.26	.07	.06	.03
Overwork	.71	.26	.19	.17	-.00
My emotional state, e.g., thinking about life negatively	.80	.25	.05	.12	.05
Spiritual or emotional worries	.65	.43	.07	.19	.12
<i>Risk factors ($\alpha=.71$)</i>					
A germ or virus	.18	.50	.00	.15	-.16
Chance or bad luck	.08	.61	-.22	.16	-.03
Poor medical care in my past	.18	.62	.38	-.13	.03
Pollution in the environment	.29	.69	.14	.01	-.14
Accident or injury	.24	.64	.01	.13	.05
<i>Behaviour ($\alpha=.60$)</i>					
Diet or eating habits	.06	-.12	.83	.02	.04
My own behaviour	.18	.02	.76	.16	-.09
Alcohol or smoking	.16	.33	.50	.08	.28
<i>Ageing/immunity ($\alpha=.43$)</i>					
Ageing	.12	-.04	.14	.77	-.01
Altered immunity	.15	.29	.07	.66	-.14
<i>Hereditary</i>					
Hereditary – it runs in my family	.05	-.11	.04	-.04	.91
<i>Items which did not load onto any factor</i>					
God's will	.05	.49	-.10	.45	.20
My personality	.31	.49	.08	.45	.15
Variance explained (%)	19.6	16.0	9.7	9.0	5.7

The rotated five-factor solution explained 60.1% of the total variance. The first factor was labelled psychosocial attributions, and accounted for 19.6% of the total variance. The second factor included risks from chance events, the environment and poor medical care in the past. This was labelled risk factors, and explained 16% of the variance. The third factor and fourth factors were labelled behaviour and aging/immunity respectively. They accounted for 9.7% and 9% of the total variance, respectively. The final factor consisted of one item with a factor loading of .91. It was labelled hereditary and explained 5.7% of the total variance. Results of the principal component analysis were similar to those reported in previous research (Moss-Morris et al., 2002), with some relatively minor variation in item loadings. Cronbach's alphas for each subscale are presented in Table 1. Acceptable levels of internal reliability were observed in the psychosocial and risk factor subscales. However, moderate to low internal consistency was evident in the subscales labelled behaviour (Cronbach's alpha = .60) and aging/immunity (Cronbach's alpha = .43). This may be due partly to the low number of items in these subscales.

Timeline acute/chronic, timeline cyclical, consequences, personal control, treatment control, illness coherence, and emotional representations were assessed in the second section. Thirty-eight items were presented with a five-point response scale; strongly disagree, disagree, neither agree nor disagree, agree, and strongly agree. Item wording was adjusted to make it condition specific: the word 'illness' was replaced by the word 'diabetes'. Seven subscales were computed as per instructions provided by the authors of this measure (R. Moss-Morris, personal communication, April 22, 2003). Both emotional representation of diabetes per se and emotional representation of diabetes treatment were measured in the current study. Because of the potential for confusion between these two scales, the IPQ-R subscale 'emotional representation' was relabelled 'diabetes concern' for the purposes of the present study. This term reflects the item content, negative emotional representation of diabetes, in the same way that the BMQ subscale medication concern reflects negative emotional representation of diabetes treatment.

Previous research has provided evidence of good internal reliability in each of the seven subscales (Moss-Morris et al., 2002). Cronbach's alphas for the present study are presented in Table 1. Four subscales (timeline cyclical, diabetes concern, diabetes coherence, and timeline acute/chronic) exhibited good internal reliability, with

Cronbach's alphas ranging from .80 to .87. Two subscales, personal control and consequences, showed moderate reliability (Cronbach's alphas = .69 and .75 respectively). One subscale (treatment control) showed low evidence of internal consistency (Cronbach's alpha = .46).

In the third section, diabetes identity was assessed using 16 commonly experienced symptoms. Thirteen were included from those listed in the IPQ-R. One item in the IPQ-R (weight change) was separated into two symptoms – 'weight gain' and 'weight loss'. One new symptom ('mood swings') was added, following advice from diabetes clinicians during the pilot study. The diabetes identity subscale was designed to distinguish between the tendency to report symptoms (somatisation) and the process of connecting symptoms to an illness label (illness identity). Respondents were presented with a list of 16 common symptoms (e.g., sore throat, headaches, sleep difficulties). For each symptom, participants were asked to indicate (1) if they had experienced this symptom since their diabetes was diagnosed, and (2) whether they believed this symptom was related to their diabetes. Responses were recorded as yes/no. The sum of the yes-rated items on this second scale comprises the diabetes identity subscale. This measure showed good internal consistency (Cronbach's alpha = .83).

Beliefs about medicines were assessed using an eleven-item instrument. The Beliefs about Medications Questionnaire (BMQ) Specific was used in the present study, as it focuses on beliefs about a specific medication or treatment regime prescribed for personal use (Horne, 1997). This instrument contains two subscales, labelled 'concern' and 'necessity', each with five core items (Horne & Weinman, 2002). One additional item was added: 'These diabetes medicines give me unpleasant side effects'. This was done to facilitate comparison of results from the present study with those from previous New Zealand diabetes research using the BMQ (Barnes, 2000). Minor amendments were made to question wording; for instance, the word 'medicines' was replaced with 'diabetes medicines'. Instructions immediately preceding the BMQ informed participants that the term 'diabetes medicines' encompassed both tablets and insulin. Thus in the present study, completion of the BMQ was not referenced to oral medication alone, but included other medical treatments prescribed for diabetes, for example, insulin.

A principal component analysis (with varimax rotation and a selection criterion of eigenvalues greater than 1) produced two factors that accounted for 59% of the total variance. Items that loaded .50 or greater were interpreted as representing that factor; all items loaded exclusively on to one of the two factors. Factor I, labelled medication concern, consisted of six items. The content of these items focused on worry and concern about taking diabetes medication, for example, dependency and side effects. Five items loaded on to the second factor, labelled medication necessity. The content of the two factors, as defined by the item loadings, supported the two theoretically derived factors this measure was designed to assess (Horne et al., 1999). The scoring on all items was reversed so that higher scores represented greater medication concern/necessity.

Subscale scores were then computed by summing the items loading on to each factor, and dividing the product by the total number of items included in that subscale. This provided two summary scores (medication concern and medication necessity), each with values ranging from 1 to 5. The BMQ has shown acceptable psychometric properties when used among people with diabetes in prior research. Horne et al. (1999) report good internal consistency in a sample of diabetic outpatients ($N = 99$), with Cronbach's alphas of .74 and .80 for the necessity and concern subscales respectively. However, items in the necessity subscale were not identical to those used in the present study. Evidence of discriminant validity has also been provided. Previous studies suggest people with diabetes have elevated scores on the BMQ-Specific necessity scale when compared with other illness groups (Horne et al., 1999). As shown in Table 1, both medication necessity and medication concern subscales showed good evidence of internal consistency in the present study (Cronbach's alphas = .97 and .94).

Socio-Medic Relationships

Two new measures were developed in the current study. These were designed to assess socio-medic relationships that may have a pertinent impact on diabetes self-management behaviour. Previous research has suggested that family relationships can act as a source of support, or conflict, for people with type 2 diabetes (Albright et al., 2001; Garay-Sevilla et al., 1995; Glasgow & Toobert, 1988; Samuel-Hodge et al., 2000; Tillotson & Smith, 1996; Wang & Fenske, 1996), and a family-centred approach

to diabetes care has been advocated (Fisher et al., 1998). In the current study diabetes-related family context was assessed using a new ten-item scale developed specifically for this project. This measure provides two summary scores; family support (six items), and family conflict (four items). The purpose of this instrument was to provide a concise, diabetes-specific assessment of (a) psychological support for self-management provided by the family network, and (b) emotional conflict over diabetes self-care within the family environment.

Although existing measures of family support with excellent psychometric properties are available (Sherbourne & Stewart, 1991), there are limited instruments specifically designed to assess family support for management of *type 2 diabetes*. A short measure that assessed both diabetes-related support and conflict in family relationships among adults with type 2 diabetes, was required for the present study. A suitable instrument was not found in a review of current literature. Consequently, a process of measure development and piloting was undertaken, as outlined in Appendix A. This provided 11 items for inclusion in the main study. These items can be viewed in Table 3. Responses were given on a five point likert scale: yes, always; yes, often; sometimes; no, not usually; no, never. In the present study, family was defined as 'anyone who you consider to be part of your immediate or extended family. This can include your spouse, partner, son/daughter, son/daughter-in-law, niece, nephew or grandchild'.

Preliminary data inspection showed suitability for factor analysis. The Kaiser-Meyer-Oklin value (.84) exceeded the recommend value of .6 (Tabachnick & Fidell, 2001), and Bartlett's Test of Sphericity reached statistical significance ($p < .001$). Eleven family context items were entered into a principal component analysis. Results revealed two components with eigenvalues greater than 1. These explained 33.8% and 20.7% of the total variance, respectively. Inspection of the scree plot showed a clear break after the second factor, suggesting it would be appropriate to retain the two-component solution. Varimax rotation was applied to aid interpretation; results are presented in Table 3. Items that loaded 0.50 or greater were interpreted as representing a particular factor. This produced two factors. Together these accounted for 54.5% of the total variance. All items loaded exclusively on to one of the two factors. The first factor in the rotated solution, labelled family support, consisted of six items. It explained 31.3% of the total variance, as shown in Table 3.

Table 3.

Principal Component Analysis of 11 Family Context Items Showing Cronbach's Alpha for Each Subscale (N = 480).

	Factor I	Factor II
<i>Family support ($\alpha = .84$)</i>		
I feel my family <u>understand</u> why <u>diet</u> is important to people with diabetes	.72	-.14
My family <u>encourage</u> me to get exercise and keep active	.70	.27
My family <u>encourage</u> me to eat foods that are healthy for my diabetes	.81	.17
I feel my family <u>understand</u> why <u>exercise</u> is important to people with diabetes	.84	.07
I feel my family <u>understand</u> why my diabetes <u>medicines</u> are important	.71	-.03
My family <u>support me emotionally</u> if I feel frustrated or down about my diabetes	.71	.09
<i>Family conflict ($\alpha = .75$)</i>		
My family <u>nag me</u> about taking my diabetes medications	.21	.67
My family <u>complain</u> about eating the kinds of foods that are good for people with diabetes	-.05	.73
My family <u>argue</u> with me about how I choose to take care of my diabetes	.14	.78
My family <u>hassle me</u> about getting more exercise	.23	.70
My family seem <u>embarrassed</u> about my diabetes*	-.18	.57
Variance explained (%)	31.3	23.3

*Denotes item not included in final family conflict subscale

The second factor contained five items and was labelled family conflict. This accounted for 23.3% of the total variance. The content of the two factors, as defined by the item loadings, supported the theoretically derived constructs labelled diabetes-related 'support' and 'conflict' that this measure was designed to assess. Further analysis of the conflict subscale highlighted one item, 'my family seem embarrassed about my diabetes', that did not fit well. This item had low correlations with other items in the conflict subscale (ranging from .18 to .32) and was the only item with an item-total correlation below .50 ($r = .32$). This item also exhibited low variance, and was subsequently removed from all further analyses. Ten items were retained for use in hypothesis testing. Eight items assessed psychological support and conflict across three core domains of self-management: diet (3 items); exercise (3 items); and medication use (2 items). Two additional items measured general psychological support ('my family support me emotionally if I feel frustrated or down about my diabetes') and conflict ('my family argue with me about how I choose to take care of my diabetes').

After reverse scoring all items, two summary scores were calculated. A family support score was computed by summing the six items that loaded on to factor I in Table 3, and dividing the product by six. This provided a final score ranging from 1 to 5, with higher values representing greater perceived family support for diabetes self-management. A family conflict score was computed by summing the first four items loading on to factor II in Table 3, and dividing the product by four to provide a final score ranging from 1 to 5. Higher values on this second summary score represented greater conflict with family members over diabetes self-care. The family support and family conflict subscales both showed good internal consistency (Cronbach's alphas = .84 and .75 respectively). A moderate to weak positive relationship was observed between the two subscales ($r = .21$, $p < .01$). This suggests they may be best treated as separate dimensions and should not be conceptualised as polar opposites of the same construct.

Previous research suggests the clinical partnership between patient and health professional can be an important determinant of health behaviour in chronic illness (DiNicola & DiMatteo, 1984; Glasgow et al., 2001; Gochman, 1997; Rose et al., 2002). Patient-provider relationship was therefore also assessed in the present study. The quality of this relationship, as seen through the patients' eyes, was measured using a

new 30-item instrument. Items selected for inclusion in the present study were developed through an extensive piloting process that involved a review of relevant literature, input from clinical and academic expertise, and feedback from people with diabetes. The pilot process also included consultation with a variety of cultural groups and incorporated both patient (tangata whaiora) and health professional (kai mahi) input into the development of this instrument. Further detail on the piloting process is provided in Appendix A. The pilot studies were used to identify items for inclusion in the present study. In the present study, a principal component analysis was used to further refine item content, and develop summary scores that could be used to assess two dimensions of the patient-provider relationship (support and conflict).

As shown in Appendix D, question (9) b of the mailed survey asked about patient-reported experiences with diabetes health professionals. First, participants nominated their main diabetes health care provider, described in this study as 'the one health professional you see most often about your diabetes'. Respondents were then presented with statements that provided examples of supportive clinical partnerships, e.g., 'I have been involved in decisions about my diabetes care as much as I have wanted to', and statements that represent experiences of conflict in the patient-provider relationship, e.g., 'Sometimes he/she ignores what I have to say'. Responses to each statement were given using a four-item likert scale: yes, definitely; yes, sort of; no, not really; no, not at all. As shown in Appendix D, positively worded items ($N = 21$) and negatively worded items ($N = 13$) were interspersed, and presented together to discourage response set bias.

Statements were designed to tap into the dimensions of patient experience that previous research suggests are most important, and the Picker Institute framework was used to guide initial item content. However, this was moderated to reflect the specific character of the research project; i.e. diabetes, in Aotearoa/New Zealand. Chapter 1 emphasised that diabetes can have a significant physical and emotional impact. Dealing with this represents a challenge to both patient and health professional. Thus items included both medically orientated questions, e.g., 'he/she has explained how I should take care of my feet in a way I can understand', and statements designed to assess holistic aspects of health care delivery such as trust, rapport, and alleviation of diabetes-related anxieties. Seven items in question (9) b were not designed to assess patient-provider support or conflict, rather they sought feedback on: behavioural

intentions (to return/recommend main diabetes care provider); patient knowledge of available services (free annual 'diabetes check' and retinal screening); and education about self-management tasks (how to use a blood glucose metre, what to do about medication in the advent of non-diabetes illness).

A principal component analysis (PCA) was used to identify underlying factors and final item content for computation of summary scores. First, the data were inspected for evidence of latent structure. A correlation matrix revealed many coefficients exceeding .3, and the Kaiser-Meyer-Olkin measure of sampling adequacy (.92) well exceeded the recommended minimum value of .6 (Tabachnick & Fidell, 2001). Bartlett's Test of Sphericity was statistically significant ($p < .001$). Thirty-four patient-provider relationship items were then entered into a PCA. Using a selection criterion of eigenvalues greater than 1, seven components were identified. These explained 31.4%, 10.2%, 5.4%, 4.1%, 3.9%, 3.2%, and 3.0% of the total variance, respectively. Varimax rotation was performed to assist interpretation. This produced seven factors that, together, explained 61% of the total variance. Results are presented in Table 4. Items that loaded .50 or greater were interpreted as representing a particular factor. Four items (14, 15, 16 and 36) did not load onto any factor, and these were dropped from further analyses. Thirty items were retained. All items loaded exclusively ($>.50$) on to one of the seven factors. Each factor was comprised solely of either support or conflict items, no factor contained both.

The first factor, labelled 'communication barriers', contained five items that explained 11.1% of variance in the rotated PCA. These items represent conflict between patient and health professional, e.g., 'When I have important questions about diabetes, it is hard to get answers that I can understand'; 'Sometimes I feel I am left out of important decisions about my diabetes care'. Endorsement indicated a communication breakdown between patient and provider, and that participants felt they were left out of important decisions. The second factor contained seven items. Labelled 'clinical partnership', it explained 10.5% of the total variance. Item content was positively worded, and focused on patient involvement in clinical decision-making, respect for patient choices, and clear communication. Example items include, 'He/she involves me in decisions about my diabetes care, we make the choices together'; 'He/she gives me enough time to say everything I want to, and ask all my questions'.

Table 4.

Principal Component Analysis of 34 Patient-Provider Relationship Items and Cronbach's Alpha for Each Subscale (N = 472).

	Factors						
	I	II	III	IV	V	VI	VII
<i>Communication Barriers</i> ($\alpha = .79$)							
Sometimes I feel I am <u>left out</u> of important decisions about my diabetes care	-.73	-.20	-.15	-.07	-.16	-.07	-.20
Sometimes my family are <u>left out</u> of important diabetes decisions when I would want them to be involved	.74	.02	-.07	-.09	-.15	.01	.15
When I have important questions about diabetes, it is <u>hard</u> to get answers that I <u>can understand</u>	.62	-.26	-.03	-.06	-.15	.17	.26
Language barriers make it <u>difficult</u> for this person and I to understand each other	.60	-.05	-.10	.09	-.12	.10	-.08
When planning diet or exercise changes he/she set goals that are just <u>too hard</u> for me	.64	-.14	.01	-.03	.13	.20	.08
<i>Clinical Partnership</i> ($\alpha = .84$)							
He/she <u>involves me in decisions</u> about my diabetes care, we make the choices together	-.10	.72	.25	.14	.09	-.03	-.06
I have been <u>involved in decisions</u> about my diabetes care as much as I have wanted to	-.18	.61	.32	.18	.09	-.21	-.02
He/she helps me feel encouraged and <u>motivated to take action</u> to care for my own diabetes	-.13	.58	.35	.18	.25	-.10	-.19
He/she shows <u>respect for my own choices</u> about how I manage my diabetes	-.19	.57	.22	.25	.10	-.22	.01
He/she has explained how I should <u>take care of my feet</u> in a way I <u>can understand</u>	-.04	.55	.04	.10	.43	.01	-.22
When I have tests for my diabetes, he/she explains the results in a way that is <u>easy to understand</u>	-.12	.53	.10	.21	.26	-.35	.04
He/she gives me <u>enough time</u> to say everything I want to, and ask all my questions	-.09	.54	.21	.15	.18	-.43	-.01
<i>Humaneness</i> ($\alpha = .84$)							
This person is <u>helpful and friendly</u> to me	-.10	.22	.82	.07	.14	-.13	-.04
He/she seems to <u>care about me</u> as a person, not just my diabetes	-.10	.23	.81	.23	.02	-.10	-.04
I could <u>trust</u> this person with personal information about me or my family	-.05	.17	.80	.02	.13	-.12	-.11
He/she shows <u>respect for my own personal</u> or <u>cultural</u> beliefs and values	-.15	.22	.61	.18	.35	-.08	-.10

Table 4. (Continued)

	Factors						
	I	II	III	IV	V	VI	VII
<i>Holistic Care</i> ($\alpha = .80$)							
He/she <u>asks if</u> I have any questions or <u>worries</u> about the effect of diabetes on my <u>family life</u> or relationships	.02	.14	.11	.81	.14	-.04	.01
He/she <u>asks if</u> I have any questions or <u>worries</u> about the effect diabetes might have on <u>my body</u> (e.g., eyes or feet)	.03	.22	.11	.56	.40	-.23	-.12
He/she <u>asks if</u> I have any questions or <u>worries</u> about the <u>financial cost</u> of diabetes (e.g., medicines or visits to specialists)	.08	.02	-.03	.74	.06	-.24	-.03
When planning diet or exercise changes, he/she sets goals that are <u>realistic for me</u>	.03	.14	.25	.55	.32	-.18	-.15
He/she <u>offers information</u> about diabetes for me to <u>give to family/close friends</u>	-.14	.19	.16	.66	.08	.20	-.04
He/she <u>asks about</u> my family, social and financial <u>commitments</u> when making suggestions about how I should take care of my diabetes	-.09	.21	.10	.62	-.6	.25	-.02
<i>Health Promotion</i> ($\alpha = .81$)							
He/she gives advice about how to <u>prevent</u> my diabetes from becoming worse	-.18	.24	.19	.25	.75	-.06	-.01
He/she gives advice on how to control my diabetes and <u>stay healthy</u> in the future	-.18	.22	.27	.19	.76	-.11	-.02
He/she has explained how <u>what I eat</u> can affect my diabetes in a way <u>I can understand</u>	-.15	.41	.11	.06	.59	.02	-.21
<i>Rapport Barrier</i> ($\alpha = .73$)							
Sometimes he/she ignores what I have to say	.24	-.25	-.13	-.08	-.04	.61	.17
At times he/she talks in front of me <u>as if I wasn't there</u>	.32	-.08	-.10	.14	-.11	.69	.09
At times he/she is <u>too busy</u> to listen properly to what I had to say	.43	-.25	-.20	-.09	-.05	.51	.17
<i>Holistic Barrier</i> ($\alpha = .90$)							
Sometimes I feel he/she <u>ignores</u> the effect diabetes can have on your moods and feelings	.29	-.12	-.14	-.07	-.10	.72	.84
Sometimes I feel he/she <u>ignores</u> the effect diabetes can have on my family life and relationships	.33	-.06	-.10	-.11	-.12	.18	.81
<i>Items removed from further analyses</i>							
It is <u>hard</u> to get clear information on what things people with diabetes should eat	.48	-.23	-.05	.12	-.06	.31	.24
He/she uses too many <u>long medical words</u> and <u>technical terms</u> when explaining what diabetes is	.49	.13	-.10	.01	-.40	.27	.09
He/she <u>ignores my opinions</u> about what works best to manage my own diabetes	.44	-.18	-.15	-.14	.02	.47	.25
He/she shows <u>respect for my choices</u> about how much I want my family to know or be involved in my diabetes care	-.20	.37	.38	.28	.27	.01	-.10
Variance explained (%)	11.1	10.5	9.7	9.5	7.9	7.0	5.6

The third factor in the rotated solution explained 9.7% of variance, and was labelled 'humaneness'. It contained four positively worded items reflecting rapport, trust, respect and caring. Example items include, 'I could trust this person with personal information about me or my family'; 'He/she shows respect for my own personal or cultural beliefs and values'; and 'He/she seems to care about me as a person, not just my diabetes'. The fourth factor included six items that asked about provision of holistic care, e.g., attention to the emotional and familial impact of diabetes. Items focused on exploration of diabetes-related anxiety (e.g., 'He/she asks if I have any questions or worries about the effect diabetes might have my family life or relationships'), and encouragement of family involvement (e.g., 'He/she offers information about diabetes for me to give to family/close friends'). This factor was labelled 'holistic care'. It explained 9.5% of the total variance.

Three items loaded onto the fifth factor, labelled 'health promotion'. Item content focused on secondary prevention through avoidance of diabetes complications (e.g., 'He/she gives advice on how to prevent my diabetes from becoming worse'). Three negative items comprised the sixth factor: 'Sometimes he/she ignores what I have to say'; 'At times he/she talks in front of me as if I wasn't there'; and 'At times he/she is too busy to listen properly to what I have to say'. This factor was labelled 'rapport barriers'. The seventh factor included two negative items showing a lack of attention by health professionals to the impact of diabetes on emotional wellbeing, and interpersonal relationships. This was labelled 'holistic barriers'. As shown in Table 4, factors 5, 6, and 7 explained 7.9%, 7%, and 5.6% of the total variance respectively.

Items loading onto each factor were used to produce seven subscales; four assessed patient-provider support, and three measured patient-provider conflict, with item content outlined previously in the description of each factor. First, the scoring for all 30 items was reversed. Subscale scores were then computed by calculating the average score across items loading on to each factor, to provide a final score ranging from 1 to 4 for each subscale. Higher values indicated either greater support, or more conflict, depending on the type of subscale.

The seven subscales showed good internal consistency (Cronbach's alphas = .73 to .90) as evident in Table 5. Two summary scores were also computed. A patient-provider support score was calculated by summing the 20 positively worded items

loading onto the four support subscales (clinical partnership, humaneness, holistic care, and health promotion), and dividing the product by 20. This provided a score ranging from 1 to 4, with higher scores representing a more supportive patient-provider relationship, as seen from the participant's point of view. This scale showed excellent reliability (Cronbach's alpha = .90). A patient-provider conflict score was computed by summing the 10 negatively worded items loading onto the three conflict subscales (communication barriers, rapport barriers, and holistic barriers), and dividing by 10. This provided an overall conflict score ranging from 1 to 4, with higher scores representing greater patient-reported conflict with diabetes health professionals (Cronbach's alpha = .87). A moderate negative relationship was observed between the two subscales ($r = -.46, p < .001$).

Table 5.

Alpha Coefficients Showing Internal Consistency for New Measures and Associated Subscales.

	Cronbach's Alpha
<i>Family Context</i>	
Support summary score ($N = 6$)	.84
Conflict summary score ($N = 4$)	.75
<i>Patient-Provider Relationship</i>	
Communication barriers ($N = 5$)	.79
Clinical partnership ($N = 7$)	.84
Humaneness ($N = 4$)	.85
Holistic care ($N = 6$)	.80
Health promotion ($N = 3$)	.81
Rapport barriers ($N = 3$)	.73
Holistic barriers ($N = 2$)	.90
Support summary score ($N = 20$)	.90
Conflict summary score ($N = 10$)	.87

Diabetes Self-Care

Diabetes self-care was measured using the revised Summary of Diabetes Self-Care Activities Questionnaire (SDSCA). This brief self-report instrument contains eleven core items covering five areas of self-care: diet, exercise, blood glucose testing, foot care and smoking behaviour (Toobert et al., 2000). All items are referenced to the preceding 7 days, with responses recorded on an eight point scale from '0 days' to '7 days'. The exception is item 11, which requests information on tobacco smoking status (recorded as yes/no), and the number of cigarettes smoked on an average day. Subscale scores were computed by calculating the average score across items included in each scale (after reversal of scoring for item four in the eating patterns scale), as per instructions provided by the authors of this measure (Toobert et al., 2000). These subscales, based on reported frequency of diabetes self-care, were labelled diet, exercise, blood glucose testing, and foot care. Scores on each subscale ranged from 1 to 8, with higher scores representing better diabetes self-care. A composite smoking score was computed by adding smoking status (0 = non smoker, 1 = smoker) to the number of cigarettes smoked on an average day. In previous research the SDSCA has shown acceptable psychometric properties. A review of seven studies incorporating data from 1,988 adults with diabetes concluded that the SDSCA shows adequate internal and test-retest reliability, evidence of convergent validity, and sensitivity to change (Toobert et al., 2000). Recent New Zealand research among Tongan and European persons with diabetes showed moderate to good internal reliability across the diet, glucose testing and exercise dimensions of the SDSCA (Barnes, 2000). In the present study high levels of internal consistency were observed among the glucose testing and diet subscales (Cronbach's alphas = .91 and .75 respectively). As can be seen in Table 1, moderate reliability was evident in the exercise and foot care subscales.

Medication Adherence

Concordance with prescribed medical regimen was assessed using the Medication Adherence Report Scale (MARS). This instrument is designed to elicit self-reported medication adherence, and has been used in a number of previous studies with chronic illness groups (Barnes, 2000; Byrne et al., 2005; Horne & Weinman, 2002). Most items are negatively worded, and thus the measure is orientated towards detecting frequency

of non-adherence. Research using the MARS has often adapted item content to align with treatments used for the specific illness under investigation. Therefore, variants of the MARS are present in the literature. These include a five-item MARS (coronary heart disease), nine-item MARS (asthma), and ten-item MARS (type 2 diabetes). Horne and Weinman (2002) used a nine-item MARS in a study designed to explain non-adherence to preventer medication in people with asthma. This measure was shown to have good internal reliability ($\alpha = .85$). In a New Zealand study focusing on cultural perceptions of diabetes, Barnes (2000) reports using a ten-item MARS. This included eight items from the original MARS, and two additional culture-orientated items. The ten-item instrument showed good internal consistency among Tongan participants, but poor reliability among the New Zealand European group (Cronbach's alphas = .81 and .35 respectively).

In the present study, eight items were used to assess self-reported adherence to prescribed diabetes medication. These are shown in Appendix D, question 14) c. All items had been used in previous New Zealand research among people with type 2 diabetes (Barnes, 2000), and six items were identical to those used by Horne and Weinman (2002). As recommended by the authors of this measure, questions were prefaced by an explanatory statement designed to reassure the respondent that all answers were confidential to the researchers, and would not be seen by any diabetes health professional involved in their care. Respondents were instructed that, in this survey, the term 'diabetes medicines' included both tablets and insulin. Responses were provided on a five-point scale: always, often, sometimes, rarely, never. After reverse scoring one item ('I use my diabetes medications regularly every day'), a composite adherence score was computed by summing all items and dividing by the total number of items, to give a final score with a range from 1 to 5. Higher scores indicated greater adherence to the prescribed medication regime. This measure demonstrated moderate internal consistency (Cronbach's $\alpha = .66$). Further investigation revealed one item that did not appear to fit well with others in this scale (item-total correlation = .09). Internal consistency improved markedly when this item, 'I use my diabetes medicines only when I need to', was removed (Cronbach's $\alpha = .82$). Thus a new composite adherence score was computed using seven of the MARS items. This was used in testing of hypotheses.

Socio-demographic measures

Information was sought on participants' age, gender, living arrangements, ethnic affiliation and highest educational qualification. These questions were modelled on those included in the 2001 New Zealand Census. Participants were also asked to indicate if they had medical insurance, or a community services card.

Physician-assessed health status

A medical database review was used to record length of diagnosis, current diabetes treatments, and HbA_{1c} for all persons invited to take part in this study. Total glycated haemoglobin A_{1c} (HbA_{1c}) is used routinely in clinical practice as an index of glycaemic control over the past 6 to 8 weeks (Harmel & Mathur, 2004). It is a strong predictor of diabetes complications and, through this, of loss of physical functioning due to diabetes. Thus HbA_{1c} was used as a condition specific measure of physical wellbeing in this study. In addition to these data, extended clinical notes held on the WRDT database were provided to the researcher for 615 cases, with participants' written permission. Diastolic blood pressure, creatinine, body mass index, tobacco smoking status, presence of sexual problems, peripheral vascular disease, and peripheral sensory neuropathy were recorded from clinical notes where available. All medical data provided to the researcher had been collected by diabetes physicians during the 18 months preceding the onset of survey data collection.

CHAPTER 6
RESULTS

CHAPTER OVERVIEW

Chapter 6 presents results from the current research. Empirical findings are preceded by a summary of the overarching analysis strategy, and explanation of the data screening process. The research sample will then be described, and a comparison of respondents and non-respondents undertaken. As delineated in chapter 4, the first objective is to generate a descriptive account of relationships between variables of primary research interest. Within this goal, the first aim is to describe bivariate associations between socio-medical context, illness/treatment representations, self-care behaviour, and illness outcomes. The second aim is to provide a descriptive account of physical and psychological wellbeing among people with type 2 diabetes in New Zealand. The second objective is to test a priori hypotheses, which have been explicated in chapter 4. Multivariate analyses will be employed for this purpose. Results from hypothesis testing constitute the second component in the current chapter. The seven main hypotheses are re-presented, accompanied by a description of research findings for each. A concise synopsis of reported results is provided at the conclusion of chapter 6. Chapter 7 will lead on from this, by appraising empirical findings and discussing the implications of the results presented in chapter 6.

ANALYSES

SPSS/PC version 11.5 was used for all statistical analyses. Three stages of analysis were undertaken. First, data were screened for inaccurate entry, missing values and fit with the assumptions of multivariate analyses. Sample descriptors were then computed. Chi-squared tests and a One Way Analysis of Variance (ANOVA) were used to compare respondents with non-respondents in this study. Second, bivariate relationships between key variables were presented and levels of physical and emotional wellbeing among the sample were examined. ANOVAs were used to determine whether group differences in wellbeing, beliefs about medication, or treatment adherence existed. Third, multivariate analyses were used to investigate the relationships between study variables. Testing of hypotheses, as specified in chapter 4, was completed. Alpha was set at .05 unless otherwise stated. Two-tailed tests were used for all analyses.

DATA SCREENING

Before the main analyses data were screened for inaccurate entry and missing values, and SPSS Missing Value Analysis (MVA) was used to assess for patterns among missing data. In the current study, patterns shown to affect more than 5% of data were considered worthy of further investigation (Tabachnick & Fidell, 2001). Using this criterion one non-random pattern of missing data was observed, affecting 84 cases (13.7%) of the sample. Three variables were identified: medication concern, medication necessity, and self-reported medication adherence. The pattern is explainable when diabetes treatments are considered. Data from medical records showed 30% of respondents had not been prescribed any oral medication or insulin for their diabetes. It makes sense that these people could not answer questions on diabetes medication use. When those without oral medication/insulin were removed and a second MVA was run, this pattern disappeared.

Evidence was considered for an association between age, gender or ethnicity and any pattern of missing data greater than 1%. None was present. Tabachnick and Fidell (2001) emphasize that non-random missing data are a serious problem. When taking into account response differences due to medical treatment, there was minimal evidence of non-random missing values in this study.

Missing Value Analysis (MVA) was also used to determine the amount of missing data in individual variables. Tabachnick and Fidell (2001) state that "there are as yet no firm guidelines for how much missing data can be tolerated for a sample of a given size" (p. 59). In the current study, a benchmark of 5% was selected. A number of summary scores exhibited missing data greater than the stated criterion, which is partially explained by the composite nature of these variables. Participant response fatigue may also have been a contributing factor given the questionnaire length.

As noted by Spicer (2005), any form of imputation represents some degree of compromise to the integrity of the data set. A conservative approach to missing data was taken in the present study. Summary scores were recomputed for all composite variables where missing data was greater than 5%, including psychological distress, medication adherence, self-care behaviour, family support/conflict, patient-provider support/conflict, medication concern and necessity. A new score was computed for

each participant who answered more than half, but not all, the items in a given measure. This was simply a mean score based on the number of questions answered, and was directly comparable with scores computed for those participants who answered all questions.

This action reduced levels of missing data considerably. As a general guideline, missing data below 5% is preferable (Tabachnick & Fidell, 2001). However, the amount of missing data is less important than the pattern; values missing in a non-random pattern present a serious problem even in small numbers. Data missing at random in a large data set pose a less serious problem. In the present study missing data below 7% were accepted for summary scores comprised of five or more items. This decision represents a compromise between ideal research practice and the response burden imposed by data collection in the present study, namely, a lengthy questionnaire survey that contained multiple items completed using a repetitive likert response format. Feedback from pilot participants highlighted this problem, as outlined in Appendix A.

Three groups of variables exceeded the threshold for acceptable levels of missing data set in the present study. Self-reported medication adherence, medication necessity, and medication concern continued to exhibit high levels of missing data (24.7–28.3%). This was considered acceptable because approximately one third (30.2%) of participants had not been prescribed oral medication or insulin to treat their diabetes, as discussed previously. Family conflict and family support showed 8.8% and 9.6% missing data, respectively. This was explainable when instructions given in the questionnaire were considered. Participants were requested to skip this measure if they did not have regular contact with any family member. It is not appropriate to assume respondents live near relatives or choose to maintain a high degree of familial contact. Thus reasonable explanations were available for missing data in both medication and family context subscales. These were retained for use in further analyses.

Unacceptable levels of missing data (10.2–17.6%) were observed among all five 'cause' subscales in the Illness Perception Questionnaire (IPQ-R). No clear explanation was evident. Because it was difficult to identify the causal mechanism responsible for producing such high levels of missing data among the causal items,

and therefore impossible to rule out the proposition that systematic bias was the reason for the high level of missing data, prudent research practice suggests these variables are unsuitable for testing of hypotheses. Consequently the five 'cause' subscales were removed from all further analyses.

The fit between data and the assumptions of multivariate analyses was examined. Transformations were undertaken to normalise variable distributions. Moderate positive skew was observed in eight variables; HbA_{1c}, diabetes-related psychological distress, smoking status, family conflict, patient-provider conflict, diabetes identity, diabetes concern, and medication concern. Square root transformation was used successfully to reduce skew among these variables. Length of diabetes diagnosis showed severe positive skew. Logarithmic transformation reduced this considerably. Family support, patient-provider support, medication necessity and health behaviour exhibited moderate negative skew. Three illness-perception subscales, timeline acute/chronic, personal control and diabetes coherence, also showed negative skew. Reflection and square root transformation was used to reduce skew in these variables. Logarithmic transformation following reflection was effective in reducing severe negative skew in medication adherence. After transformation, all variables showed approximately normal distributions.

The presence of multivariate outliers was assessed by requesting mahalanobis distances in a preliminary run of regression analyses for hypotheses one and two. Results revealed five cases that met the $p < .001$ criterion for critical χ^2 values. After deletion of these cases no further multivariate outliers were identified. The remaining 610 cases were retained for use in hypothesis testing. Normal probability and residual plots were used to confirm multivariate normality, linearity, homoscedasticity and independence of residuals.

When negatively skewed variables are reflected before transformation, interpretation of the relationship direction becomes counterintuitive. Thus all descriptive statistics present untransformed means and standard deviations for ease of interpretation. Tests of significance are undertaken on transformed variables and reported as such, except when variables have been reflected. In this instance, the relationship direction has been reversed for clarity of interpretation. Cases with missing values were deleted in

all analyses. Thus the number of cases will vary across individual analyses and N is reported separately for each.

SAMPLE DESCRIPTION

Socio-Demographic Characteristics and Self-Reported Health

Of the 629 completed questionnaires that were returned, 615 respondents gave permission for their medical records to be released to the researcher in non-identifiable form. After the deletion of five cases previously identified as multivariate outliers, 610 cases remained. All descriptions of the sample are referenced to this group ($N = 610$) unless otherwise stated.

Forty-seven percent of respondents were female. The mean age of participants was 63 years ($SD = 11.6$) with a range from 27 to 90. Fifty-seven percent self-identified as New Zealand European/Pakeha. Thirty percent identified as Māori. Pacific peoples (participants whose cultural origins are located in the Pacific Island nations surrounding New Zealand) comprised 6.4% of the respondents in this study. Data released by the Ministry of Health forecast that, by 2006, Māori and Pacific peoples will represent 25% and 9% of the New Zealand diabetes population, respectively (PricewaterhouseCoopers, 2001). Thus the proportions of Māori and people of Pacific origin who took part in this study are an approximate match with those reported for the national diabetes population.

While 13% of participants had completed University study, 33% reported no school qualification. Health complications that often result from diabetes were present among the sample: 14.9% had received cataract surgery or laser treatment, and 3.6% had a lower-extremity amputation. In addition to diabetes, 81% of respondents reported at least one other comorbid health problem, with 15% reporting previous diagnosis of depression by a medical professional. The majority of participants (59.3%) preferred a physician in the community (general practitioner) as the main provider of health services for their diabetes. Further demographic and self-report health information for the sample is provided in Table 6.

Table 6

Summary of Demographics and Self-Reported Health Status for Respondents (N = 610)

	Number of Respondents	Percentage of Respondents
Gender		
Female	290	47.5
Male	320	52.5
Age (Years)		
<40	16	2.6
40–59	206	33.8
60–79	318	52.1
≥80	49	8.0
Ethnicity		
NZ European	349	57.2
Māori	186	30.5
Pacific (e.g., Samoan, Tongan)	39	6.4
Other	36	5.9
Living Arrangements		
Spouse/partner	386	63.3
Extended family or relatives	83	13.6
Friends	8	1.3
Alone	136	22.3
Highest Educational Qualification		
No school qualification	201	33.0
Secondary school qualification	159	26.1
Trade certificate/professional diploma	87	14.3
University qualification	82	13.4
Other	38	6.2
Medical Insurance		
Yes	182	29.8
No	402	65.9
Community Services Card		
Yes	324	53.1
No	260	42.6
Preferred Main Diabetes Provider		
General practitioner	362	59.3
Diabetes physician specialist	32	5.2
General practice nurse	39	6.4
Diabetes nurse specialist	53	8.7
Diabetes educator	14	2.3
Māori or Pacific health worker	16	2.6
Diabetes Operations/Procedures		
Cataract surgery or laser treatment	91	14.9
Lower-extremity amputation	22	3.6
Coronary surgery	43	7.0
Renal CAPD, Hemo CAPD or renal transplant	8	1.3
Comorbid Health Problems		
Cardiovascular problems	401	65.4
Cancer	41	6.7
Arthritis/Rheumatism	194	31.8
Breathing problems	159	26.1
Memory loss	49	8.0
Depression	91	14.9

Medical Descriptors

Table 7 provides a clinical description of the sample. Individual medical data were collected by physicians as part of the national 'Get Checked' diabetes programme, and was released to the researcher, in non-identifiable form, with participants' permission. Data were screened for inaccurate entry before collation of clinical descriptors. On average, length of diagnosis with diabetes was 8.1 years ($SD = 5.8$), with a range from 4 months to 33 years. As shown in Table 7, 9.2% of this group used insulin to treat their diabetes. Forty-two percent had an HbA_{1c} below 7%. The average HbA_{1c} was 7.5% ($SD = 1.5$), with a range from 4.5 to 13.5. Of these 610 people, 325 (53.3%) were obese (body mass index ≥ 30). More than half were past or present tobacco smokers. Information on the risk of a cardiovascular (CV) event was available for 370 people. In this group 194 (52.4%) had a 5-year CV risk greater than the target for people with type 2 diabetes (<15%) set by the New Zealand Best Practice Evidence-based Guidelines (New Zealand Guidelines Group, 2003).

Comparison of Respondents with Non-Respondents

One-way Analysis of Variance and chi-square tests were used to determine whether respondents differed significantly from non-respondents. Four socio-demographic and medical variables were considered: ethnicity, gender, length of diabetes diagnosis, and HbA_{1c}. Chi-square tests showed there was no significant difference in gender between respondents and non-respondents.

However, a significant difference was observed for ethnicity, $\chi^2(3, N = 1275) = 59.83, p < .001$. Those who completed the questionnaire were more likely to be of New Zealand European ethnicity. Non-response rates differed noticeably across ethnic groupings. These were 41.1%, 54.2% and 73.4% for New Zealand European, Māori and Pacific peoples, respectively. This was anticipated as the primary data collection method, mailed questionnaire survey, is not a preferred mode of research interaction for many people from Māori and Pacific cultural groups (Glover, 2002). Completion of the questionnaire is likely to have been burdensome to those for whom English is a second language. This may have contributed to the high non-response rate among Pacific persons.

Table 7

Summary of Physician Assessed Clinical Characteristics for Consenting Respondents (N = 610)

	Number of Respondents	Percentage of Respondents
Length of Diagnosis (Years)		
2≥	66	10.8
3–5	194	31.8
6–10	183	30.0
≥11	166	27.2
Current Diabetes Treatments		
Diet and exercise only	184	30.2
Oral medications	397	65.1
ACE inhibitors	300	49.2
Statins	151	24.8
Insulin	56	9.2
Haemoglobin A _{1c}		
<7%	257	42.1
7–8%	194	31.8
8.1–9%	79	13
>9%	79	13
Body Mass Index		
>18.5 (Underweight)	8	1.3
18.5–24.99 (Healthy)	72	11.8
25–30 (Overweight)	198	32.5
≥30 (Obese)	325	53.3
5-Year Cardiovascular Event Risk *		
<10% (Mild)	91	14.9
10.1–15% (Moderate)	85	13.9
15.1–20% (High)	77	12.6
>20% (Very high)	117	19.2
Tobacco Smoking Status		
Current smoker	91	14.9
Past smoker	225	36.9
Never smoked	294	48.2

*Cardiovascular event is defined as: myocardial infarction, angina, ischaemic stroke, transient ischaemic attack or peripheral vascular disease.

Note: Summation of variables categories does not equal 100% in all instances due to missing data.

Analysis of variance showed no significant difference in response for length of diabetes diagnosis. A significant difference between respondents and non-respondents was present for HbA_{1c}, $F(1,1273) = 13.67$, $p < .001$. On average, non-respondents had a higher HbA_{1c} ($M = 7.79$, $SD = 1.67$) than respondents ($M = 7.45$, $SD = 1.52$), representing worse metabolic control.

BIVARIATE RELATIONSHIPS BETWEEN SOCIO-MEDIC CONTEXT, ILLNESS/TREATMENT REPRESENTATIONS AND ILLNESS OUTCOMES

The first aim explicated in chapter 4 was to examine the data for evidence of associations between socio-medic context, illness/treatment representations, and illness outcomes. Bivariate correlations were used to explore the relationships between age, illness duration, socio-medic context and illness/treatment representations, and through this identify factors that were associated with differences in the way people see diabetes or its treatments. Pearsons r correlations are reported in Table 8. Connections between illness and treatment perceptions, and emotional and cognitive representations, were examined. Attention was also given to associations between psychosocial factors, health behaviour, and wellbeing among people with type 2 diabetes. These bivariate relationships are presented in Table 9. As stated previously, six subscales were reflected during the transformation process. Reported correlation coefficients for these variables are reversed in Tables 8 and 9 for ease of interpretation.

Demographic and Socio-Medic Correlates of Illness and Treatment Representations

Results showed significant relationships between age, illness duration, socio-medic context, and illness/treatment representations. Six demographic and socio-medic context variables are included in Table 8. Among these, patient-provider conflict was the most consistent associate across the eight illness representation subscales. This variable was the strongest correlate of timeline acute/chronic, timeline cyclical, personal control, diabetes coherence, and diabetes concern ($r = -.20$ to $-.37$). Age was the strongest associate of consequences, followed closely by family conflict, and patient-provider conflict ($r = .19$ to $-.21$). Patient-provider support was the variable that showed the strongest relationship with treatment control ($r = .18$), while family conflict ($r = .22$), patient-provider conflict ($r = .21$), and age ($r = -.21$) had the strongest associations with diabetes identity. Among the six demographic and socio-medic variables included in Table 8, the strongest associate of medication necessity was length of diabetes diagnosis ($r = -.24$). The strongest relationships for medication concern were those observed with patient-provider conflict ($r = .43$) and family conflict ($r = .30$). To summarize, Table 8 shows evidence of significant relationships between

age, illness duration, socio-medic context, and illness/treatment representations. Hypothesis three will examine the relationships between socio-medic context and illness/treatment representations in further detail.

Relationships between Illness and Treatment Representations

Results showed evidence of connections between illness representations and treatment representations (measured using the IPQ-R and BMQ, respectively). As shown in Table 8, medication concern was associated with all eight subscales from the IPQ-R. Higher medication concern was linked to higher scores on timeline cyclical, consequences, diabetes concern, and diabetes identity ($r = .27$ to $.58$), and lower scores on timeline acute/chronic, personal control, treatment control, and diabetes coherence ($r = -.12$ to $-.45$). Correlations between medication necessity and illness representations were of a smaller magnitude ($r = .10$ to $.28$), and were only observed among four of the eight IPQ-R subscales (timeline acute/chronic, consequences, personal control, and treatment control)

Relationships between Cognitive and Emotional Representations

Significant bivariate relationships were observed between the emotional illness representation subscale, labelled diabetes concern, and all other dimensions of the IPQ-R. As shown in Table 8, diabetes concern had a moderate positive relationship with timeline cyclical, consequences, and diabetes identity ($r = .39$ to $.58$). Diabetes concern also had a moderate negative relationship with diabetes coherence ($r = -.47$), and weak negative relationships with treatment control, personal control, and timeline acute/chronic ($r = -.11$ to $-.19$). While results show evidence of a connection between cognitive and affective representations of diabetes, no significant association was observed between perceptions of medication concern and medication necessity.

Associations between Psychosocial Variables and Self-Care Behaviours

A second goal was to examine any associations between psychosocial factors, health behaviours, and wellbeing among people with type 2 diabetes. Bivariate relationships are reported in Table 9. Correlates of diabetes self-care behaviours were examined first. Four behaviours were included: self-reported adherence to prescribed diabetes

medication(s), blood glucose testing, exercise self-care, and dietary self-care. Greater age was linked to higher medication adherence ($r = .21$), and better dietary habits ($r = .31$). Illness duration showed a weak positive relationship with medication adherence and glucose testing ($r = .10$ and $.15$, respectively). Socio-medic variables showed evidence of significant associations with some aspects of self-care behaviour. Family conflict and patient-provider conflict were related to lower medication adherence ($r = -.19$ and $-.22$, respectively); socio-medic support was not associated with medication use. None of the four socio-medic variables showed a reliable relationship with blood glucose testing; however, family support, family conflict, patient-provider support, and patient-provider conflict each showed a significant association with exercise habits and dietary patterns. The direction of observed associations was such that greater support and lower conflict were linked to more active engagement in diabetes self-care activities.

Connections between views about diabetes, diabetes treatments, and health behaviour were also present. Each of the ten illness and treatment representation variables included in Table 9 showed a significant relationship with medication adherence. The strongest correlate of adherence was medication concern ($r = -.32$). Medication necessity also showed a significant relationship with medication adherence ($r = .22$). Relationships were in the predicted direction with lower concern about taking medication, and higher belief in the need to take it, both associated with greater adherence. Three illness/treatment variables – timeline cyclical, consequences, and medication necessity – showed a significant positive relationship with blood glucose testing. Of the ten illness/treatment variables included within this study, only one showed a significant correlation with exercise self-care. The direction of the observed relationship indicates the perception that diabetes is understandable (high coherence) is linked to greater levels of exercise.

In contrast, nine illness/treatment representations showed significant relationships with dietary self-care behaviour. As evident in Table 9, greater personal control, greater treatment control, a stronger belief in the need for medication, and a perception that diabetes is comprehensible were each associated with better dietary self-management. Conversely, greater worry about diabetes, higher concern about diabetes treatments, stronger diabetes identity, strong belief that diabetes has serious life consequences,

and a perception that diabetes symptoms are cyclical, were each related to poor dietary self-care.

Associations between Psychosocial Variables and Illness Outcomes

Correlates of physical wellbeing were assessed in two ways. Attention was first given to variables that showed a relationship with general physical functioning, measured by the SF-12® PCS. Second, associates of diabetes-specific physical wellbeing (Haemoglobin A_{1c}) were examined. General physical functioning was associated with seven demographic and psychosocial variables in this study ($r = -.10$ to $-.25$). Better physical function was associated with lower age, shorter illness duration, and lower patient-provider conflict. This variable also showed a weak relationship with four illness representation subscales: timeline cyclical, consequences, personal control and diabetes coherence.

Haemoglobin A_{1c} showed significant relationships with twelve of the sixteen demographic and psychosocial variables in Table 9. Higher HbA_{1c} was associated with greater illness duration, lower age, conflict with family over diabetes, and conflict with health professionals ($r = .15$ to $-.25$). Relationships were observed between HbA_{1c}, and both illness and treatment representations. Higher HbA_{1c} was related to higher scores on timeline cyclical, consequences, diabetes concern, diabetes identity, and medication concern. Three subscales (timeline acute/chronic, personal control and diabetes coherence), showed a negative relationship with HbA_{1c}. The strongest correlates of HbA_{1c} were medication concern ($r = .26$) and timeline cyclical ($r = .26$).

General emotional wellbeing and diabetes-related distress were measured using the SF-12® MCS and Problem Areas In Diabetes (PAID), respectively. The strongest correlates of general emotional function were the IPQ-R subscales diabetes concern, timeline cyclical, and consequences ($r = -.34$ to $-.41$). Significant correlations were also observed with personal control, diabetes coherence and diabetes identity. While no relationship was observed between the MCS-12 and medication necessity, a moderate negative association was shown between medication concern and emotional wellbeing ($r = -.30$). As shown in Table 9, a number of significant correlations were present between illness perceptions and diabetes-related distress. Emotional illness representation, measured using the IPQ-R, had a moderately strong association with

diabetes distress ($r = .69$), as did emotional treatment representation ($r = .59$). Scores on the PAID were also correlated with timeline cyclical, consequences, personal control, diabetes coherence, and diabetes identity ($r = -.10$ to $.51$).

Results show socio-medical context was related to general emotional wellbeing, and diabetes-related distress. All correlations were in the expected direction. Higher family support and patient-provider support were both linked to better general emotional function, and lower diabetes specific distress. Higher levels of conflict were associated with lower general psychological wellbeing, and greater distress about diabetes. Age was also linked to differential illness outcomes in this study. However, no relationship was found between illness duration and either general, or diabetes-related, emotional health.

Psychosocial variables demonstrated significant associations with quality of life, as evident in Table 9. Greater socio-medical support, and lower socio-medical conflict were related to higher quality of life. Nine of the ten illness/treatment variables also exhibited a significant correlation with quality of life. Better quality of life was associated with less worry about diabetes, lower concern about prescribed medication, weaker identification with diabetes, fewer perceived consequences associated with diabetes, and a low belief in the cyclical nature of diabetes symptoms. Higher quality of life was also related to greater perceived personal control, greater treatment control, and a belief that type 2 diabetes is a lifelong condition. Diabetes concern and consequences showed the strongest bivariate relationships with quality of life ($r = -.42$ and $-.38$, respectively).

Table 8

Pearson's r Correlations between Demographics, Socio-Medic Context and Illness/Treatment Representations (N = 610)

	Timeline acute/chronic	Timeline cyclical	Consequences	Personal control	Treatment control	Diabetes coherence	Diabetes concern	Diabetes Identity	Medication concern	Medication necessity
Age	-.06	-.13**	-.21***	-.14**	-.13**	-.10	-.22***	-.21***	-.24***	.16**
Length of diagnosis	.09*	.08	.11**	-.05	-.07	.00	-.01	.01	-.11*	-.24***
Family support	.02	-.08	-.10*	.04	.13**	.12**	-.10*	.02	-.08	.10*
Family conflict	-.16***	.26***	.20***	-.07	.05	-.20***	.30***	.22***	.30***	-.02
Patient-provider support	-.02	-.09*	-.07	.06	.18***	.21***	-.12**	-.02	-.17***	.12*
Patient-provider conflict	-.20***	.34***	.19***	-.21***	-.13**	-.37***	.34***	.21***	.43***	-.08
Timeline acute/chronic										
Timeline cyclical	-.17***									
Consequences	.22***	.43***								
Personal control	.43***	-.19***	.12**							
Treatment control	-.04	-.04	-.04	.38***						
Diabetes coherence	.31***	-.42***	-.16***	.44***	.30***					
Diabetes concern	-.12**	.58***	.49***	-.19***	-.11*	-.47***				
Diabetes identity	-.01	.41***	.39***	-.03	.06	-.13**	.39***			
Medication concern	-.23***	.45***	.32***	-.23***	-.12*	-.45***	.58***	.27***		
Medication necessity	.22***	.07	.28***	.10*	.14**	.07	.04	.02	.03	

* p < .05

** p < .01

*** p < .001

Table 9

Pearson's r Correlations between Personal Characteristics, Socio-Medic Context, Illness/Treatment Representations and Illness Outcomes (N = 610)

	HbA _{1c}	PAID	Quality of life	MCS-12	PCS-12	Medication adherence	Glucose testing	Exercise self-care	Dietary self-care
Age	-.25***	-.37***	.06	.20***	-.25***	.21**	-.04	-.01	.31***
Length of diagnosis	.19***	-.06	-.02	-.05	-.11**	.10*	.15***	-.01	.02
Family support	-.03	-.16***	.10*	.09*	-.02	.09	-.02	.18***	.22***
Family conflict	.17***	.33***	-.15**	-.18***	-.03	-.19***	.01	-.09*	-.19***
Patient-provider support	-.02	-.20***	.18***	.13**	.06	.08	.03	.16***	.16***
Patient-provider conflict	.15***	.38***	-.25***	-.21***	-.11*	-.22***	.06	-.11*	-.24***
Timeline acute/chronic	-.08*	-.06	.10*	-.01	.06	.18***	.01	-.01	.08
Timeline cyclical	.26***	.51***	-.36***	-.35***	-.11**	-.23***	.18***	-.05	-.24***
Consequences	.24***	.48***	-.38***	-.34***	-.10*	-.12*	.15**	-.04	-.11*
Personal control	-.09*	-.10*	.22***	.04*	.19***	.14**	.02	.03	.08*
Treatment control	-.02	-.07	.16***	.05	.06	.10*	.04	.08	.12**
Diabetes coherence	-.15***	-.34***	.30***	.14**	.14**	.22***	-.03	.09*	.16***
Diabetes concern	.23***	.69***	-.42***	-.41***	-.06	-.19***	.07	-.05	-.20***
Diabetes identity	.21***	.37***	-.20***	-.32***	-.05	-.18***	.06	.06	-.15***
Medication concern	.26***	.59***	-.31***	-.30***	.00	-.32***	.06	.00	-.23***
Medication necessity	.06	.02	-.08	-.08	-.06	.22***	.21***	.03	.18***

* p < .05

** p < .01

*** p < .001

EXAMINING PHYSICAL AND PSYCHOLOGICAL WELLBEING

The second aim of this study was to report on levels of physical and psychological wellbeing among people with type 2 diabetes in New Zealand, using standardized measures for which international data are available. Results are presented in Table 10. Evidence of group differences in physical or psychological wellbeing among the sample was also examined. Research findings are shown in Table 11.

Describing Levels of Wellbeing

Self-reported physical and mental functioning was assessed using the SF-12®. The mean MCS-12 score was 50.5 ($SD = 9.3$), as shown in Table 10. The mean score on the PCS-12 was 44.0 ($SD = 10.0$); thus results show evidence of a discrepancy between self-reported physical and mental health among research participants. As seen in Table 10, the average score on the Problem Areas In Diabetes (PAID) scale was 19.6 ($SD = 19.1$). HbA_{1c} was assessed as a measure of diabetes-specific physical wellbeing. Table 10 shows that the mean HbA_{1c} was 7.5 ($SD = 1.5$). Published guidelines for people with diabetes in New Zealand recommend an HbA_{1c} of less than 7%. Current quality of life was assessed using a single item from the Audit of Diabetes-Dependent Quality of Life (ADDQoL) (Bradley et al., 1999). The mean score on this seven-point scale was 2.7 ($SD = .96$).

Table 10

Means and Standard Deviations for Diabetes Distress, HbA_{1c}, Quality of Life, MCS-12 and PCS-12 (N = 610)

	M	SD
Diabetes-related emotional distress (PAID)	19.6	19.1
Haemoglobin A _{1c}	7.5	1.5
Quality of life	2.7	.96
General psychological wellbeing (MCS-12)	50.5	9.3
General physical wellbeing (PCS-12)	44.0	10.0

Table 11

Means, Standard Deviations, and Significant F Ratios Showing between-Groups Differences in Physical Wellbeing, Emotional Wellbeing, Treatment Beliefs and Behaviour across Gender and Ethnic Groups (N = 610)

	Gender					Ethnicity								
	Male		Female		F	New Zealand European		Māori		Pacific		Other		F
	M	SD	M	SD		M	SD	M	SD	M	SD	M	SD	
Physical wellbeing														
Haemoglobin A _{1c}	7.50	1.50	7.43	1.50	.40	7.11	1.29	7.97	1.62	8.40	1.96	7.34	.90	20.55***
PCS-12	45.03	9.61	42.85	10.27	7.04**	43.59	10.63	44.51	9.12	44.55	9.93	45.04	7.40	.50
Emotional wellbeing														
PAID	18.63	18.68	20.66	19.57	1.76	15.39	15.55	22.79	21.61	34.15	21.39	26.96	21.10	15.19***
MCS-12	50.66	9.37	50.29	9.18	.23	51.54	8.90	48.61	9.84	51.23	9.11	49.18	8.73	4.25**
Medication Beliefs and Behaviour														
Medication Concern	2.39	.87	2.33	.74	.24	2.21	.76	2.37	.79	3.08	.91	2.74	.71	13.87***
Medication Necessity	3.92	.79	3.93	.80	.04	3.96	.81	3.95	.79	3.74	.92	3.79	.48	1.27
Medication Adherence	4.64	.59	4.73	.45	2.92	4.80	.39	4.57	.62	4.35	.76	4.69	.40	12.71***

* p < .05 ** p < .01 *** p < .001 (two-tailed)

Note: All descriptive statistics (M, SD) report untransformed variables, for ease of comparison with standardised data from previous research. Significance testing (ANOVAs) was undertaken on transformed variables, although the same outcome is achieved when using untransformed variables.

Examining Group Differences in Wellbeing

One-way analyses of variance (ANOVA) were used to test for significant group differences in general and diabetes-related wellbeing. As shown in Table 11, mean PCS-12 scores were found to differ across gender, with males reporting higher physical functioning than females, $F(1,583) = 7.04, p < .01$. No significant differences between men and women were found for HbA_{1c}, diabetes-related distress, or general emotional wellbeing.

Differences in wellbeing across four ethnic groups (New Zealand European, Māori, Pacific, and Other) were also examined. On average, people of Pacific origin had the highest HbA_{1c}, although it should be noted that they had the largest variation in HbA_{1c} as well ($M = 8.40, SD = 1.96$). This group also reported the greatest diabetes-related distress, with the mean PAID score for Pacific peoples ($M = 34.15, SD = 21.39$) more than double the mean reported for New Zealand Europeans ($M = 15.39, SD = 15.55$). One-way ANOVAs showed there was a significant difference among the four groups for HbA_{1c} $F(3,605) = 20.55, p < .001$, PAID $F(3,568) = 15.19, p < .001$, and MCS-12 $F(3,581) = 4.25, p < .01$, as evident in Table 11.

Post hoc analyses, using Scheffe's test, were undertaken to examine the nature of these differences further. Results for the PAID showed that New Zealand Europeans were different from all other groups, and there was also a difference between Māori and Pacific peoples. Significant differences in mean HbA_{1c} were observed between New Zealand European and Māori, New Zealand European and Pacific, and Others and Pacific. For mean MCS-12, the only difference across the groups was between Māori and New Zealand European.

Examining Group Differences in Beliefs about Medication, and Treatment Adherence

Group differences in views about medication and self-reported medication adherence, were considered. Results, reported in Table 11, show no significant differences across gender. However, group differences across ethnicity were present for medication concern $F(3,451) = 13.87, p < .001$, and medication adherence $F(3,432) = 12.71, p < .001$.

Post hoc analyses, using Scheffe's test, indicate significant differences in adherence between New Zealand Europeans and Māori, and between New Zealand Europeans and people of Pacific origin. Results for medication concern showed that New Zealand Europeans were different from Pacific people and the ethnic group Others, and that there was also a difference between Māori and Pacific peoples.

TESTING OF HYPOTHESES

This section presents the results of hierarchical multiple regression analyses used for hypothesis testing. It is comprised of seven main hypotheses; a number of sub-hypotheses are also explicated. The analyses undertaken represent testing of specific a priori predictions, as outlined previously in chapter 4. Self-regulatory literature stipulates the existence of causal relationships (Hagger & Orbell, 2003). However, it is important to acknowledge that this cannot imply temporal prediction in the present study, due to the cross-sectional nature of data collected.

Hypotheses 1, 2, and 3

The first three hypotheses examined the percentage of variance in key diabetes illness outcomes (HbA_{1c}, diabetes-related distress, and quality of life) that can be attributed to psychosocial and behavioural factors measured in this study. Because ethnic group differences in HbA_{1c} and diabetes distress were identified in exploratory analyses, as shown in Table 11, three dichotomous cultural variables were computed for use as control variables (New Zealand European/other, Māori/other, Pacific Island/other). Predictor variables were entered in four steps.

First, demographic and medical characteristics correlated with each outcome were entered as control variables. Second, variables assessing socio-medic context were entered into the regression equation. Illness and treatment representations were entered at step 3. Following this, health behaviours were entered at step 4. In hypothesis 3 an additional step was included: at step 5, indicators of diabetes-specific wellbeing (HbA_{1c} and diabetes distress) were entered into the regression equation to determine their relationship with quality of life.

In each regression analysis, only those variables showing a significant bivariate association with the dependent variable were included as predictors. The variables that were assessed as potential candidates for entry into the regression analyses included age, length of diagnosis, treatment type, ethnicity, the four socio-medic variables and ten illness/treatment representation variables included in Table 8, the SDSCA subscales diet, exercise, glucose testing, foot care and smoking, and medication adherence as measured using the MARS. The standardised beta coefficients (*Beta*) for each variable are reported in Tables 12, 13, and 14. Total variance explained at each step is presented (R^2 and adjusted R^2). The additional variance explained by each block of variables, after controlling for previous blocks, is also provided (R^2 change). The first three hypotheses are restated below, along with a summary of the results for each.

Hypothesis 1. Psychosocial and behavioural factors will explain a significant proportion of the variance in metabolic control among people with type 2 diabetes

As shown in Table 12, together demographic, psychosocial and behavioural factors accounted for approximately 15% of the variance (adjusted R^2) in HbA_{1c}. Total adjusted R^2 at step 4 was found to be significantly different from zero $F(19,286) = 3.93$, $p < .001$. By examining R^2 change for each block, it is possible to observe the relative contribution of three groups of variables that are of particular interest in the present study (socio-medic context, illness/treatment representations, and self-care behaviours). At step 1 age, illness duration, and three dichotomous cultural variables were entered to control for demographic and medical bivariate correlates of HbA_{1c}. These accounted for 10% of variance (adjusted R^2) in HbA_{1c}, $F(5,300) = 7.93$, $p < .001$. The addition of four socio-medic variables at step two did not result in a significant change in explained variance. After step 3, total variance in HbA_{1c} explained by variables included in the regression model was 13% (adjusted R^2), $F(15,290) = 4.10$, $p < .001$. R^2 change statistics show illness and treatment representations were found to contribute an additional 6% to explained variance in this model, when controlling for variables previously entered into the regression equation. Four health behaviour variables were entered at step 4. These contributed a further 3% (R^2 change) of unique explained variance in HbA_{1c}. R^2 change after entry of variables at step 3 was

significantly different from zero, $F(8,290) = 2.45$, $p < .05$, as was R^2 change after entry of variables at step 4 $F(4,286) = 2.88$, $p < .05$.

Four variable blocks were included in this regression analysis. Among these, socio-medical context alone was not able to account for a significant proportion of the variance HbA_{1c} . An estimate of the variance accounted for by psychosocial and behavioural factors can be obtained by subtracting adjusted R^2 at step 1 from total adjusted R^2 at step 4. This calculation suggests psychosocial and behavioural factors account for 5% of the variation in metabolic control. As noted above, R^2 change after entry of variables at step 3, and step 4, were both significantly different from zero. It is concluded that results of the present study support hypothesis 1. Psychosocial and behavioural factors were found to explain a significant proportion of the variance in metabolic control among people with type 2 diabetes.

Through examination of *Beta* coefficients at each step it is possible to observe the effects of individual variables on HbA_{1c} , while controlling for the impact of all other variables in the regression model at that point. At step 4, with all variables entered into the regression equation, four variables were significantly related to HbA_{1c} . Observed relationships showed lower age, greater length of diagnosis, Pacific ethnicity, and tobacco smoking were all associated with worse metabolic control. Lower age, longer illness duration, and Pacific ethnicity were all significantly correlated with HbA_{1c} at step 1, and continued to be at all subsequent steps in the regression analysis. Māori ethnicity showed a significant relationship with metabolic control at steps 1, 2, and 3 of the regression, but showed a non-significant association at step 4. Medication concern was significantly related to HbA_{1c} when entered at step 3, but this relationship did not show evidence of statistical significance ($p < .05$) at step 4. Among the health behaviour variables entered at step 4, tobacco smoking was the only significant correlate of HbA_{1c} . Inspection of *Betas* revealed a negative association between medication adherence and HbA_{1c} ; this trend was close to reaching the threshold for statistical significance ($p = .051$). The direction of this trend was in the expected direction, showing greater medication adherence was related to lower HbA_{1c} (better metabolic control).

Table 12

Hierarchical Multiple Regression of Haemoglobin A_{1c} on Control Variables, Socio-Medic Context, Illness/Treatment Representations and Health Behaviour Showing Standardised Regression Coefficients, R, R², Adjusted R², and R² change (N = 356)

Predictors	Step 1	Step 2	Step 3	Step 4
Controls				
Age	-.210***	-.212**	-.214***	-.167*
Length of diagnosis	.13*	.132*	.171**	.166**
NZ European dichotomy	.026	.035	.099	.043
Māori dichotomy	.218*	.237*	.250*	.171
Pacific dichotomy	.172*	.183*	.173*	.143*
Socio-medic context				
Family conflict		-.034	-.097	-.108
Patient-provider conflict		.046	-.072	-.083
Illness/treatment representations				
Timeline cyclical			.031	.007
Timeline acute/chronic			-.103	-.073
Consequences			.059	.061
Personal control			.035	.037
Diabetes coherence			-.109	-.088
Diabetes concern			.014	.006
Diabetes identity			.026	.020
Medication concern			.153*	.130
Health behaviour				
Medication adherence				-.118
Dietary self-care				-.066
Blood glucose testing				.046
Smoking				.137*
Multiple R	.342***	.345***	.418***	.455***
Total R²	.117	.119	.175	.207
Adjusted R²	.102	.099	.132	.154
R² change	.117***	.002	.056*	.032*

* p < .05

** p < .01

*** p < .001

Hypothesis 2. Psychosocial and behavioural factors will explain a significant proportion of the variance in diabetes related emotional distress

In the present study, demographic, psychosocial and behavioural factors together were found to explain 54% (adjusted R^2), of the variance in diabetes-related emotional distress. Total adjusted R^2 at step 4 was significantly different from zero $F(17,315) = 24.06, p < .001$. The *Beta* coefficients for each variable, R^2 , adjusted R^2 , and R^2 change at each step can be seen in Table 13. Age, treatment type, and three dichotomous cultural variables were entered at step 1, as control variables. These explained 20% (adjusted R^2) of the variance in distress. Four variables measuring socio-medic context were entered at step 2. Socio-medic variables accounted for an additional 14% (R^2 change) of the variance in distress, over and above the explanatory power provided by variables in step 1. At step 3, illness and treatment representations were entered into the regression model. These variables were found to contribute a further 20% (R^2 change) to explained variance in distress about diabetes, when controlling for variables entered at previous steps. Medication adherence and dietary self-care were entered at step 4. This did not result in a significant change in explained variance. As shown in Table 13, R^2 change was significantly different from zero after entry of variables at step 1 $F(5,327) = 17.80, p < .001$, step 2 $F(4,323) = 18.04, p < .001$, and step 3 $F(6,317) = 23.94, p < .001$. Among the four variable blocks in this regression analysis, health behaviour was the only block that did not make a significant contribution to explained variance in diabetes-related distress. The IPQ-R subscale labelled 'diabetes concern' did show a significant bivariate relationship with the outcome variable of interest (diabetes related emotional distress measured using the PAID) as evident in Table 9. However, the magnitude of this association ($r = .69, p < .001$) indicates colinearity is likely to be present, thus diabetes concern was excluded from the regression shown in Table 13.

Beta coefficients allow for identification of relationships present at the multivariate level. As shown in Table 13, nine variables – age, treatment type, family support, family conflict, timeline cyclical, consequences, diabetes identity, medication concern, and medication adherence – were significantly related to diabetes distress at step four in the regression analysis. Each of these variables was significant on entry into the regression model and remained so at all subsequent steps of the analysis, with the exception of diabetes treatment. Inspection of *Beta* coefficients showed lower age,

less intensive diabetes treatment, lower family support, and greater family conflict were associated with higher reported distress about diabetes. A belief that diabetes has serious consequences, and a perception that diabetes symptoms come and go in cycles were also correlated with higher distress. Stronger diabetes identity, greater concern about medication, and higher medication adherence each showed a positive relationship with diabetes-related distress.

Attention was given to any significant alteration in the *Beta* coefficient of an individual variable across analysis steps. It is possible then, to identify the extent to which the addition of variables in subsequent steps may influence previously observed relationships. NZ European ethnicity was associated with lower distress at step 1 in the regression (*Beta* = -.21, $p < .05$); however, this was reduced to a non-significant trend after socio-medic variables were entered at step 2. Treatment type did not show any significant relationship with distress at steps 1 and 2 of the regression; however, a weak negative association was present at steps 3 and 4. While patient-provider conflict was correlated with diabetes distress at step 2 of the regression analysis (*Beta* = .18, $p < .01$), this relationship became non-significant when illness and treatment representations were entered at step 3.

To summarise, variables entered into the regression model shown in Table 13 explained more than half of the total variance in diabetes-related emotional distress (adjusted R^2). The change in explained variance (R^2 change) after entry of variables at steps 1, 2, and 3 was significantly different from zero. The magnitude of observed relationships suggests that, among variables included in the present study, worry about the use of prescribed pharmaceutical treatments (*Beta* = .30, $p < .001$), lower age (*Beta* = -.19, $p < .001$), stronger diabetes identity (*Beta* = .15, $p < .01$), and an expectation that diabetes will have serious life consequences (*Beta* = .14, $p < .01$) show the strongest relationships with diabetes-related distress. The variance accounted for by psychosocial and behavioural factors was estimated in the same way as for hypothesis 1. This suggests that, after controlling for the impact of medical and demographic characteristics, psychosocial and behavioural factors account for 33% of the variation in diabetes-related distress. Thus reported results support hypothesis 2. Psychosocial and behavioural factors were found to explain a significant proportion of the variance in emotional distress about diabetes.

Table 13

Hierarchical Multiple Regression of Diabetes-Related Distress on Control Variables, Socio-Medic Context, Illness/Treatment Representations, and Health Behaviour, Showing Standardised Regression Coefficients, R, R², Adjusted R², and R² change (N = 355)

Predictors	Step 1	Step 2	Step 3	Step 4
Controls				
Age	-.366***	-.283***	-.192***	-.194***
Diabetes treatment	.011	-.029	-.082*	-.093*
NZ European dichotomy	-.208*	-.152	.060	.067
Māori dichotomy	-.153	-.115	.075	.067
Pacific dichotomy	.112	.071	.056	.065
Socio-medic context				
Family support		-.186***	-.107*	-.110*
Family conflict		.266***	.113*	.117*
Patient-provider support		-.047	-.034	-.034
Patient-provider conflict		.184**	.044	.047
Illness/treatment representations				
Timeline cyclical			.119*	.122*
Consequences			.150**	.144**
Personal control			.067	.070
Diabetes coherence			.071	.072
Diabetes identity			.141**	.145**
Medication concern			.286***	.301***
Health behaviour				
Dietary self care				-.035
Medication adherence				.098*
Multiple R	.462***	.598***	.747***	.752***
Total R²	.214	.357	.558	.565
Adjusted R²	.202	.339	.537	.541
R² change	.214***	.144***	.200***	.007

* p < .05

** p < .01

*** p < .001

Hypothesis 3. Psychosocial factors, self-care behaviour, and diabetes-related wellbeing will explain a significant proportion of the variance in quality of life

Quality of life was a key variable of research interest. A five-step hierarchical multiple regression was employed to determine whether variables included within the present study could account for a significant proportion of the variance in quality of life. Results are reported in Table 14. These show that, collectively, demographics, psychosocial factors, diabetes-related self-care behaviours and wellbeing accounted for one quarter of the variance (adjusted R^2) in reported quality of life. At step 5 total adjusted R^2 was found to be significantly different from zero $F(22,270) = 5.39, p < .001$. The relative contribution of different groups of variables was examined by observing R^2 change at each step in the regression analysis. At step 1, diabetes treatment and two dichotomous cultural variables were entered to control for demographic and medical variables showing a bivariate relationship with quality of life. These accounted for 3% of variance (adjusted R^2) in the dependent variable, $F(3,289) = 3.71, p < .05$. Four socio-medical variables were entered at step 2, R^2 change statistics suggest these explained an additional 6% of the variance in quality of life $F(4,285) = 4.53, p < .01$. Nine illness/treatment variables were entered into the regression model at step 3. These variables contributed an additional 16% (R^2 change) to explained variance in this model $F(9,276) = 6.78, p < .001$, when controlling for variables previously entered into the regression equation. At step 4, four diabetes self-care behaviours variables were entered; this did not result in a significant increase in explained variance. HbA_{1c} and diabetes specific emotional distress were entered into the regression at step 5, to determine whether indicators of diabetes related wellbeing were able to account for differences in quality of life. A 2% increase in explained variance (R^2 change) was observed at step 5, $F(2,270) = 4.33, p < .05$. Table 14 provides an overview of total variance explained at each of the five steps; this is reported in the row labelled 'Adjusted R^2 '. An estimate of the variance accounted for by variables of key interest (entered at steps 2, 3, 4, and 5) was obtained by subtracting adjusted R^2 at step 1 from total adjusted R^2 at step 5. After removing the impact of demographic and treatment characteristics, the remaining variables were found to explain approximately one fifth of the variability in reported quality of life. Psychosocial factors, self-care behaviour, and diabetes related wellbeing were found to explain a significant proportion of the variance in quality of life among people with type 2 diabetes. Thus results supported hypothesis 3.

Table 14

Hierarchical Multiple Regression of Quality of Life on Control Variables, Socio-Medic Context, Illness/Treatment Representations, Behaviour, and Diabetes Wellbeing Showing Standardised Regression Coefficients, R, R², Adjusted R², and R² change (N = 283)

Predictors	Step 1	Step 2	Step 3	Step 4	Step 5
Controls					
Diabetes treatment	-.118*	-.097	-.036	-.003	-.014
NZ European dichotomy	.216*	.183*	.080	.065	.056
Māori dichotomy	.100	.051	-.002	.006	.019
Socio-medic context					
Family support		.093	.025	.001	-.023
Family conflict		-.083	.038	.054	.084
Patient-provider support		.125	.131*	.127*	.117
Patient-provider conflict		-.090	.007	.030	.038
Representations					
Timeline acute/chronic			.018	.005	.007
Timeline cyclical			-.061	-.033	-.023
Consequences			-.281***	-.278***	-.259***
Personal control			.099	.115	.137*
Treatment control			.069	.033	.059
Diabetes coherence			-.010	-.031	-.020
Diabetes concern			-.081	-.093	.004
Diabetes identity			-.098	-.102	-.084
Medication concern			-.058	-.055	-.003
Behaviour					
Dietary self-care				.050	.025
Blood glucose testing				-.118*	-.114*
Exercise self-care				.096	.094
Medication adherence				.063	.072
Diabetes related wellbeing					
HbA _{1c}					-.057
Diabetes-related distress					-.225**
Multiple R	.192*	.308***	.508***	.532***	.552***
Total R²	.037	.095	.259	.283	.305
Adjusted R²	.027	.072	.216	.230	.249
R² change	.037*	.058**	.164***	.024	.022*

* p < .05

** p < .01

*** p < .001

Examination of *Beta* coefficients enable the relationships between individual variables and quality of life to be observed, while controlling for the impact of all other variables in the regression model at that point. At step 5, with all variables entered into the regression equation, four variables showed a significant relationship with quality of life. The direction of these associations implies strong belief in personal control over diabetes, lower diabetes-related emotional distress, lower belief that diabetes has negative life consequences, and less frequent blood glucose testing are each linked to better quality of life. Inspection of *Betas* at each step in the regression reveals other variables that show some (albeit inconsistent) evidence of a relationship with quality of life. At step 1, less intensive diabetes treatment and New Zealand European ethnicity were significantly related to better quality of life. However, these associations were reduced to non-significant trends at steps 2 and 3 of the regression analysis. Although patient-provider support showed a significant positive relationship with quality of life at steps 3 and 4, this became a non-significant trend at step 5 ($p = .057$). Further, personal control did not show a significant association with quality of life upon entry into the analysis at step 2. The magnitude of this relationship grew across steps 4 and 5, and in the final regression model it was above the threshold for statistical significance as determined in the present study ($p < .05$).

As shown in Table 14, variables entered into the regression model explained 25% of the total variance in quality of life (adjusted R^2 at step 5). Variables were entered in five blocks and of these blocks, four resulted in a significant increase in explained variance upon entry to the regression. R^2 change after entry of variables at steps 1, 2, 3, and 5 was significantly different from zero. Self-care behaviour was the only block that did not demonstrate an ability to account for variation in quality of life. The magnitude of observed relationships suggests that, among variables included in the present study, perceived consequences of diabetes ($Beta = -.26, p < .001$), and level of diabetes-related emotional distress ($Beta = -.23, p < .01$) show the strongest association with quality of life.

Hypothesis 4

As stated in chapter 4, one seminal research aim was to explore the link between socio-medic context and views about diabetes/treatments for diabetes. The fourth hypothesis predicted that differences in support/conflict from socio-medic relationships

would be related to variation in diabetes concern, and medication concern. Four directional relationships were specified as sub-hypotheses. These are stated below. Multivariate analyses were used to control statistically for the impact of other variables related to diabetes concern/treatment concern. This enabled a more accurate understanding of the relationships between socio-medic context and emotional illness/treatment representations than is provided by the bivariate correlations in Table 8. Two regression analyses were used to test the predicted relationships. In each analysis, medical and demographic variables identified as bivariate correlates of the dependent variable were entered at step 1, as control variables. Relevant socio-medic variables were then entered at step 2. Results are shown in Tables 15 and 16. An overview of research findings for each predicted relationship is presented below.

Hypothesis 4a. Higher conflict with family/health professionals over diabetes self-management will be associated with greater concern about diabetes

Hypothesis 4b. Greater support for diabetes self-management from family/health professionals will be associated with lower concern about diabetes

Table 15 shows the relationships between socio-medic context and diabetes concern. At step 1 of the regression model age, gender, New Zealand European dichotomy, Māori dichotomy, and treatment type, were all significant correlates of diabetes concern. Higher age, male gender, NZ European ethnicity, Māori ethnicity, and less intensive diabetes treatment, were associated with lower concern about diabetes. These variables were also related to diabetes concern at the second step. The exception was treatment type, which showed a significant *Beta* at step 1, but was non-significant (*Beta* = .076, *p* = .059) at step 2. Four socio-medic variables were entered into the regression analysis at the second step. *Betas* showed that lower family support, higher family conflict, and higher patient-provider conflict, were each linked to greater diabetes concern. Results indicate that greater socio-medic conflict over diabetes self-management is associated with higher concern about diabetes. Thus research findings support hypothesis 4a. Table 15 shows that higher family support was linked to lower concern about diabetes. Patient-provider support showed no significant relationship with diabetes concern in this regression analysis, although a significant bivariate correlation between these variables was shown in Table 8. Thus results provide partial support for hypothesis 4b.

Table 15

Hierarchical Multiple Regression of Diabetes Concern on Control Variables and Socio-Medic Context Showing Standardised Regression Coefficients, R, R², Adjusted R², and R² change (N = 497)

Predictors	Step 1	Step 2
Controls		
Age	-.175***	-.099*
Gender	-.084*	-.096*
NZ European dichotomy	-.317***	-.283**
Māori dichotomy	-.204*	-.186*
Pacific dichotomy	.078	.074
Diabetes treatment	.125**	.076
Socio-Medic Context		
Family conflict		.200***
Patient-provider conflict		.182***
Patient-provider support		-.021
Family support		-.138**
Multiple R	.387***	.503***
Total R²	.150	.253
Adjusted R²	.139	.238
R² change	.150***	.103***

* p < .05

** p < .01

*** p < .001

Table 16

Hierarchical Multiple Regression of Medication Concern on Control Variables and Socio-Medic Context Showing Standardised Regression Coefficients, R, R², Adjusted R², and R² change (N = 402)

Predictors	Step 1	Step 2
Controls		
Age	-.194***	-.148**
NZ European dichotomy	-.315**	-.191*
Māori dichotomy	-.282**	-.202*
Pacific dichotomy	.060	.045
Length of diagnosis	-.023	-.018
Socio-Medic Context		
Patient-provider support		-.025
Family conflict		.195***
Patient-provider conflict		.327***
Multiple R	.348***	.537***
Total R²	.121	.288
Adjusted R²	.110	.274
R² change	.121***	.167***

* p < .05

** p < .01

*** p < .001

Hypothesis 4c. Higher conflict with family/health professionals over diabetes self-management will be associated with greater concern about prescribed medication

Hypothesis 4d. Greater support for diabetes self-management from family/health professionals will be associated with lower concern about prescribed medication

The regression analysis shown in Table 16 was used to test hypotheses 4c and 4d. Because family support did not show a significant bivariate relationship with medication concern, as shown in Table 8, this variable was not included in the regression presented in Table 16. Inspection of standardised beta coefficients show that age, New Zealand European dichotomy and Māori dichotomy were significantly correlated with concern about diabetes treatment at steps 1 and 2. Three socio-medic variables were entered at the second step of the analysis. Results show that greater age, NZ European ethnicity, Māori ethnicity, lower patient-provider conflict, and less family conflict, were each associated with lower levels of concern about diabetes treatment. Research findings provide support for hypothesis 4c as higher diabetes-related conflict with family, and conflict with health professionals, were both associated with greater concern about prescribed medication. Results do not support hypothesis 4d. Neither patient-provider support nor family support showed a reliable relationship with concern about prescribed diabetes treatments.

In addition to the four directional hypotheses stated above, two further sub-hypotheses sought to test a proposed connection between social communication and emotional illness/treatment representations (shown in Figure 1, chapter 2). Hypothesis 4e predicted that when entered as a variable block, socio-medic context would explain a significant portion of variance in diabetes concern. Hypothesis 4f predicted that socio-medic variables would, together, account for a significant amount of the variation in medication concern. Research findings presented in Tables 15 and 16 provide support for the proposed pathway between socio-medic context and emotional illness/treatment representations. These show that socio-medic variables explained 10% (R^2 change) of the variance in diabetes concern $F(4,487) = 17.74, p < .001$, and 17% (R^2 change) of differences in medication concern $F(3,394) = 33.57, p < .001$, after controlling for demographic and medical characteristics. In summary, hypotheses 4a, 4c, 4e and 4f were supported by research findings. However, hypothesis 4d was not supported, and hypothesis 4b received only partial support.

Hypothesis 5

Hypothesis 5 predicted that psychosocial variables will explain variance in diabetes self-care behaviours. Four sub-hypotheses were presented in chapter 4; these focused on dietary patterns, exercise habits, medication use, and blood glucose testing. Separate regression analyses were used to test each sub-hypotheses; results are presented in Tables 17, 18, 19, and 20. In each analysis, medical and demographic variables were entered at step 1, as control variables. Relevant socio-medical variables were then entered at step 2, with illness/treatment representations entered at step 3. At each step, only those variables showing evidence of a significant bivariate association with the dependent variable were included in the regression model.

Hypothesis 5a. Psychosocial factors will explain a significant proportion of the variance in dietary patterns

Demographic and psychosocial variables were found to explain 20% (adjusted R^2), of the variance in dietary self-care behaviour $F(16,332) = 6.28, p < .001$, as shown in Table 17. At each step in the regression, a significant increase in explained variance (R^2 change) was observed. At step 3, four variables showed a significant relationship with dietary behaviour. Inspection of *Beta* coefficients revealed greater age, higher family support, lower family conflict over diabetes, and stronger belief in the need for prescribed treatments, were each associated with healthy dietary habits. New Zealand European ethnicity was associated with better diet at step 1 of the regression; however, this relationship did not retain statistical significance at steps 2 and 3. All other reported relationships were significant upon entry into the regression, and remained so at subsequent stages of the analysis. As shown in Table 17, R^2 change statistics indicate that demographic variables accounted for 10% of variation in scores on the SDSCA dietary subscale, socio-medical context explained an additional 8% of variance in dietary behaviour, and illness/treatment representations were shown to contribute a further 5% of unique explained variance. Thus after controlling for the impact of demographic characteristics, psychological variables explained (approximately) an additional 10% of the variability in dietary self-care behaviour. This figure was determined by subtracting the adjusted R^2 reported at step 1 from the total adjusted R^2 at step 3.

Table 17

Hierarchical Multiple Regression of Dietary Self-care on Control Variables, Socio-Medic Context, and Illness/Treatment Representations Showing Standardised Regression Coefficients, R, R², Adjusted R², and R² change (N = 340)

Predictors	Step 1	Step 2	Step 3
Control			
Age	.256***	.192***	.193**
NZ European dichotomy	.164*	.153	.115
Māori dichotomy	.045	.025	-.010
Socio-Medic Context			
Family support		.196***	.161**
Family conflict		-.162**	-.127*
Patient-provider support		.085	.075
Patient-provider conflict		-.078	-.009
Illness/treatment representations			
Diabetes identity			-.040
Timeline cyclical			-.082
Consequences			.022
Treatment control			.079
Personal control			.024
Diabetes coherence			.048
Diabetes concern			.090
Medication concern			-.117
Medication necessity			.124*
Multiple R	.319***	.430***	.482***
Total R²	.101	.185	.232
Adjusted R²	.094	.169	.195
R² change	.101***	.084***	.047*

* p < .05

** p < .01

*** p < .001

Table 18

Hierarchical Multiple Regression of Exercise Self-care on Control Variables, Socio-Medic Context, and Illness/Treatment Representations Showing Standardised Regression Coefficients, R, R², Adjusted R², and R² change (N = 485)

Predictors	Step 1	Step 2	Step 3
Control			
Diabetes treatment	-.140**	-.114*	-.113*
Socio-Medic Context			
Family support		.158**	.156**
Family conflict		-.130**	-.128**
Patient-provider support		.103*	.102*
Patient-provider conflict		-.015	-.010
Illness/treatment representations			
Diabetes coherence			-.017
Multiple R	.140**	.276***	.277***
Total R²	.020	.076	.076
Adjusted R²	.018	.067	.065
R² change	.020**	.057***	.000

* p < .05

** p < .01

*** p < .001

Table 19

Hierarchical Multiple Regression of Medication Use on Control Variables, Socio-Medic Context, and Illness/Treatment Representations Showing Standardised Regression Coefficients, R, R², Adjusted R², and R² change (N = 367)

Predictors	Step 1	Step 2	Step 3
Control			
Age	.036	.014	-.027
NZ European dichotomy	.122	.068	.015
Māori dichotomy	-.142	-.178	-.206*
Pacific dichotomy	-.184**	-.176*	-.166*
Socio-Medic Context			
Family conflict		-.076	-.018
Patient-provider conflict		-.168**	-.026
Illness/treatment representations			
Diabetes identity			-.076
Timeline chronic			.087
Timeline cyclical			-.078
Consequences			-.029
Treatment control			.076
Personal control			-.041
Diabetes coherence			.089
Diabetes concern			.101
Medication concern			-.206**
Medication necessity			.153**
Multiple R	.324***	.376***	.488***
Total R²	.105	.141	.238
Adjusted R²	.095	.127	.204
R² change	.105***	.036**	.097***

* p < .05

** p < .01

*** p < .001

Table 20

Hierarchical Multiple Regression of Blood Glucose Testing on Control Variables and Illness/Treatment Representations Showing Standardised Regression Coefficients, R, R², Adjusted R², and R² change (N = 388)

Predictors	Step 1	Step 2
Control		
Diabetes treatment	.256***	.210***
Length of diagnosis	.091	.076
Illness/treatment representations		
Timeline cyclical		.159**
Consequences		.007
Medication necessity		.120*
Multiple R	.293***	.356***
Total R²	.086	.126
Adjusted R²	.081	.115
R² change	.086***	.041**

* p < .05 ** p < .01 *** p < .001

Hypothesis 5b. Psychosocial factors will explain a significant proportion of the variance in exercise habits

As shown in Table 18, variables included in the current study accounted for a significant proportion of differences in self-reported exercise behaviour. Collectively, variables in the regression model explained approximately 7% of the variability in exercise patterns $F(6,478) = 6.60, p < .001$. Variables were entered in three steps, as described previously. Prescribed treatment was entered at step 1. This was the only demographic or medical variable to show a significant bivariate correlation with exercise. Four socio-medical context variables were entered at step 2, and diabetes coherence was entered at step 3 as the sole representative of illness/treatment representations. A significant increase in explained variance (R^2 change) was observed at steps 1 and 2 of the regression analysis; illness/treatment representations were not shown to account for differences in exercise behaviour. R^2 change statistics reported in Table 18 indicate that diabetes treatment was found to explain 2% of variance in exercise patterns; socio-medical context was shown to account for a further 6% of variability in the dependent variable. *Beta* coefficients showed that less intensive treatment, greater family support for diabetes, lower family conflict, and a positive patient-provider relationship, were each associated with greater participation in physical activity. Among variables included in the present study, diabetes related family support showed the strongest relationship with exercise behaviour. As shown in Table 18, after controlling for the impact of demographic characteristics, psychosocial variables explained (approximately) an additional 5% of the variability in self-reported physical activity. Results suggest interpersonal factors (relationships with family or health professionals) appear to be more important than individual illness/treatment representations in explaining variation in exercise behaviour.

Hypothesis 5c. Psychosocial factors will explain a significant proportion of the variance in medication use

Demographic and psychosocial variables were found to explain 20% (adjusted R^2), of the variance in medication use $F(16,355) = 6.94, p < .001$. The *Beta* coefficients for each variable, R^2 , adjusted R^2 , and R^2 change at each step can be seen in Table 19. A significant increase in explained variance (R^2 change) was observed at each step in the regression. As shown in Table 19, R^2 change statistics indicate age and ethnicity

explained approximately 10% of variance in medication use, socio-medic context variables accounted for a further 4% of variance, and illness/treatment representations contributed an additional 10% to explained variance in the dependent variable. At step 3 of the regression analysis, four variables showed a significant relationship with medication use. The direction of observed *Betas* implies lower adherence to the prescribed medication regimen is associated with Pacific ethnicity, Māori ethnicity, greater concern about medication, and lower perceived need for pharmaceutical treatments. Inspection of *Beta* coefficients reveals two variables showed changes in the statistical significance of their relationship with medication use across stages in the analysis. Māori ethnicity showed a non-significant association with lower medication use at steps 1 and 2 of the model; at step 3 this trend reached the threshold for statistical significance used in the present study ($p < .05$). Patient-provider conflict was associated with lower medication adherence upon entry at step 2 of the regression model ($Beta = -.17, p < .01$), but the magnitude of this relationship reduced substantially when illness/treatment representations were entered into the regression equation at step 3. After controlling for the impact of demographic characteristics, psychological variables explained a further 11% of unique variance in medication use.

Hypothesis 5d. Psychosocial factors will explain a significant proportion of the variance in blood glucose testing

As shown in Table 20 demographic and psychosocial variables were found to explain approximately 12% (adjusted R^2), of the variance in blood glucose testing $F(5,385) = 11.14, p < .001$. None of the four socio-medic context variables showed a significant bivariate correlation with glucose testing, as evident in Table 9. Only two variable blocks were therefore entered into the regression equation (control variables, and illness/treatment representations). R^2 change was significantly different from zero at both step 1 and step 2 of the model. Of the five variables regressed onto glucose testing in this analysis, three showed a significant relationship with the dependent variable. Inspection of *Beta* coefficients indicates that greater treatment intensity (e.g., a treatment regimen that prescribes use of insulin rather than lifestyle change), strong belief in the need for prescribed medication, and a perception that diabetes symptoms come and go in cycles, were each associated with more frequent testing of blood glucose levels. Although length of diagnosis and perceived consequences of diabetes showed a significant bivariate association with glucose testing as shown in Table 9,

these relationships were not evident in the multivariate analysis reported in Table 20. When controlling for explained variance accounted for by treatment type and length of diagnosis, illness/treatment representations were shown to account for an additional 3% of the variability in blood glucose testing.

In summary, hypothesis 5 predicted that psychosocial variables will explain variance in diabetes self-care behaviours. Four sub-hypotheses were presented in chapter 4; these focused on dietary patterns, exercise habits, medication use, and blood glucose testing. Results shown in Tables 17, 18, 19 and 20 provide support for sub-hypotheses (5a, 5b, 5c, and 5d). After controlling for the impact of medical and demographic characteristics, psychosocial variables were shown to explain an additional 10% of variance in dietary self-care behaviour; 5% of variance in physical activity; 11% of variance in medication use; and 3% toward explained variability in blood glucose testing.

Hypothesis 6

The relationships between illness/treatment representations and active behavioural management of type 2 diabetes are a central theme of interest in the present study. Chapter 4 outlined ten directional sub-hypotheses. The purpose of hypothesis 6 is to test for evidence of these predicted relationships. To encourage parsimonious presentation of results, the four regression analyses used to test hypothesis 5 will be also be used for hypothesis 6. Thus predicted relationships will be evaluated using *Betas* shown in Tables 17, 18, 19, and 20. Multivariate analyses were selected because they enable a greater degree of statistical control than the simple correlations shown in Table 9, and thus more rigorous evaluation of proposed relationships. The directional sub-hypotheses are restated below, with a description of the results for each.

Hypothesis 6a. Higher treatment control will be associated with active self-care behaviour

Treatment control did not show evidence of a significant bivariate relationship with exercise self-care or blood glucose testing, as evident in Table 9. However, simple correlations did show higher treatment control was associated with better medication

adherence, and greater dietary self-care. Multivariate analyses reported in Tables 17 and 19 indicate that, when controlling for the impact of demographic characteristics and relationships among predictor variables, treatment control did not show a significant relationship with either dietary self-care, or medication adherence. Thus results do not support hypothesis 6a.

Hypothesis 6b. Higher personal control will be associated with active self-care behaviour

Bivariate correlations reported in Table 9 show a significant relationship between personal control and both medication adherence and dietary self-care; however, no significant bivariate relationship was observed with exercise self-care or blood glucose testing. Multivariate analyses reported in Tables 17 and 19 indicate that, when controlling for the impact of demographic characteristics and relationships among predictor variables, personal control did not show a significant relationship with either dietary self-care, or medication adherence. Reported results do not support hypothesis 6b.

Hypothesis 6c. Higher perceived consequences will be associated with active self-care behaviour

Table 9 shows significant bivariate correlations between consequences and three aspects of diabetes self-care behaviour (medication adherence, glucose testing, and dietary patterns). Although consequences was entered as a potential predictor in multivariate analyses shown in Tables 17, 19, and 20, inspection of *Betas* revealed consequences did not show a significant relationship with diabetes self-care behaviour when controlling for demographic characteristics and relationships with other psychosocial variables. Thus results do not support hypothesis 6c.

Hypothesis 6d. Stronger belief in a chronic timeline for diabetes will be associated with active self-care behaviour

A significant bivariate correlation was observed between chronic timeline and medication adherence in Table 9. However, this relationship was no longer statistically significant when included within the multivariate analysis reported in Table 19. Chronic

timeline did not show a significant relationship with any other aspects of diabetes self-care. Thus results do not support hypothesis 6d.

Hypothesis 6e. Stronger belief in a cyclical timeline will be associated with less active self-care behaviour

Table 9 shows significant bivariate correlations between the IPQ-R variable labelled 'timeline cyclical' and diabetes self-management behaviours. However, these are in differing directions. A perception that diabetes symptoms come and go in cycles is associated with lower medication adherence, and less healthy dietary patterns, but more frequent blood glucose testing ($r = -.23, -.24, \text{ and } .18$, respectively, $p < .001$). Multivariate analyses reported in Tables 17 and 19 show timeline cyclical did not show a significant relationship with medication use, or dietary self-care. However, the *Beta* for timeline cyclical in Table 20 suggests stronger belief in cyclical symptoms is associated with more active blood glucose testing. Although this relationship is statistically significant ($Beta = .16, p < .01$), it is in the opposite direction to that predicted. Therefore, results do not support hypothesis 6e.

Hypothesis 6f. Stronger diabetes identity will be associated with less active self-care behaviour

Table 9 shows significant bivariate correlations between diabetes identity and two aspects of diabetes self-care behaviour (medication adherence, and dietary patterns). The direction of these associations was consistent with hypothesis 6f. However, when identity was entered as a potential predictor in multivariate analyses shown in Tables 17 and 19, inspection of *Betas* indicated identity did not show a significant relationship with diabetes self-care behaviour when controlling for demographic characteristics and relationships with other psychosocial variables. Thus results do not support hypothesis 6f.

Hypothesis 6g. Greater coherence will be associated with active self-care behaviour

Significant bivariate correlations were observed between coherence, and both medication adherence and dietary self-care in Table 9. The direction of observed relationships indicates greater coherence is associated with more active self-

management of diabetes. However, these relationships were no longer statistically significant when included within the multivariate analyses shown in Tables 17 and 19. Reported results do not support hypothesis 6g.

Hypothesis 6h. Stronger emotional representation of diabetes will be associated with less active self-care behaviour

Diabetes concern showed a negative relationship with both dietary self-care and medication use in bivariate correlations reported in Table 9. However, when entered into the regression analyses shown in Tables 17 and 19, negative emotional representation of diabetes did not show a significant relationship with diabetes self-care. Thus results do not support hypothesis 6h.

Hypothesis 6i. Higher treatment necessity will be associated with active self-care behaviour

Table 9 shows significant bivariate correlations between treatment necessity and three aspects of diabetes self-care behaviour. The direction of these associations was consistent with hypothesis 6i: higher treatment necessity showed a positive relationship with self-care behaviour. Medication necessity was entered as a potential predictor in the multivariate analyses shown in Tables 17, 19, and 20. Inspection of *Betas* reveals medication necessity showed a statistically significant relationship with dietary patterns ($Beta = .12, p < .05$), medication adherence ($Beta = .15, p < .01$), and blood glucose testing ($Beta = .12, p < .05$). Thus medication necessity showed a significant relationship with three out of four dimensions of diabetes self-care behaviour, and evidence of these associations remained even when controlling for demographic characteristics and relationships with other psychosocial variables. Reported results provide partial support for hypothesis 6i.

Hypothesis 6j. Lower treatment concern will be associated with active self-care behaviour

Bivariate correlations show treatment concern was associated with both medication adherence and dietary self-care. The direction of these relationships was as predicted (negative). The multivariate analysis reported in Table 17 indicates that, when controlling for the impact of demographic characteristics and relationships among

predictor variables, medication concern did not show a significant relationship with dietary self-care. However, multivariate results reported in Table 19 show evidence that medication concern is related to medication use ($Beta = -.21, p < .01$). Thus results provide partial support for hypothesis 6j.

Hypothesis 7

In the final hypothesis, attention was focused on medication adherence as a possible mediator in the relationships between treatment representations and Haemoglobin A_{1c}. Previous self-regulatory literature has recommended using a path analysis to investigate for mediating relationships between variables in the common sense model (Hagger & Orbell, 2003). Baron and Kenny (1986) present a diagrammatic representation of the mediation process. This can be viewed in Figure 2.

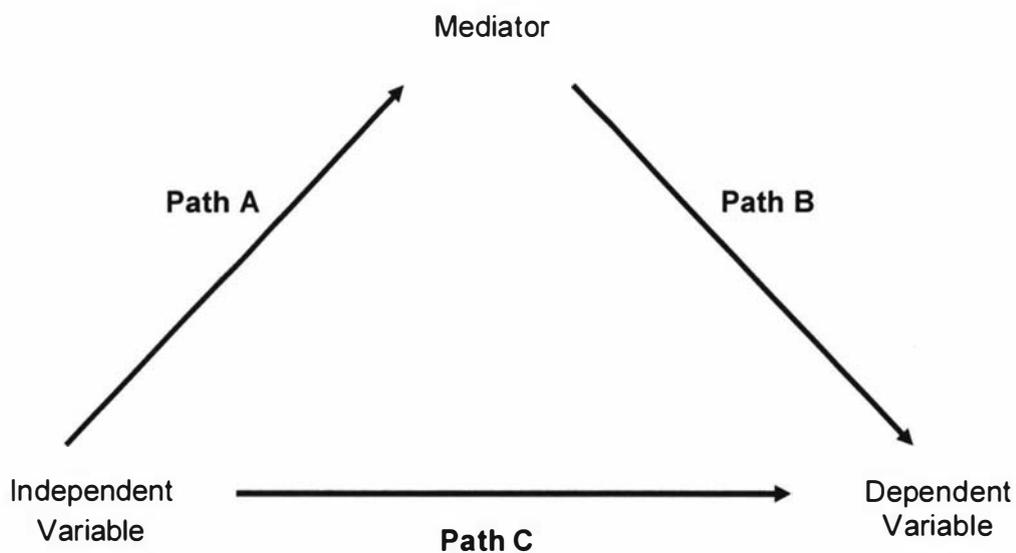


Figure 2. Replication of relationship pathways in the mediating model, as proposed by Baron and Kenny (1986).

The model shows two causal pathways. First, a direct relationship between the independent and dependent variables (Path C). Second, an indirect relationship via the proposed mediator (Paths A and B). Multiple regression analysis is recommended when testing for mediating relationships (Baron & Kenny, 1986; Holmbeck, 1997). To establish the presence of a mediating relationship, evidence of each of the three paths (A, B, and C) is required. One further condition must also be satisfied. When Paths A and B are controlled, the magnitude of the relationship previously shown in Path C must be reduced. If this relationship is reduced until it is no longer significantly different from zero, total mediation is shown. If the relationship is reduced in magnitude, but remains significant, partial mediation is present. In practical terms, this means comparing the standardized beta coefficient for the independent variable under two sets of conditions: first, when entered into a regression analysis alone (Path C); and second, when entered with the mediator (Path C with control for Paths A and B).

Holmbeck (1997) recommends that, before formal testing of mediation, empirical evidence of a connection between the proposed independent and dependent variables is established (Path C in Figure 2). Preliminary analyses were undertaken to ensure there were significant relationships between HbA_{1c} and both medication concern and medication necessity in the present study. Although a link between medication necessity and medication adherence was shown, no significant bivariate relationship between medication necessity and HbA_{1c} was evident in Table 9. Furthermore, an initial run of analysis two for hypothesis 7a showed no significant relationship between medication necessity and HbA_{1c} at the multivariate level. Without evidence showing support for Path C (Figure 2), no further analyses were undertaken for this hypothesis. It was concluded that results did not support hypothesis 7a.

However, as Table 9 demonstrated evidence of a significant relationship between medication concern, and both medication adherence and HbA_{1c}, formal testing of the proposed mediating relationship was undertaken. Three regressions were used to test the mediating relationship presented in hypothesis 7b, as recommended in research literature (Baron & Kenny, 1986; Feldman & Weinberger, 1994). Socio-medic characteristics showing a bivariate association with any of the three variables of interest (independent, dependent or mediator) were entered at step 1 of the analysis, as control variables. Table 21 shows the *Beta* coefficients and explained variance (Adjusted R^2 , R^2 Change) for each of the three hierarchical regressions.

The dependent variable in each analysis is shown in heading row 2, while predictor variables are presented in column 1. First, the mediator was regressed on the independent variable (Path A). Results are presented in columns two and three, headed 'Medication adherence (A*)'. Second, the dependent variable was regressed on the independent variable (Path C). The results of this analysis are shown in columns four and five, headed 'Haemoglobin A_{1c} (C*)'. Third, the dependent variable was regressed on the independent variable and the mediator in the same analysis. Results of the third analysis test for Path B, they also test for the final condition necessary to show mediation, namely that when Paths A and B are controlled, the magnitude of the relationship previously shown in Path C is reduced. Results of this last analysis are shown in columns six and seven, headed 'Haemoglobin A_{1c} (B*)'. This approach is consistent with that used in previous psychological literature (Feldman & Weinberger, 1994). The regression analyses relevant to hypothesis 7b are presented in Table 21; a diagrammatic representation of these relationships is provided in Figure 3.

Hypothesis 7b. Medication adherence will mediate the relationship between medication concern and HbA_{1c}

Three regression analyses were used to test hypothesis 7b. In the first analysis, medication adherence was regressed on control variables at step 1. Medication concern was entered into the analysis at step 2. Inspection of *Betas* show age and Pacific ethnicity were related to medication adherence at step 1; however, these associations were not present at step 2. Medication concern showed a moderate relationship with adherence, such that greater concern was linked to lower medication adherence (*Beta* = -.26).

Columns four and five show the results of the second regression analysis for hypothesis 7b. At step 1, HbA_{1c} was regressed on the six control variables. Of these, age, Māori ethnicity, Pacific ethnicity, length of diagnosis and treatment type all showed *Betas* that were significantly different from zero. These relationships were consistent across both steps of the analysis. Medication concern was entered into the regression at step 2. This variable showed a significant relationship with HbA_{1c}, with greater concern about prescribed treatment associated with higher HbA_{1c} (*Beta* = .19).

The third regression presented in Table 21 shows the relationship between medication concern and HbA_{1c} when controlling for socio-medic characteristics and medication adherence. *Betas* at step 1 and step 2 show that age, Māori ethnicity, Pacific ethnicity, illness duration, and treatment type were each related to the dependent variable. When entered at step 2, medication adherence and medication concern, both showed a significant relationship with HbA_{1c} (*Betas* = -.17 and .13, respectively). Lower medication adherence and greater concern about prescribed treatment were associated with higher HbA_{1c}. Standardized beta coefficients for medication concern with, and without, controlling for adherence are shown in columns seven and five of Table 21, respectively. In the second analysis, without medication adherence in the regression, the *Beta* for medication concern was .19. However, it is possible to compare this with the *Beta* shown in analysis three, when controlling for the mediation pathway, where the *Beta* for medication concern was .13. These relationships are shown as Path C in Figure 3. Although Path C shows both *Betas* for medication concern were significantly different from zero, the observed reduction in magnitude when controlling for medication adherence suggests partial mediation was present. It was concluded that research findings provided support for hypothesis 7b.

In summary, hypothesis 7 predicted that medication adherence would mediate the relationships between treatment representations and HbA_{1c}. Research findings showed no support for hypothesis 7a. However, results displayed in Figure 3 provide evidence that medication adherence mediates the relationship between medication concern and HbA_{1c}.

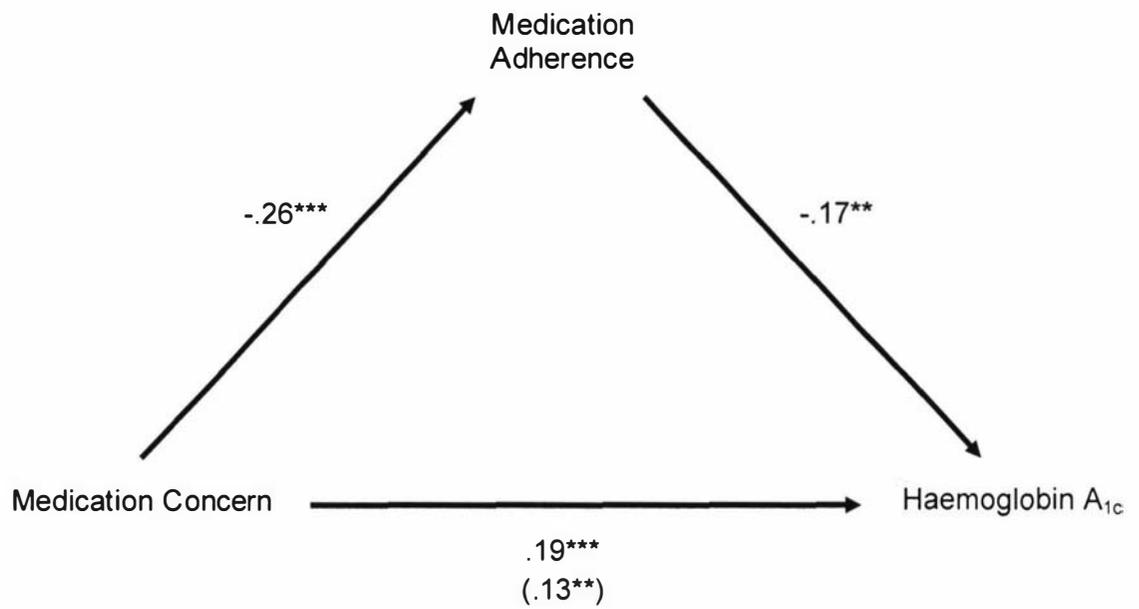
Table 21

Hierarchical Multiple Regression Analyses Assessing Medication Adherence as a Mediator of the Relationship between Medication Concern and Haemoglobin A_{1c} Showing Standardised Regression Coefficients (Beta), and Adjusted R²

Predictors	Outcomes of regression analyses					
	Medication adherence (A*) (N = 420)		Haemoglobin A _{1c} (C*) (N = 440)		Haemoglobin A _{1c} (B*) (N = 419)	
	Step 1	Step 2	Step 1	Step 2	Step 1	Step 2
Age	.144**	.090	-.24***	-.205***	-.234***	-.181***
NZ European dichotomy	.115	-.046	.03	.086	.038	.093
Māori dichotomy	-.076	-.133	.203*	.246**	.199*	.214*
Pacific dichotomy	-.154*	-.128	.215**	.199**	.225**	.184**
Length of diagnosis	.027	.004	.159**	.172***	.152**	.170***
Diabetes treatment	-.076	.091	.134**	.124**	.122**	.128**
Medication Concern		-.260***		.187***		.131**
Medication adherence						-.172***
R² Change	.111***	.057***	.167***	.030***	.157***	.051***
Adjusted R²	.098***	.154***	.155***	.184***	.144***	.192***

* p < .05 ** p < .01 *** p < .001

A* This analysis tests for Path A, Figure 2. B* This analysis tests for Path B, Figure 2. C* This analysis tests for Path C, Figure 2.



* $p < .05$ ** $p < .01$ *** $p < .001$

Figure 3. Diagrammatic representation of results from multiple regressions testing medication adherence as a mediator in the relationship between medication concern and HbA_{1c}. Coefficients outside brackets are standardized regressions weights (*Beta*); the value within the bracket is the *Beta* for medication concern when medication adherence was added into the third regression.

SUMMARY OF FINDINGS FROM HYPOTHESIS TESTING

The first hypothesis was supported. Psychosocial and behavioural factors were found to explain approximately 5% of the variation in HbA_{1c}.

The second hypothesis was supported. Psychosocial and behavioural factors were found to explain approximately 33% of the variation in diabetes-related distress.

The third hypothesis was supported. Psychosocial factors, self-care behaviour, and diabetes related wellbeing were found to explain approximately 20% of the variability in reported quality of life.

The fourth hypothesis that socio-medical context would be related to emotional illness/treatment representations was supported for the predicted relationships between conflict and diabetes concern (3a), and conflict and medication concern (3c). It was not supported for the relationship between support and medication concern (3d), and partially supported for the predicted association between support and diabetes concern (3b).

The fifth hypothesis was supported by research findings. After controlling for the impact of demographic and medical characteristics, psychosocial variables were shown to explain an additional 10% of variance in dietary self-care behaviour; 5% of variance in physical activity; 11% of variance in medication use; and 3% toward explained variability in blood glucose testing. These results demonstrate support for sub-hypotheses 5a, 5b, 5c, and 5d.

The sixth hypothesis was largely unsupported by reported results. Ten directional sub-hypotheses were stated. Multivariate analyses showed no support for sub-hypotheses 6a, 6b, 6c, 6d, 6e, 6f, 6g, or 6h. There was partial support for sub-hypotheses 6i and 6j. Medication necessity showed a statistically significant relationship with dietary patterns, medication adherence, and blood glucose testing. Medication concern was related to differences in medication use.

The seventh hypothesis that medication adherence would mediate the relationship between treatment representations and Haemoglobin A_{1c} was supported in regard to

medication concern (sub-hypothesis 7b). It was not supported for the predicted mediating relationship between medication necessity, medication adherence and HbA_{1c}.

CHAPTER 7
DISCUSSION

CHAPTER OVERVIEW

The purpose of chapter 7 is to discuss research findings from the present study, and integrate these with previous literature. This chapter will commence with a brief review of results from the current study. A synopsis of bivariate findings will be provided, attention will then be given to examining multivariate results in relation to five broad themes: (1) the relationships between psychological variables and metabolic control; (2) evidence for an emotional pathway in diabetes; (3) psychosocial factors related to quality of life; (4), psychosocial variables related to self-care; and (5) direct and indirect relationships in diabetes self-regulation. The focus will be on integration of key themes within an overarching framework, rather than extensive or detailed description of specific components or hypotheses.

Implications for self-regulatory theory will be discussed; following this the potential implications of research findings for clinical care are highlighted. Reflection on the conceptual approach and research methods employed in the present study provides an appreciation of its strengths and limitations. Recommendations for future research are made, and three areas are identified as pertinent targets for further empirical investigation. Chapter 7 will conclude by summarising the contribution of the present research to conceptual development within self-regulatory theory, and knowledge of diabetes self-management processes.

BIVARIATE AND DESCRIPTIVE FINDINGS

The purpose of the current section is to summarise key findings relating to the first research objective as described in chapter 4. This will focus on two aims: (1) summarising bivariate relationships of importance; and (2) providing a descriptive account of wellbeing among New Zealanders with type 2 diabetes. In relation to the first aim, as outlined in chapter 4, emphasis will be placed on relationships between (a) cognitive and emotional representations, and (b) illness and treatment perceptions.

Bivariate Relationships between Cognitive and Emotional Representations

The self-regulatory model presents two parallel pathways used in making sense of illness; cognitive and emotional (Leventhal et al., 2003; Leventhal et al., 1984). It also postulates an interactive relationship between these dimensions (Hagger & Orbell, 2003; Leventhal et al., 1984). Recent research using the IPQ-R among people with coronary heart disease has demonstrated a connection between cognitive and affective representations of illness (Byrne et al., 2005). Previous New Zealand research has also shown a link between cognitive and emotional illness perceptions among people with type 2 diabetes (Barnes, 2000).

In the present study, diabetes concern (negative emotional representation of diabetes, measured using the IPQ-R) was significantly associated with all other illness/treatment perceptions assessed, bar one (medication necessity). This indicates there are important connections between emotional and cognitive representations of diabetes. Current results imply people who are worried about diabetes (and/or prescribed treatments for diabetes) are more likely to: perceive they have less control over diabetes; agree that diabetes has serious consequences; find it hard to 'make sense' of diabetes; have a strong diabetes identity; and report fluctuating symptoms.

Earlier New Zealand research also reported correlations among representation variables. In a study by Barnes (2000), greater concern about diabetes was associated with stronger illness identity, higher perceived consequences, lower personal control, a belief that diabetes is difficult to make sense of, and the perception that diabetes symptoms fluctuate. The direction of relationships reported by Barnes is identical to those observed in the present study. Further, in both studies the cognitive representation variable showing the strongest relationship with diabetes concern was timeline cyclical.

Previous research using the IPQ-R has also reported a strong positive correlation between emotional representation and timeline cyclical among people with coronary heart disease (Byrne et al., 2005). The positive relationship between changeable illness symptoms and emotional representation is consistent with results from a large study ($N = 711$) incorporating participants from eight illness groups (Moss-Morris et al., 2002). It is concluded that variable symptoms may play a significant role in explaining

emotional responses among people living with chronic illness; this proposal is consistent with conceptual theorising in self-regulatory literature (Leventhal et al., 1980). Where researchers are interested in emotional aspects of illness, use of the IPQ-R is recommended over the Brief IPQ; as the latter does not assess cyclical timeline beliefs.

Results from the present study indicate emotional representation of diabetes *treatments* also shows significant associations with cognitive variables. Medication concern demonstrated a significant bivariate association with each of the seven cognitive IPQ-R variables; the direction of these relationships is consistent with those reported for diabetes concern. In the present study, treatment necessity did not demonstrate a significant bivariate correlation with emotional representation of diabetes, or emotional perceptions of prescribed medication. The absence of a significant relationship between medication concern and medication necessity concurs with the findings of previous research focused on asthma management (Horne & Weinman, 2002). Authors of the BMQ propose that beliefs about treatment necessity should be viewed as conceptually distinct from treatment concern, and these constructs should not be presented as “opposite poles of a more general attitude towards prescribed medication” (Horne & Weinman, 2002, p. 29). However, other self-regulatory research has reported a weak (statistically significant) positive correlation between medication concern and medication necessity (Byrne et al., 2005). The relationship between medication concern and medication necessity remains inconclusive.

Present findings and results from earlier research (Barnes, 2000) show preliminary evidence of relationship clusters within diabetes self-regulation. One group of cognitive variables (cyclical timeline, consequences, and diabetes identity) appears to show *positive* relationships with emotional representation of diabetes/treatments; a second group appears to demonstrate *negative* relationships with emotional representation of diabetes (chronic timeline, personal control, treatment control, and diabetes coherence). Some variables only show a very weak correlation with emotional representation of diabetes; in other cases, a moderately strong association is evident (for example, cyclical timeline, consequences, coherence, and identity). Bivariate relationships described thus far indicate that certain cognitive variables may play an

important role in emotional regulation, while other cognitive variables are disconnected from the common sense models emotional pathway.

Bivariate Relationships between Illness and Treatment Representations

Previous literature has shown relationships exist between the way people see an illness, and the way they view medical treatments (Byrne et al., 2005; Horne, 2003; Horne & Weinman, 2002). In the current study, medication concern demonstrated a significant bivariate association with each of the eight illness representation subscales. Among these relationships, the strongest correlation was between medication concern, and diabetes concern, suggesting that worry about diabetes is strongly connected with worry about diabetes treatments. Previous research examining secondary prevention in coronary heart disease has also reported a strong positive relationship between emotional representation of illness and concern about treatment (Byrne et al., 2005).

Medication concern showed moderate positive relationships with cyclical timeline, consequences, and identity; and a moderate negative correlation with diabetes coherence in the present study. Findings indicate people who are concerned about using medication also believe diabetes is difficult to make sense of, find their symptoms fluctuate, agree diabetes has serious consequences, and have a strong diabetes identity. This conceptual proposition is consistent with results reported by Byrne et al. (2005) in reference to coronary heart disease patients, excepting the positive relationship shown between medication concern and illness coherence. Findings reported by Broadbent et al. (2006) provide additional support for the proposed links between consequences, identity, and medication concern.

The present research shows that medication necessity is related to illness representations among people with diabetes, although the magnitude of correlations involving medication necessity is smaller than those observed between medication concern and illness representation variables. Greater belief in the need for treatment was weakly associated with perceptions that diabetes is a chronic condition, has serious consequences, and can be controlled by both personal action and prescribed treatments.

Horne et al. (1999) cite positive correlations between the subscale labelled 'specific-necessity' (illness specific need for medication) and the IPQ variables timeline, and identity. Similar results have also been reported in a more recent study (Broadbent et al., 2006). The positive relationship between treatment control and medication necessity observed in the current study is consistent with predictions made by Horne and Weinman (2002) in research focusing on asthma management. This implies people who believe pharmaceutical treatments are necessary are also likely to report such treatments are effective in controlling diabetes.

Wellbeing among New Zealanders with Type 2 Diabetes

As outlined in chapter 4, the second aim of the present study was to examine physical and psychological wellbeing among people with type 2 diabetes in New Zealand. Examination of age-based norms is important because previous research using the SF-36 suggests that as age increases, on average, self-reported physical functioning decreases while mental wellbeing increases (Ministry of Health, 2004).

Typically, diagnosis of type 2 diabetes occurs in middle adulthood (Clark & Asimakopoulou, 2005). The mean age of participants in the current research was 63 years ($SD = 11.6$). Comparison of mean score on the SF-12 PCS in the current study (44.0) with appropriate age-based norms from New Zealand and American (non-diabetes) research reveals a contrast. Results show physical function was lower than American norms for the 55–64 age category ($M = 46.55$) (Ware et al., 1998); it was also lower than New Zealand norms for adults aged 45–64 ($M = 48.9$ and 49.2 for males and females, respectively), and New Zealanders aged 65–74 ($M = 45.5$ and 45.3 for males and females, respectively) (Ministry of Health, 1999). When age-related differences are acknowledged, people with diabetes show lower than average physical functioning. Thus in comparison with general population-based norms, and norms *for their age group*, those with diabetes show evidence of impaired physical functioning.

However, participants in the present study showed a similar (or in some cases greater) level of physical functioning than people with type 2 diabetes in other parts of the world (mean PCS score = 35.6 (Edelman, Olsen, Dudley, Harris, & Oddone, 2002); 39.5 (Nichols & Brown, 2004); 44.84 (Ware et al., 1998); 40.96 (Lange & Piette, 2006)). Thus physically, people with diabetes in New Zealand appear worse off than those

without diabetes; but they do not seem worse off than peers with diabetes in other countries. On the basis of these results it is concluded that in New Zealand physical wellbeing among people with type 2 diabetes currently remains comparable with international levels. This is an important, and positive, finding.

In the present research, participants' mean score on the SF-12 MCS was 50.5. This is similar to American norms for the 55–64 age category ($M = 50.57$) (Ware et al., 1998), and only slightly lower than New Zealand norms for men ($M = 51.9$) and women ($M = 51.2$) aged 45–64 (Ministry of Health, 1999). These results imply that emotional functioning among people with diabetes in New Zealand is not notably different from their same-age peers without diabetes, both within New Zealand, and in America. When results from the present study were compared with those obtained in previous diabetes research, it appears that New Zealanders with type 2 diabetes exhibit a similar level of emotional functioning to diabetes peers located in other countries (mean MCS score = 48.8 (Edelman et al., 2002); 51.4 (Nichols & Brown, 2004); 52.49 (Ware et al., 1998)).

Based on results from the SF-12 it appears diabetes does not have a marked impact on emotional wellbeing, consistent with the categorisation of diabetes as a 'physical' illness. Many of the serious health consequences that accompany diabetes are of bodily nature (e.g., retinopathy, nephropathy), but patient narratives clearly illustrate the significant impact diabetes can have on emotional and social functioning. Further, the conclusion that diabetes does not have a notable impact on emotional wellbeing is at odds with recent research documenting the substantive emotional burden of diabetes (Peyrot, Rubin, Lauritzen, Snoek et al., 2005; Pouwer et al., 2005; Rubin, 2005), and elevated prevalence of clinical depression among people with diabetes (Goldney, Phillips, Fisher, & Wilson, 2004). Such findings lead to questions regarding the sensitivity of the SF-12 to detect compromise in emotional functioning among people with type 2 diabetes (Nichols & Brown, 2004). This issue warrants further discussion.

First, it is necessary to determine whether the SF-12 is capable of detecting serious impairment in mental health functioning. Authors of the SF-12 provide data enabling comparison of mean scores for patients with minor medical conditions, for example, uncomplicated hypertension ($N = 898$), with mean scores for patients with clinical

depression ($N = 242$) (Ware et al., 1998). Both groups showed a similar level of physical functioning (mean scores on the PCS-12 = 47.88 (depression) and 47.10 (minor medical)). However, people with clinical depression showed much greater compromise to mental health functioning (mean MCS-12 = 34.42) compared with the minor medical group (mean MCS-12 = 53.62). The mean difference between these groups (-19.20) was statistically significant ($F = 929.64$, $p < .001$). This provides some evidence that the SF-12 is capable of detecting serious impairment in mental health functioning.

Second, it is important to determine whether the SF-12 is sensitive enough to detect more modest compromise in emotional functioning, for example, the elevated emotional distress that may emerge from living with a serious, ongoing, health threat. Nichols and Brown (2004) compared people recently diagnosed with type 2 diabetes to an age- and gender-matched comparison group who did not have diabetes. Examination of mean scores on the PCS revealed a significant between-groups difference: people who met the criteria for diagnosis of diabetes were in lower physical health than those without diabetes. The authors of this study had anticipated the diabetes group would also exhibit compromise to emotional wellbeing. This argument was founded on three central premises: (1) depression is associated with lower scores on the MCS (Ware et al., 1998); (2) the prevalence of depression is higher among those with diabetes, than those without diabetes (Goldney et al., 2004); and (3) where diabetes and depression are found to coexist, evidence suggests depression is more likely to predate diagnosis of diabetes than the reverse (Talbot & Nouwen, 2000). The expectation that people with diabetes would exhibit lower mean MCS than the non-diabetic group was not supported by research findings. There was no significant difference in mean scores on the MCS for the two groups (Nichols & Brown, 2004). A similar result has emerged in other diabetes studies (Edelman et al., 2002).

To summarise two key points: first, people with type 2 diabetes in New Zealand appear to experience a similar level of physical and emotional wellbeing to peers with diabetes in other countries. Thus the SF-12 is useful because it enables comparison with norms from large national studies, and allows analysis of the similitude between results from the present study and previous diabetes research. Second, examination of the research literature suggests the SF-12 MCS may lack sensitivity when used as a measure of psychological wellbeing or quality of life in diabetes research. The MCS

has shown limited ability to differentiate between people who do, and do not, have diabetes (Nichols & Brown, 2004), although it is capable of detecting serious compromise to mental health, for example clinical depression (Ware et al., 1998).

One possible explanation for the observed disparity between mean scores on the MCS-12 ($M = 50.5$, $SD = 9.3$) and PCS-12 ($M = 44.0$, $SD = 10.0$) is that diabetes has no impact on emotional wellbeing. An alternative proposal suggests diabetes can have a measurable negative emotional impact but the SF-12, as a tool for assessing general functioning, is not capable of detecting this. The latter proposition is consistent with points raised in recent diabetes literature (Nichols & Brown, 2004). Such issues highlight the need for inclusion of both general, and *illness specific* measures of wellbeing, in diabetes research (Davidson, 2005; Hill-Briggs, Gary, Baptiste-Roberts, & Brancati, 2005; Woodcock, Julious, Kinmonth, & Campbell, 2001).

Alongside the SF-12, diabetes-specific measures of wellbeing were used in the current research. The Problem Areas In Diabetes (PAID) scale has been used to assess diabetes-related emotional distress in many previous studies (Pouwer et al., 2006; Pouwer et al., 2005; Snoek et al., 2000; Snoek & Visser, 2003; Welch et al., 2003). As seen in Table 10, mean PAID score in the present study was 19.6 ($SD = 19.1$). This is similar to average scores reported in previous research, although these range considerably and appear to vary according to participants' medical and socio-demographic characteristics (Pouwer et al., 2005; Snoek et al., 2000). In the current study, mean HbA_{1c} was 7.5 ($SD = 1.5$), as shown in Table 10. Chapter 1 described published medical guidelines for type 2 diabetes in New Zealand; these recommend an HbA_{1c} less than 7% (as evidence of 'good' diabetes control) (New Zealand Guidelines Group, 2003). Thus the average HbA_{1c} among participants in the present study was greater than that recommended by New Zealand medical guidelines. However, as shown in Table 7, 257 participants (42.1%) did meet this recommended goal. The level of glycaemic control shown in the present study is similar to that found in previous research (Lange & Piette, 2006; Pouwer et al., 2006; Pouwer et al., 2005; Snoek et al., 2000), although mean HbA_{1c} is lower (representing better metabolic control) than that reported in a number of intervention studies (Snoek & Visser, 2003; Weinger & Jacobson, 2001). A single item from the Audit of Diabetes-Dependent Quality of Life (ADDQoL) was used to assess self-reported quality of life (Bradley et al., 1999), with higher scores representing lower quality of life; the average score on this seven-point

scale was 2.7 ($SD = .96$). Descriptive statistics indicate that 45% of participants in the present research rated their quality of life as 'excellent' or 'very good'.

In the current study, potential group differences in wellbeing were evaluated. There was no evidence of gender differences in emotional wellbeing, medication beliefs, or self-reported medication adherence. Similarly, there was no significant variation in mean HbA_{1c} between men and women; however, there was a statistically significant difference in mean scores on the SF-12 PCS. Results reveal that, in the present study, on average men reported higher general physical functioning than women. This is consistent with trends shown in previous diabetes research using the SF-36 (Woodcock et al., 2001) and previous New Zealand research using the SF-36 (Ministry of Health, 2004).

Results from the present study reveal evidence of ethnic differences in emotional wellbeing, metabolic control, concern about diabetes medication, and use of prescribed medication. Across four cultural groups, Pacific ethnicity was associated with highest HbA_{1c}, greatest diabetes-related distress, strongest concern about use of prescribed medication, and lowest reported concordance with the recommended pharmaceutical regimen. This suggests that, across indicators of physical health (HbA_{1c}) and emotional wellbeing (PAID), Pacific people bear the greatest burden as a result of type 2 diabetes. These findings are consistent with previous research by Barnes (2000) showing Tongan patients have lower dietary self-care, less frequent blood glucose testing, lower reported adherence to prescribed medication, and worse metabolic control than people of New Zealand European ethnicity (Barnes, 2000). Tongan participants were also more concerned about using prescribed medication, and displayed greater worry about diabetes.

Results from the present study, and findings reported in previous research (Barnes, 2000) suggest the overall character of diabetes self-regulation among Pacific people may be notably different from New Zealand Europeans. For example, because Pacific people display greater emotional distress about diabetes, and higher concern about use of medication, regulation of affect may become more salient. This implies affect, rather than cognition, might become the primary determinant of coping strategies among Pacific people with diabetes. As a result, cultural differences in coping styles are hypothesised, such that, in comparison with other ethnic groups, diabetes self-

regulation among Pacific people might be more likely to draw on coping strategies aimed at reducing the salience of the perceived threat rather than coping strategies that focus on getting an accurate understanding of the health threat (i.e. employment of directed processing rather than substantive strategies (Cameron, 2003)).

It is interesting to note the *absence* of significant differences between Pacific people and any other cultural group in mean scores on the SF-12 PCS, and SF-12 MCS in the current study. This implies that people of Pacific ethnicity do not differ from other cultural groups in terms of their *general* emotional and physical functioning; the differences between Pacific people and other ethnic groups were only observed in relation to indicators of *diabetes specific* physical and emotional wellbeing. Results of the present study are consistent with a British study that reported no significant ethnic differences in scores on the SF-36 PCS among adults with type 2 diabetes (Paschalides et al., 2004).

To summarise, findings from the present study imply that, on average, people with type 2 diabetes in New Zealand experience a similar level of physiological and self-reported health as those with diabetes in other countries. Results from the AD-DQoL suggest people with diabetes can continue to experience good quality of life despite living with a chronic health condition. However, there is evidence of cultural variability in diabetes specific indicators of wellbeing.

As emphasised in chapter 4, examination of bivariate relationships and descriptive findings is a constructive first step in research. However, further detailed discussion of these is deemed inappropriate (for example, focusing on each significant association) because bivariate results do not constitute strong evidence of reliable relationships, and there is a risk of over-interpretation. This risk is compounded in areas where there is a dearth of previous literature, such as self-regulatory process in diabetes. Therefore, attention will now be turned toward examination of multivariate results.

SYNOPOSIS OF MAIN FINDINGS FROM HYPOTHESIS TESTING

Hypotheses 1, 2, and 3 predicted that psychosocial variables would account for variance in key outcomes of interest (HbA_{1c}, diabetes-related emotional distress, and quality of life, respectively). Multivariate analyses showed that, when controlling for demographic and medical characteristics: (a) illness/treatment representations and self-care behaviour accounted for significant variability in metabolic control; (b) socio-medical context and illness representations explained variance in diabetes-related distress; and (c) socio-medical context, illness/treatment representations, and diabetes-related wellbeing accounted for differences in quality of life. Results show psychosocial and behavioural variables are better at explaining variation in diabetes distress (33%) and quality of life (20%) than metabolic control (5%). Hypothesis 4 tested for relationships between support and conflict from socio-medical sources, and affective representations of diabetes. Results showed higher perceived interpersonal conflict over diabetes is associated with greater concern about diabetes and prescribed treatments for diabetes.

Hypothesis 5 predicted that psychosocial variables would account for differences in diabetes self-care behaviour. This hypothesis was supported, though self-regulatory variables were better at explaining variance in medication use (11%) and dietary self-care (10%), than physical activity (5%) or blood glucose testing (3%). Ten directional sub-hypotheses were specified in hypothesis 6. These were largely unsupported; illness representations demonstrated few significant relationships with diabetes self-care in multivariate analyses. The seventh, and final, hypothesis stated that medication adherence would mediate the relationship between treatment representations and HbA_{1c}. Results showed medication use mediates the relationship between treatment concern and metabolic control. In summary, self-regulatory variables demonstrate explanatory power in regard to key diabetes outcomes. Findings show the common sense model provides a useful conceptual framework for examining self-care and wellbeing among people with type 2 diabetes.

THEMATIC DISCUSSION OF KEY RESEARCH FINDINGS

This section examines key findings under five broad thematic headings encompassing (a) key relationship pathways within the common sense model, and (b) variables of central importance in diabetes management.

Psychosocial Variables Related to Metabolic Control

The first thematic discussion examines the relationships between psychosocial variables and metabolic control. Diabetes literature has debated whether HbA_{1c} is the “most appropriate outcome variable on which to focus in a study of psychological variables” (Hampson et al., 1990, p. 644). However, HbA_{1c} plays a pertinent role in determining physical *and* psychological wellbeing among people with diabetes. At present we do not have a good knowledge of the relations between psychological variables and HbA_{1c}. Some studies show illness representations can explain differences in metabolic control (Griva et al., 2000; Hampson et al., 1995; Skinner et al., in press); others report contrary findings (Eiser et al., 2001; Paschalides et al., 2004).

Bivariate results from the current study suggest people who (a) agree diabetes is a lifelong condition, (b) have a strong sense of personal control over diabetes, and (c) feel they can make sense of diabetes, are likely to show better metabolic control. Conversely, people who (a) find diabetes causes family conflict, (b) report a poor relationship with diabetes health professionals, (c) believe diabetes symptoms come and go, (d) agree that diabetes has serious consequences, (e) have a strong diabetes identity, (f) worry a lot about diabetes, and (g) are concerned about using prescribed medication, are likely to exhibit poor metabolic control. These findings are largely consistent with previous research. However, anomalies can be noted. Three of these have been selected for discussion: first, the importance of interpersonal conflict over interpersonal support; second, the absence of relationships between treatment representations and HbA_{1c}; and third, the lack of an association between perceived control and HbA_{1c}.

In the present study, conflicts over diabetes with family and with health professionals were both related to lowered metabolic control. It is interesting to note the absence of

any significant associations between family support/patient-provider support and metabolic control. To date, the majority of diabetes research has focused on the positive impact of interpersonal support in diabetes self-management (e.g., Albright et al., 2001; Fisher et al., 1997; Lo, 1999; Tillotson & Smith, 1996; Wang & Fenske, 1996). However, findings from the present study highlight the important role interpersonal conflict may play in determining wellbeing among people with type 2 diabetes. This is consistent with results from research among adolescents with type 1 diabetes (Schafer et al., 1986), but contrasts with themes emerging from previous research among people with type 2 diabetes (Glasgow & Toobert, 1988).

Results from the present study imply the absence of conflict may be more important than the presence of support in promoting positive good metabolic control. Previous literature has recommended that diabetes clinicians consider ways of encouraging positive family involvement in diabetes care (Wen et al., 2004); current findings indicate clinicians might also want to consider interventions to reduce negative family interactions. Reflective self-analysis of clinical practice is also encouraged. In the medical context, it is often presumed that patients *should* act in a rational way; and that 'rational' is synonymous with clinical recommendations. This creates both a moral expectation that patients comply with medical advice in order to stay well; and conversely, the potential to blame the person with diabetes if illness outcomes are poor (Broom & Whittaker, 2004; Paterson et al., 2001).

While personal behaviour may often deviate from clinical recommendations, it is almost always *rational to the individual concerned*, in that context and at that point in time (Lyons & Chamberlain, 2006). Indeed, a synthesis of 10 qualitative diabetes studies has suggested strategic 'non-compliance' may be associated with acceptance of diabetes, and improved glycaemic control (Campbell et al., 2003). It is important that health professionals recognise plurality in views about diabetes/self-care (Gillespie & Bradley, 1988; Hornsten et al., 2004; Zoffmann & Kirkevold, 2005), and do not dismiss the validity of the patient's perspective (Paterson et al., 1999). Conflict between patient and doctor/nurse may arise when disparity in viewpoints is combined with privilege of the medical perspective in clinical settings. In a study by Paterson (1999), people with diabetes reported experiencing conflict with clinical staff whose views did not correspond with their own needs or preferences about diabetes care.

In conclusion, analysis of narratives from physicians indicates “management of diabetes is frequently a difficult and frustrating process for both parties” (Loewe et al., 1998, p. 1274). However, both patients and health professionals seem somewhat unaware of the presence of interpersonal conflict within clinical relationships (Zoffmann & Kirkevold, 2005). In diabetes, the patient-provider relationship may benefit from research that identifies (a) common sources of conflict, and (b) effective strategies for resolution. For example, the usefulness of a mutuality-expecting approach over a compliance-expecting approach has been highlighted in recent research (Zoffmann & Kirkevold, 2005).

Previous literature has emphasised the importance of perceived control over diabetes, as a potential determinant of HbA_{1c}. In a prospective study, Hampson et al. (2000) employed multiple regression analyses to compare the predictive utility of personal model variables (seriousness, control, and treatment effectiveness) and depression in determining diabetes outcomes across a three-month period. Results showed that perceived control was a significant determinant of metabolic control, with the direction of this relationship implying greater perceived control is related to lower HbA_{1c} (partial $r = -.26, p < .01$), that is, better metabolic control. Other studies have also presented evidence of an association between perceived control over diabetes, and HbA_{1c} (e.g., Wearden et al., 2005).

Bivariate correlations in the present study showed no significant correlation between treatment control and HbA_{1c}, and a very weak association ($r = -.09, p < .05$) between personal control and HbA_{1c}. Multivariate findings imply perceived control does not make a significant contribution to explaining variance in metabolic control among people with type 2 diabetes in New Zealand. This is consistent with results reported by Griva et al. (2000), in which hierarchical regression analysis showed diabetes identity, consequences, and diabetes self-efficacy were positively and significantly associated with HbA_{1c}, while perceived control failed to show a significant relationship with HbA_{1c}. Similarly, Broadbent et al. found no significant correlations between HbA_{1c} and perceived personal control ($r = .02, p = .86$), or treatment control ($r = .18, p = .09$), using the IPQ-R (Broadbent et al., 2006).

Recent evidence suggests the relationships between perceived control and HbA_{1c} are complex, and observed associations may depend on the *specific* type of control

variable under examination. For example, although Broadbent and colleagues report no significant association between HbA_{1c} and either personal control or treatment control when using the IPQ-R, when the Brief IPQ was employed higher personal control was related to lower HbA_{1c} ($r = -.30, p < .01$), while higher treatment control was significantly associated with higher HbA_{1c} ($r = .21, p < .05$). The authors imply this intriguing finding may be the result of connections between high personal control and internal locus of control and, conversely, an association between high treatment control and external locus of control (Broadbent et al., 2006).

An alternative explanation for these results may lie in the links between high personal control and self-efficacy. Personal control over diabetes has shown a strong positive relationship with diabetes specific self-efficacy in prior research (Griva et al., 2000). Both variables share a conceptual foundation; namely, confidence that personal action is effective in managing diabetes. Cross-sectional research among adults with diabetes has shown diabetes specific self-efficacy is an important correlate of both self-care behaviour, and metabolic control (Griva et al., 2000). A recent study among Japanese with type 2 diabetes has also shown greater self-efficacy is an important prospective predictor of exercise and dietary self-care behaviour (Nakahara et al., 2006).

Current findings suggest that when controlling for the impact of demographic and medical characteristics (age, length of diagnosis, ethnicity), and relationships *among* variables entered into the regression, psychological and behavioural variables only explain a small proportion of differences in metabolic control. Interpersonal relationships did not explain a significant proportion of variance in metabolic control; although illness/treatment representations and self-care behaviour explained variance in HbA_{1c} this contribution was small (approximately 6%, and 3%, respectively). Inspection of *Beta* coefficients at step four of the analysis reveals that, among the 14 psychological and behavioural variables entered, only one (smoking) showed a significant relationship with metabolic control. However, it should be noted that medication concern showed a significant positive association with HbA_{1c} at step 3 of the regression analysis. This relationship was reduced to non-significance when health behaviour was entered at step 4 of the analysis. The observed change in *Beta* value implies a mediating relationship may be present, whereby self-care behaviour acts to mediate the relationship between treatment representations and metabolic control.

This proposition was explicitly tested in hypothesis 7; findings will be described in detail in a later subsection entitled 'Direct and indirect relationships in diabetes self-regulation.'

In summary, variables included in the present study explained 15% of the variation in metabolic control. The majority of this explained variance can be attributed to demographic and medical characteristics. Multivariate findings indicate self-regulatory variables make a very modest contribution to explanation of variability in HbA_{1c}. The ecological environment surrounding diabetes (interpersonal support/conflict) was not found to explain a significant proportion of the variance in metabolic control; illness/treatment representations and self-care behaviour did make a significant contribution to explained variance (approximately 6%, and 3%, respectively). On the basis of these results it is concluded that self-regulatory variables account for a small, but statistically significant, percentage of variability in HbA_{1c} among people with type 2 diabetes.

The conclusion that psychological variables included in the present study make a very modest contribution to explained variance in regard to disease state is consistent with the conclusion reached by Hagger and Orbell (2003) in their meta-analytic review of self-regulatory literature. Previous diabetes literature has placed strong emphasis on the significant role self-care plays in promoting good metabolic control, as described in chapter 1. In the current study, illness/treatment representations were found to explain a greater proportion of the variability in HbA_{1c} than self-care variables. This notable finding implies it would be premature for researchers to discount entirely the importance of illness/treatment representations in determining physiological outcomes.

Preliminary Evidence for an Emotional Pathway in Diabetes

The second thematic discussion focuses on evidence for an emotional pathway in diabetes self-regulation. Variables included in the current study were found to explain 54% of variability in scores on the PAID, in comparison with 15% of differences in HbA_{1c}. After controlling for the impact of demographic and medical characteristics, psychosocial variables accounted for an additional 34% of unique variance in diabetes related distress. Findings imply socio-medic relationships explain approximately 14% of variability in scores on the PAID; illness/treatment representations account for a

further 20% of variance in emotional distress about diabetes. Differences in self-care behaviour did not make a significant contribution to explained variation in diabetes distress. Findings from the current study show both interpersonal and intrapersonal factors make a significant, unique, contribution to explained variability in emotional distress about diabetes.

Results from the current study highlight individual variables that may play an important role in regulating emotion in chronic illness. It is sensible to integrate bivariate and multivariate findings, as these emphasise complementary themes. All four socio-medical variables showed a significant bivariate correlation with scores on the PAID. Greater interpersonal conflict over diabetes, and lower perceived support, were both related to higher emotional distress about diabetes. Multivariate results provide additional evidence of connections between the ecological context surrounding diabetes self-management and emotional aspects of diabetes self-regulation, these show less family support, greater family conflict, and higher patient-provider conflict are associated with increased emotional representation of diabetes; greater conflict over diabetes with family and health professionals is also associated with increased concern about prescribed treatments.

Collectively, results presented in Tables 13, 15, and 16, suggest the emotional tone (support versus conflict) of interpersonal relationships pertinent to diabetes management might shape individually held emotional representations of diabetes and diabetes medication; these illness/treatment representations may in turn mould psychological outcomes for people with diabetes. Current findings fuel speculation that illness/treatment representations act to mediate the relationship between the interpersonal environment and diabetes-related distress (scores on the PAID). Results presented in Table 13 show that at step four of the analysis, only family support and family conflict maintained significant *Beta* coefficients. Although patient-provider conflict demonstrated a significant *Beta* when entered at step 2 of the analysis, this relationship was not maintained when illness/treatment representations entered the regression at step 3. Family support and family conflict also showed a substantial reduction in *Beta* values at step 3 of the regression. These changes imply probable mediating relationships.

Multivariate findings intimate that family support may play a more important role in the regulation of distress about diabetes than supportive interaction with health professionals. Conceptually, this makes some sense, as the vast majority of day-to-day interaction regarding diabetes management takes place in the home environment (Scott & Brown, 1989). Furthermore, diabetes health services in New Zealand are not currently equipped to, or focused on, meeting the emotional needs of people with diabetes. Instead there is a strong emphasis on evidence-based guidelines for managing physiological changes. As a result, people with diabetes are unlikely to find clinicians expect to discuss or help manage any emotional concerns they may be experiencing in relation to diabetes, or its life consequences. It is therefore not so surprising to find patient-provider support failed to show a significant association with diabetes distress in the multivariate analysis displayed in Table 13. Results are likely to reflect the current status quo (limited attention to emotional aspects of diabetes in clinical care). However, these findings may not give credence to the *potential* positive impact health professionals could have on dealing with diabetes worries. They simply suggest that this is not evident in the present study.

Reported findings should not dissuade researchers from examining the impact of patient-provider relationship on emotional adjustment to diabetes. More importantly, they should not discourage health professionals from attending to both the physical *and* emotional consequences of living with diabetes. People with diabetes emphasise the important contribution positive family relationships can make in helping manage diabetes worries (Kelleher, 1988; Rubin, 2005; Wen et al., 2004). However, they also emphasise the importance of finding a 'good' doctor (or nurse), someone who understands them personally. New Zealand literature suggests physicians who are conscious of the connections between psychosocial wellbeing and diabetes management, and attentive to the emotional needs of their patients, experience greater success in achieving good metabolic control among their patients (Scott & Brown, 1989).

Although reported findings suggest social environment can play an important role in regulation of affect, in the present study individual illness/treatment representations were found to explain a larger proportion of variability in diabetes distress. As expected, diabetes concern and medication concern demonstrated strong positive relationships with scores on the PAID. Current findings also highlight *specific* cognitive

patterns that may contribute to elevated distress about diabetes. Bivariate correlations suggest people who agree that diabetes has serious consequences, believe that diabetes symptoms fluctuate, have a stronger diabetes identity, and find diabetes is hard to make sense of, are more likely to show greater emotional distress about diabetes.

Diabetes identity showed positive bivariate relationships with diabetes concern and treatment concern, and identity also demonstrated a significant relationship with diabetes distress (assessed using the PAID) at both bivariate and multivariate levels. Similarly, timeline cyclical showed moderate to strong bivariate relationships with diabetes concern and treatment concern, and a significant positive association with diabetes-related distress in the hierarchical regression presented in Table 13. Bivariate and multivariate results are consistent, implying timeline cyclical and diabetes identity are connected to regulation of affect among people with type 2 diabetes. Timeline cyclical and identity are both forms of symptom appraisal. Thus findings from the present study provide emerging evidence of a notable connection between symptom perception and regulation of affect among people with type 2 diabetes. Further empirical investigation in this area is recommended.

Perceived consequences and coherence may also play a pertinent role in the regulation of emotion in chronic illness. Bivariate relationships show agreement that diabetes has serious consequences was associated with greater emotional distress about diabetes; conversely, higher coherence (a belief that diabetes 'makes sense') was related to lower scores on the PAID. A significant multivariate association between consequences and diabetes distress was also evident, although coherence did not demonstrate a significant relationship with the dependent variable in this analysis. Previous research has emphasised the significance of perceived seriousness in determining self-care behaviour among people with diabetes (Glasgow et al., 1997; Hampson et al., 1990; Skinner et al., in press; Skinner et al., 2002). Findings from the current study extend this, by suggesting the perception that diabetes has serious consequences is also related to differences in emotional adjustment to diabetes.

Results from the current study demonstrate a positive relationship between emotional concern about diabetes, and worry about diabetes treatments. Medication concern showed a strong bivariate correlation with both diabetes concern (measured using the

IPQ-R) and diabetes-related distress (assessed using the PAID). Further, inspection of *Beta* coefficients displayed in Table 13 reveals that, among variables included in this analysis, medication concern showed the strongest association with diabetes-related distress. This attests to the important connection between emotional representations (a) chronic illness per se, and (b) prescribed treatments. Findings from the current study support the assertion that "patients' beliefs about medicines and illness seem to be related in a logical way" (Horne, 1997, p. 177).

Collectively, results from the present study and previous self-regulatory research (e.g., Barnes, 2000) imply people who are worried about diabetes (and/or prescribed treatments for diabetes), are more likely to agree that diabetes has serious consequences, find it hard to 'make sense' of diabetes, have a strong diabetes identity, and report fluctuating symptoms. Findings suggest activation of illness-specific affect is associated with particular cognitive patterns. Some variables only show weak relationships with emotional representation of diabetes, others demonstrate a moderately strong association (for example, cyclical timeline, consequences, coherence, and identity). Further, inspection of bivariate correlations shows a network of moderate to strong associations *among* these four cognitive variables. Consequences, identity, and timeline cyclical are positively and significantly related, and each of these three variables shows a significant negative relationship with coherence. Conceptually, this indicates evidence of a possible relationship cluster within diabetes self-regulation.

Earlier self-regulatory research reveals support for this proposed relationship cluster. In a New Zealand study by Barnes (2000), greater emotional representation of diabetes showed moderate to strong relationships with timeline cyclical, identity, consequences, and coherence. Byrne et al. (2005) also report similar relationship patterns among people with coronary heart disease. In a large study ($N = 711$) incorporating eight chronic illness groups, emotional representation also demonstrated significant correlations with timeline cyclical, consequences, and coherence; however, no relationship between emotional representation and identity was evident in this study (Moss-Morris et al., 2002). Among the seven cognitive representations assessed in this latter study, three (consequences, timeline cyclical, and coherence) were shown to be significant predictors of emotional representations among people with multiple sclerosis.

Empirical evidence shows stronger illness identity, serious consequences and lower coherence are associated with negative emotional *adjustment* among people with diabetes. Findings reported by Paschalides et al. (2004) and Wearden et al. (2005) show strong positive associations between diabetes identity and depression, anxiety, and fatigue. Research among adolescents with diabetes has also shown positive relationships between illness identity and both depression and anxiety (Edgar & Skinner, 2003; Skinner et al., 2003). Research by Skinner and Hampson (1998) demonstrated a positive relationship between serious consequences, depression and anxiety. Greater perceived consequences has shown a positive relationship with anxiety in other studies among adolescents with type 1 diabetes (Law et al., 2002), and adults with type 2 diabetes (Wearden et al., 2005). Watkins et al. (2000) report a poor understanding of diabetes treatments is related to feelings that diabetes (a) is burdensome and (b) has a negative psychological impact; this proffers support for the negative association between coherence and emotional representations evident in the current research.

Critical reflection raises two key issues: the need to distinguish between generalised negative affect and illness-specific affect, and consideration of wider self-regulatory literature that shows a discrepancy with the proposed relationship cluster. First, earlier research shows identity, cyclical timeline, consequences, coherence, and emotional representations are significantly correlated with negative affect, but the magnitude of observed relationships indicates *illness specific* emotional responses are conceptually distinct from a generalised disposition towards negative affect (Moss-Morris et al., 2002).

Second, while self-regulatory research has shown low perceived control is associated with negative emotional responses to chronic illness, these relationships are generally weak in magnitude (e.g., Hagger & Orbell, 2003; Hagger & Orbell, 2005; Moss-Morris et al., 2002). Where earlier diabetes research has shown an association between perceived control and negative emotional outcomes (depression, anxiety, and fatigue), the magnitude of this relationship has been smaller than those demonstrated between emotional outcomes and identity or consequences (Law et al., 2002; Paschalides et al., 2004; Wearden et al., 2005). The same caveat is applicable to research showing a significant relationship between chronic timeline and negative emotional outcomes (depression, anxiety, and fatigue) (Paschalides et al., 2004; Wearden et al., 2005).

Although timeline acute/chronic has demonstrated a moderate positive relationship with emotional illness representation among people with an abnormal cervical screening result (Hagger & Orbell, 2005), this association might be less likely among people with type 2 diabetes. Belief about the expected timeline for illness duration will show greater variability where curative potential remains (e.g., cervical abnormalities). There is no cure for type 2 diabetes at present, and most people know this already; almost all people with type 2 diabetes report they will have diabetes for life (Hampson et al., 1990). As a result, there may be very little variation in beliefs about how long diabetes will last; this assertion is consistent with published literature (Law et al., 2002). If, as hypothesised, the IPQ-R variable 'timeline acute/chronic' shows restricted variance among people with diabetes, researchers might not expect to see a strong relationship between timeline acute/chronic and other illness representations.

Arguably, the nature of association between timeline acute/chronic and emotional representations might depend on the illness specific context. This could explain why chronic timeline is more likely to be associated with emotional responses to some illnesses (e.g., cervical abnormalities), and not others (e.g., type 2 diabetes). Conversely, variability in blood glucose levels means the IPQ-R variable 'timeline cyclical' plays a very important part in self-regulation of diabetes, but not in contexts where the illness is largely asymptomatic (Hagger & Orbell, 2005).

Earlier self-regulatory theory has identified a positive relationship between greater perceived control (personal control and treatment control, but particularly the latter) and acute timeline (Hagger & Orbell, 2005); suggesting these three variables may form a second relationship cluster separate to that identified in current findings. Multivariate results from the present research imply that if perceived control and chronic timeline contribute to regulation of diabetes related affect, their role is subsidiary; other variables appear to play a more central role in affect regulation among people with type 2 diabetes (e.g., perceived consequences, and cyclical symptoms). On the basis of relationships observed in the current study, it is proposed that negative emotional responses to chronic illness are likely to occur in the context of a serious (long-term) threat to health that is hard to understand, has serious consequences, and exhibits symptoms that come and go. Strong illness identity also appears to be linked to negative emotional representation. This proposition is largely consistent with the

network of associations hypothesised in prior self-regulatory research (e.g., Hagger & Orbell, 2005; Hagger & Orbell, 2006).

In summary, while self-regulatory literature postulates that illness representations will show “a systematic and logical pattern of relationships” (Hagger & Orbell, 2003, p. 144), few previous studies have discussed the presence of a relationship cluster involving more than a simple dichotomy. The identification of a possible relationship cluster connecting emotional illness responses with cyclical symptoms, serious consequences, strong identity, and low coherence, is an important theoretical contribution arising from the present study. This provides embryonic evidence of an emotional pathway in diabetes self-regulation.

Betas shown in Table 13 indicate that medication adherence displayed a significant relationship with diabetes distress at the multivariate level. The direction of this association, showing greater self-reported adherence to prescribed pharmaceutical treatments is associated with *greater* emotional distress about diabetes, demands discussion. Although this relationship was weak in magnitude, it was statistically significant even when controlling for the impact of demographic variables, socio-medical context, and illness/treatment representations. At present, the causal direction of this association remains ambiguous. Findings might imply that strong adherence to medical recommendations is good for your physical health but, perhaps, not so good for your mental health. This interpretation receives some support from narratives within patient literature. Kelleher (1988) describes a gentleman whose belief in the need for strict adherence to his prescribed insulin regimen interfered substantially with his social functioning (and likely, the marital satisfaction of his wife); he was reluctant to go out for a shared meal with friends because of a fear this would prevent proper timing of glucose testing and insulin administration. To summarise a key point; findings reported in the current study offer critique to the presumption that tight adherence is ‘good’ for you; this reflects a (largely unstated) privilege of physical health and may downplay the negative psychological and social impact rigid treatment adherence could have.

Demographic and medical characteristics may also shape emotional responses to diabetes. In the present study bivariate correlations show a negative association between age and scores on the PAID; greater age was also related to lower diabetes distress in multivariate results displayed in Table 13. On average, younger adults will

have less previous experience with chronic illness compared with older adults, as the relative risk for many common chronic diseases increases with age (e.g., coronary heart disease). Because experience provides an opportunity to build up coping skills, older adults may be better able to adjust when faced with a serious health threat; it is possible that younger persons may be less well equipped, and as a result diagnosis of diabetes has a greater impact on their life. It is useful for clinicians to be aware that younger people are at greater risk of experiencing high emotional distress about diabetes and therefore might require assistance in managing the emotional impact of living with diabetes.

Length of diagnosis did not show a significant association with diabetes distress in the current study; however, more intense treatment regimen (for example, use of insulin) did show a weak negative relationship with scores on the PAID. As discussed previously, there were significant between-group differences in scores on the PAID. Results from step 1 of the hierarchical regression in Table 13 show NZ European ethnicity is associated with lower distress about diabetes; however, the *Beta* value for this variable reduced considerably at step 2 (to non-significance), and again at step 3. This intimates a possible mediating relationship, whereby cultural differences in diabetes distress may arise, in part, from variation in interpersonal support/conflict for diabetes management and differences in beliefs about diabetes.

Observed changes in *Beta* coefficients shown in Table 13 imply complex relationships may exist between psychological variables and diabetes specific emotional distress. There is preliminary evidence that: (a) psychosocial variables mediate the relationship between ethnicity and distress; (b) illness/treatment representations mediate the relationship between patient-provider conflict, family support/conflict, and diabetes distress; and (c) suppressor variables may be present (the *Beta* for diabetes treatment only became statistically significant at 3 of the analysis). There is also evidence of direct relationships. Four illness representation variables (timeline cyclical, consequences, diabetes identity, and medication concern) show a relationship with emotional adjustment to diabetes; this does not appear to be mediated by self-care behaviour.

One interesting finding arising from the current research is the positive association demonstrated between medication adherence and distress in Table 13. As outlined

previously in the current section, it may be that tight adherence to medical advice results in increased emotional distress about diabetes. An alternative proposition implies emotional arousal may activate health-promoting behaviour; i.e. negative affect is necessary to encourage good self-care. This suggestion is consistent with conclusions drawn by Lawson and colleagues (2004) in reference to use of diabetes health services. Early self-regulatory literature also emphasised the importance of perceived threat, concluding that “fear ... can serve to motivate behavior” (Leventhal et al., 1980, p. 11).

For the most part, emotional arousal appears to be a healthy and appropriate response when illness threatens one’s personal wellbeing. As argued by Cameron (2003), from an evolutionary perspective, emotional arousal is *primarily* health promoting. It alerts us to danger, and prompts us to take action to reduce this threat. In the context of diabetes, emotional arousal may have many, sometimes contradictory, relationships with self-care behaviour. Whether emotional arousal is health promoting or not may depend on three core features: (a) the *level* of emotional arousal; (b) the *chronicity* of this state; and (c) whether coping mechanisms are effective in *successfully regulating* levels of negative affect.

It is suggested that extreme emotional arousal (very high, or very low) is likely to have a negative impact on self-care behaviour. This implies a curvilinear relationship may be present; self-care behaviour is optimised when moderate emotional arousal is present. Level of arousal may also form an interactive relationship with chronicity. Short periods of high emotional arousal regarding diabetes are not likely to have a substantive negative impact on self-care. In fact the opposite may be true: these could help to stimulate and re-energise self-care behaviours among people who live with an ongoing illness. However, if high distress about diabetes continues across months or years, this may have a notable negative impact on self-care behaviour, and mental wellbeing. As early self-regulatory theory noted, ongoing elevated distress about illness is linked to feelings of hopelessness and vulnerability (Leventhal et al., 1980). Chronic distress about diabetes is likely to have negative impact on self-care; it may also have a direct negative impact on physiological processes that govern metabolic control (Griva et al., 2000).

Conversely, disinterest in diabetes or its potential consequences is likely to result in very low emotional distress about diabetes. Behavioural markers of disinterest in diabetes might include irregular blood glucose testing, missed medication, and failure to make recommended dietary and exercise changes; extended periods of inattention to one's health are likely to have serious, negative physiological consequences for people with diabetes (these include compromise to metabolic control, and increased likelihood of serious complications). To summarise, dual arguments suggest long-term patterns of extreme emotional arousal (very high or low distress about diabetes) are both associated with worse self-care.

The most important factor may not be whether people experience very high levels of emotional distress about diabetes; the pertinent issue is whether coping mechanisms are effective in *successfully regulating* levels of negative affect, so high distress about diabetes does not become a chronic, ingrained, personal pattern. Thus the third feature delineated may play the most significant role in determining whether emotional arousal has a positive or negative impact on self-care. In the context of chronic illness, successful coping is likely to involve balanced use of various strategies. When illness-related distress is high, engagement of directed processing may be useful to reduce distress through, for example, use of defensive bias mechanisms such as self-serving social comparisons (Wiebe & Korbel, 2003). Employment of substantive processing is needed to help self-care planning and motivate action because it involves "open and effortful reasoning aimed at developing accurate evaluations of information" (Cameron, 2003, p. 161) (for example, encouraging people to see diabetes as a serious health threat, but one they can have personal control over). Affect may interact with coping mechanisms: high negative affect stimulates use of directed processing, while emotional distress may interfere with substantive processing. Both substantive and directed processes can operate simultaneously (Cameron, 2003).

To emphasise a key point – detailed discussion critiques the proposal that negative affect is necessarily bad for self-care. Instead it is suggested that the relationship between emotional arousal and self-care depends on (for example) the severity of distress, how long it continues and, most importantly, what coping responses are activated. The association between affect and diabetes self-care behaviour may take many forms. Our empirical understandings in this area are currently limited. Replication is required to ensure the positive relationship observed between medication

adherence and diabetes-related distress is not an anomaly peculiar to the current study. Due to cross-sectional data collection, the causal direction of this association remains indeterminable. It is clear that further research is needed to unpack the potentially complex relationships between self-care behaviour and emotional adjustment to diabetes.

Psychosocial Factors Related to Variance in Quality of Life

The third thematic discussion identifies psychosocial factors related to variance in quality of life. Living with a chronic illness such as diabetes can have a significant negative impact on one's quality of life. This 'quality of life burden' may come as a result of diabetes complications, or be brought on by the recommended self-care regimen with its ongoing demands and pervasive infiltration of so many aspects of everyday functioning (Funnell & Anderson, 2005; Ramachandran, 2006; Vijan et al., 2005; Weiss, 2006). Multivariate findings indicate psychological variables explain a significant portion of variability in quality of life for people with type 2 diabetes. Among the five variable blocks shown in Table 14, illness/treatment representations were found to account for the largest percentage of explained variance (16%), although socio-medical context and diabetes wellbeing also made small contributions (6%, and 2%, respectively). Findings accentuate the importance of perception: objective illness severity (HbA_{1c}) appears to be less important than subjective perception of the illness (illness/treatment representations) in explaining quality of life. This concurs with the emphasis on perceptual and interpretative processes in self-regulatory theory (Leventhal et al., 1980).

Multivariate findings imply (a) perceived interpersonal support/conflict may mediate the relationship between diabetes treatment and quality of life, and (b) illness/treatment representations act to mediate the observed association between New Zealand European ethnicity and quality of life. Evidence for possible mediation is stronger in the latter instance.

Results from the current study show people who identify as New Zealand European report greater quality of life than those from other cultural backgrounds. However, a large portion of this association may be explained by differential cognitive patterns. When illness/treatment representations were entered at step 3 of the regression shown

in Table 14, the *Beta* for New Zealand European ethnicity reduced substantially (from .18 to .08) such that it no longer retained statistical significance. Of the nine variables entered at step 3, only consequences showed a significant association with quality of life at the multivariate level. Thus it appears that perceived consequences may, potentially, act to mediate between ethnicity and quality of life. Previous research has described a cultural gradient in diabetes complications: the negative health consequences of diabetes are more severe for Māori and Pacific groups (Foliaki & Pearce, 2003; Simmons, 1997, 1999; Simmons & Voyle, 1996). Findings from the present study suggest this may filter through into differences in quality of life. Particular cultural groups may experience lower quality of life, in part, because of (ethnic) variation in the consequences of diabetes.

Nine illness/treatment representations showed a significant bivariate relationship with quality of life; only one (consequences) continued to demonstrate a significant association with quality of life at the multivariate level. The importance of perceived consequences evident in the current study is consistent with findings from previous quality of life research. Self-regulatory literature states the personal model variable 'seriousness' has strong conceptual similitude to IPQ-R variable 'consequences' (Hampson et al., 2000). In a prospective study, Hampson and colleagues examined predictors of quality of life, assessed using the SF-20. Multiple regression analysis was used to compare the predictive utility of personal model variables (seriousness, control, and treatment effectiveness) and depression in determining diabetes outcomes across a 3-month period. Perceived seriousness was found to be a significant prospective predictor of self-reported physical and mental wellbeing, with agreement that diabetes is a serious illness related to worse physical health and lower psychological health (Hampson et al., 2000). In corroboration with these findings, a recent prospective study (Skinner et al., in press) has shown people who believe that diabetes will *not* have a major life impact report better quality of life (assessed using the WHOQOL-BREF). To summarise, earlier self-regulatory literature indicates the perceived consequences of diabetes are related to differential quality of life. Findings from the current study support this assertion.

Symptom appraisal may play an important role in shaping views about the seriousness of diabetes. Empirical evidence shows a positive relationship between perceived seriousness of diabetes and both physical symptoms and number of diabetes

complications (Lange & Piette, 2006). This indicates complications might play an important role in generating views about the seriousness of diabetes, a proposition that is strongly endorsed by clinical experts in diabetes (H. Snell, personal communication, February 16, 2005). It is likely a mediating relationship exists, such that beliefs about consequences mediate the relationship between perceived symptoms and quality of life. This emphasises that it is the *interpretation* of bodily experiences, rather than somatic experience per se, that may be most important in determining views about quality of life. Two key steps in this interpretative process are highlighted: the interpretation of bodily experience as a 'symptom' (that is, indicator of illness); and interpretation of the meaning of this 'symptom' (e.g., 'I think diabetes must be a serious illness').

Multivariate results highlight significant relationships between quality of life and both self-care, and diabetes-related distress. Greater emotional distress about diabetes and more frequent blood glucose testing were both related to lower quality of life. The negative relationship between diabetes-related distress and quality of life was anticipated. The observed association between quality of life and glucose testing is less expected. The direction of this relationship indicates greater attention to self-care (more frequent glucose testing) is linked to reduced quality of life among people with type 2 diabetes, implying frequent testing of blood glucose levels might, potentially, have a negative impact on quality of life.

As discussed in the preceding subsection, stringent adherence to the prescribed pharmaceutical regimen might elevate emotional distress about diabetes. In a similar way, highly frequent blood glucose testing may become burdensome, in effect reducing quality of life, although it is not possible to determine the causal direction of this association within the present study. The relationship between frequent blood glucose testing and low quality of life could also be the product of a third variable, glycaemic control. Poor metabolic control is linked to onset of health complications and consequentially reduced quality of life, as well as the need for an intensive treatment regimen (and use of insulin is associated with increased blood glucose testing).

Current findings are consistent with patient narratives pointing out that a large part of the burden of diabetes is living with current complications, and/or fear of future complications (Samuel-Hodge et al., 2000). It is concluded that the *consequences* of

diabetes constitute a significant quality of life burden for many people. Diabetes literature also stresses the intensive demands of self-management (Vijan et al., 2005; Woodcock & Kinmonth, 2001), implying the treatment regimen is also burdensome. This is consistent with the association between higher frequency of blood glucose testing, and lower quality of life reported in current results. It is concluded that both health consequences of diabetes and demands of treatment are potentially important determinants of quality of life among people with diabetes.

Psychosocial Variables Related to Differential Self-Care Patterns

The fourth thematic discussion examines associations between psychosocial variables and diabetes self-care. The present study focused on four diabetes self-management behaviours: medication use; blood glucose testing; physical activity; and dietary patterns. These variables represent both medical and lifestyle elements of the treatment regimen commonly prescribed for people with type 2 diabetes. Bivariate results reveal many significant associations between psychological variables and self-care. Trends are evident within this data. Generally, it appears a greater number of psychological variables show a relationship with dietary patterns and medication use, than with glucose testing or physical activity. There is minimal evidence of consistent relationships *across* self-care dimensions. Of the 14 psychological and social variables presented in Table 9, none showed significant relationships with all four dimensions of self-care. Further, correlations suggest where psychological variables are related to more than one aspect of self-care, the direction of observed associations may be inconsistent (e.g., timeline cyclical, and consequences).

Multivariate findings show that, when controlling for medical and demographic characteristics, psychological and social variables together accounted for a modest proportion of variance in self-care (10%, 5%, 11%, and 3%, for diet, exercise, medication use, and blood glucose testing, respectively). Current findings are consistent with previous research showing that psychological variables account for a significant proportion of the variance in diabetes self-care. The magnitude of explained variance is less than reported in some earlier research (Glasgow et al., 1997; Griva et al., 2000), but is similar to that reported in a previous New Zealand study (Barnes, 2000).

Some interesting themes emerge from the reported results. Most diabetes research founded upon self-regulatory theory has to date focused on the relationships between illness representations and self-care behaviour. However, where a significant association with diabetes self-care was evident in the current study, multivariate findings suggest that the psychosocial variable was more likely to be a measure of interpersonal support/conflict or treatment perceptions than one of the eight illness representation variables. The demonstration of significant associations between variables representing an interpersonal, or ecological, context and individual self-care behaviour is an important finding arising from the current study. Earlier research indicates interpersonal relationships are central to diabetes management (e.g., with family and/or health professionals) (Albright et al., 2001; Garay-Sevilla et al., 1995; Glasgow & Toobert, 1988; Schafer et al., 1986; Tillotson & Smith, 1996; Wang & Fenske, 1996); current findings endorse this proposition.

A second notable finding is the connection between treatment representations and diabetes self-care. This connection does not appear to be limited to medication use, other aspects of self-care also show a significant relationship with treatment perceptions. Assessment of treatment perceptions other than treatment effectiveness has been infrequent in previous diabetes literature. Findings from the present study (highlighting the role of medication concern and medication necessity in diabetes self-care) are consistent with results reported in prior New Zealand research (Barnes, 2000). It is concluded comprehensive models are necessary to create an accurate understanding of the relationship between psychological variables and diabetes self-care behaviour.

In the current research, both bivariate and multivariate results show inconsistencies across the four dimensions of self-care. For example, while timeline cyclical and consequences showed significant negative correlations with medication adherence and dietary self-care, both these representation variables demonstrated a significant positive relationship with glucose testing. While many illness/treatment representations showed a significant bivariate correlation with medication use and dietary self-care, fewer significant associations were found for exercise or glucose testing. These results imply it is inappropriate to combine aspects of self-care to produce an 'overall diabetes self-care' score, although some previous studies have done so (Griva et al., 2000).

Findings support the proposition that different aspects of diabetes self-care should be treated as discrete (Toobert et al., 2000).

Hierarchical regression analyses were used to investigate the relationships between psychosocial variables and self-care behaviour because the increased statistical control provides a more robust test of predicted relationships than simple bivariate correlations. Inspection of *Beta* coefficients shows (a) greater family support, lower family conflict, and higher belief in the necessity for medication, are each associated with better dietary self-care behaviour; (b) greater family support, greater patient-provider support, and lower family conflict over diabetes, are each related to higher levels of physical activity; (c) a perception that medication is necessary, and belief that diabetes symptoms come and go in cycles, are associated with more frequent blood glucose testing, and; (d) greater perceived need for medication, lower concern about medication, and less patient-provider conflict, are associated with greater adherence to prescribed pharmaceutical treatments.

In comparison with illness/treatment representations, interpersonal relationships demonstrated greater explanatory power in regard to diet and exercise patterns, but less explanatory power in regard to medical aspects of the treatment regimen (blood glucose testing, and medication use). This is consistent with previous research showing relationships between family support/conflict and both diet and exercise, but no significant correlations between family context and medication adherence or blood glucose testing (Williams & Bond, 2002). Multivariate findings imply interpersonal variables are more important than individual illness/treatment representation when accounting for variation in lifestyle aspects of diabetes self-care. It is possible there is an interactive relationship between family context and personal beliefs about diabetes, such that illness/treatment perceptions are only related to self-care where family interaction (support or conflict over diabetes) is low. It is helpful to explain how an interactive relationship between family context and personal beliefs about diabetes might occur.

The pre-eminent role of family relationships in dietary management of diabetes is consistent with literature showing many people with diabetes prefer to partake in shared meals, rather than eat separately from other family members (Scott & Brown, 1989). One person within the family circle often takes on responsibility for shopping

and preparation of meals, sometimes this might be the person with diabetes, in other cases it will not. Where shared family meals are the norm, food choices frequently involve collective negotiation among the preferences of each individual. In this case individual beliefs about diet (or preferred food choices) are subsumed within, and sometimes subordinate to, the prevailing family consensus. Some families may be very conscious of the relationship between nutrition and diabetes; others might show little awareness, and no interest in preparing meals with, for example, a low glycaemic index. Where families eat together, dietary self-care will be most strongly influenced by *family* dynamics (that is, preferred food choices among the group); individual views about diabetes/treatments may only play a small role under these circumstances. However, personal views about diabetes/treatments are likely to influence diet when the family context is absent (for example, when preparing a snack for oneself).

Bivariate relationships shown in Table 9 are largely supportive of the directional associations predicted in hypothesis 6. However, multivariate findings do not support the majority of these sub-hypotheses. Diabetes literature has demonstrated a significant relationship between perceived control and diabetes self-care (Griva et al., 2000; Skinner & Hampson, 1998, 2001; Skinner et al., 2002), and earlier research has shown a significant association between serious consequences and diabetes self-care (Hampson et al., 1990; Skinner et al., 2002). Results from the current research are inconsistent with these findings. Close inspection of published literature reveals other studies have also failed to demonstrate significant associations between perceived control and diabetes self-care (Barnes, 2000; Hampson et al., 2000); empirical investigation has also failed to show evidence of a relationship between consequences and self-care (Glasgow et al., 1997; Hampson et al., 1995; Hampson et al., 2000). Variation in participant characteristics may partially explain these inconsistent results. Almost all the studies showing support for an association between diabetes self-care and control or consequences, focused on adolescents with type 1 diabetes. Congruent with this, in studies that have failed to show evidence of these associations, most participants have type 2 diabetes (e.g., Barnes, 2000; Hampson et al., 2000).

In comparison with type 2 diabetes, personal actions to control diabetes (frequent testing of blood glucose, administration of insulin) and treatment control (effectiveness of insulin) are more salient in management of type 1 diabetes. Further, the immediate consequences of failing to self-manage diabetes are more aversive in type 1 diabetes.

Few people with type 2 diabetes experience hypoglycaemia; in comparison, most people with type 1 diabetes will have experienced a hypoglycaemic episode, and will be aware of the possible consequences (death) of falling into a coma as a result of ketoacidosis. To summarise, while people with type 1 and type 2 diabetes face the possibility of long-term health complications (e.g., retinopathy, nephropathy), the daily consequences of poor self-management are more significant for people with type 1 diabetes. Further, personal management (that is, control) of blood glucose levels also requires more intensive effort in type 1 diabetes, primarily because of a reliance on exogenous insulin.

On this basis it could be argued that, in comparison with type 2 diabetes, perceived control and serious consequences are a more pertinent part of the illness schema for people with type 1 diabetes and, as such, are more likely to show a relationship with self-care behaviour. Thus possible differences between people with type 1 versus type 2 diabetes may help explain the absence of significant relationships between self-care and control or consequences in the current research. However, perceived control and consequences were not the only variables that failed to show a significant relationship with diabetes self-care. Broader discussion of other contributing factors is required.

First, and perhaps most important, previous research has not always controlled for relationships among cognitive variables when examining associations between illness/treatment representations and individual dimensions of diabetes self-care (e.g., Barnes et al., 2004; Griva et al., 2000), and very few studies have controlled for interpersonal relationships pertinent to self-management. In the current study, hierarchical regressions controlled for the impact of demographic/medical characteristics, interpersonal relationships pertinent to self-care, and associations among illness/treatment representations. Thus the level of statistical control applied in multivariate analyses used to test hypothesis 6 is notably greater than that employed in many previous studies examining the relationship between illness representations and diabetes self-care. This observed difference in statistical control could help explain the disparity between findings reported in previous studies, and those evident in the current research.

It is also plausible that limitations in variable measurement within the present research lead to underestimation of the relationships between illness/treatment representations

and diabetes self-care. Although in an ideal research setting the use of *self-reported* diabetes self-care might be substituted for behavioural observation or electronic monitoring (for medication adherence), this is beyond pragmatic constraints applicable in the present study. Ordinal measurement of self-report could be considered a crude method of assessing self-care behaviour; it is also plagued by potential social-desirability and recall biases (Horne & Weinman, 1999). Therefore use of behavioural self-report is identified as one measurement issue that could have contributed to observed results. Further, the methods used to assess illness/treatment representations (closed, likert-scale items in questionnaire format) may lack sensitivity (Byrne et al., 2005) when compared with methodologies used in other studies, for example, structured interview using the PMDI.

Potentially, compromise to statistical assumptions associated with regression analysis might help explain results reported in relation to hypothesis 6. As stated by Tabachnick and Fidell (2001, p. 116), "regression will be best when each IV is strongly correlated with the DV but uncorrelated with other IVs". Statistical literature suggests that multicollinearity becomes problematic when correlations among predictor variables are ≥ 0.6 (conservative estimate) or ≥ 0.7 (Monash University, n.d.). Where such correlations are evident, statistical power is reduced (Monash University, n.d.), and as a consequence the ability to detect significant relationships is compromised. Inspection of bivariate correlations in Table 8 reveals no coefficients ≥ 0.6 , and tolerance values requested in regression syntax suggest multicollinearity was not a significant problem in the regressions used to examine self-care behaviour. Further, using the guiding sample size criteria for testing individual predictors within regression provided by Tabachnick and Fidell (2001), all analyses appear to possess adequate statistical power (assuming a moderate effect size). Nonetheless, some level of concern about multicollinearity remains. Table 8 shows three reasonably strong bivariate relationships between diabetes concern and timeline cyclical, consequences, and medication concern.

Another assumption of hierarchical regression analysis is that relationships between IVs and the DV are linear. Previous research proposes the relationship between affect and self-care behaviour may be non-linear (Jessop & Rutter, 2003). This implies reported findings may have underestimated the relationship between emotional representations and self-care in the present study. However analysis of residuals

suggests no notable compromise to the regression assumptions of normality, linearity, or homoscedasticity in the current study. To summarise, evidence of excessive multicollinearity or non-linear relationships is scant, but some degree of compromise to regression assumptions may exist in the current study.

Hierarchical relationships between illness/treatment representations could also help explain current findings. In a study of asthma self-management, Horne and Weinman (2002) showed the relationships between illness perceptions and medication adherence were largely mediated by beliefs about treatment necessity. Multivariate analyses in the present research displayed significant relationships between perceived need for medication and dietary self-care, blood glucose testing, and medication use. Potentially, treatment necessity may have acted to mediate the relationship between illness representations and self-care in the current study. The hypothesised importance of treatment necessity in diabetes self-care is consistent with earlier research comparing six chronic illness groups (asthma, diabetes, renal, cardiac, psychiatric, and general medical). Comparison of mean scores on the BMQ subscale treatment necessity revealed a statistically significant between-groups difference: people with diabetes had significantly higher belief in the need for treatment than any of the other illness groups (Horne et al., 1999).

In summary it is difficult to present a singular argument to explain the absence of predicted directional relationships between illness representations and self-care behaviour. Multiple contributory factors have been identified; it is probable that observed results arise from the compounding joint effect of these factors. The high level of statistical control provided by multivariate analyses, measurement choices, collinearity among predictor variables, possible non-linear associations, and hierarchical relationships, may all help explain the absence of predicted directional relationships.

It is interesting to compare findings from the present study with published diabetes literature pertaining to people resident in the South Pacific region. Previous New Zealand research by Barnes (2000) also employed hierarchical regressions to examine the relationship between illness/treatment representations and four aspects of self-care (diet, exercise, blood glucose testing, and medication use). Results are similar to those observed in the current study. First, when hierarchical regressions were employed, few

individual variables showed a significant association with diabetes self-care behaviour. Second, where relationships were evident, these were between treatment representations and self-care, not illness perceptions and self-care. Third, there was a discrepancy between bivariate results and relationships evident at the multivariate level. Results reported by Barnes (2000) showed very few variables displayed a significant *Beta* coefficient. When blood glucose testing was regressed on illness/treatment perceptions, none of the eight representation variables showed a significant association with the dependent variable. In the regressions for diet and exercise, medication necessity (alone) displayed a significant *Beta* value; medication concern showed a significant relationship with medication adherence (Barnes, 2000). Multivariate results revealed no significant associations between self-care and (a) perceived consequences of diabetes, (b) personal control, or (c) treatment control. This is similar to findings emerging from the present study.

In a number of diabetes studies, less than half the illness representation variables entered into a regression model demonstrate a significant relationship with the outcome of interest (e.g., Barnes, 2000; Hampson et al., 1995; Lange & Piette, 2006; Lawson et al., 2004; Skinner et al., 2002). These observations suggest that, when a high degree of statistical control is applied (e.g., control for demographic/medical factors and relationships among predictor variables), empirical precedent indicates few individual psychological variables will display a significant association with diabetes self-care. This implies the role of psychological variables in explaining diabetes self-care behaviour should not be overstated. Similar cautions may apply in other chronic illness contexts (Byrne et al., 2005).

In summary, while there are notable disparities between previous research and findings from the present study (for instance, regarding the relationship between perceived control and self-care), convergent themes are also evident. For example, both current and previous findings conclude that (a) psychological variables account for a significant proportion of the variance in diabetes self-care, (b) psychological variables are better at explaining certain aspects of self-care (e.g., diet), and (c) dimensions of self-care are discrete and should not be combined to create a composite behavioural variable. Results show that, when controlling for demographic and medical factors as well as relationships among predictor variables, there is limited evidence of significant associations between individual psychosocial variables, and diabetes self-care

behaviour. Findings from the current study are largely consistent with results reported in previous New Zealand research by Barnes (2000).

Direct and Indirect Relationships in Diabetes Self-regulation

The fifth theme examines evidence of direct and indirect relationships in the current study. As stated by Hagger and Orbell “a major tenet of the CSM is that a causal relationship exists between illness cognitions and outcomes that is mediated by coping” (2003, p. 179). However, prior research has largely failed to demonstrate empirical support for this proposition (e.g., Edgar & Skinner, 2003; Kaptein et al., 2006). Results from the present study indicate that medication use acts to mediate between concern about prescribed diabetes treatments, and HbA_{1c}. The path analysis displayed in Figure 3 suggests partial mediation: medication concern demonstrates both direct, and indirect, relationships with metabolic control. Thus results from the current study provide empirical support for an important mediating pathway indicated in self-regulatory theory.

In addition to the mediating relationship formally tested in hypothesis 7, results imply other indirect relationships are present in diabetes self-regulation. Current findings propose that (a) cultural differences in metabolic control can be partially explained by variation in behavioural self-care, (b) illness/treatment representations (particularly perceived consequences) may act to mediate the positive relationship between New Zealand European ethnicity and quality of life, and (c) interpersonal support/conflict, and variability in illness/treatment representations, may act to mediate the relationships between demographic characteristics and emotional distress about diabetes.

This information is helpful to clinicians and researchers with an interest in reducing emotional distress about diabetes. Age and ethnicity are not amenable to change. But illness/treatment representations are potential candidates for moderation. Results highlight specific variables (for example, medication concern and diabetes identity) that could form useful targets for psychological interventions aiming to decrease diabetes distress. Current findings imply that a poor relationship with diabetes clinicians is related to greater diabetes distress indirectly through differences in the way diabetes/medication is perceived. Results emphasise the importance of building a

good rapport with patients, and developing effective ways to reduce interpersonal conflict should it occur within the clinical context.

Direct relationships were also evident in the current study. Family support/conflict, and patient-provider support showed a direct relationship with exercise behaviour (illness/treatment representations do not appear to mediate this association), and the negative association between perceived consequences of diabetes and quality of life does not appear to be mediated by self-care behaviour, or diabetes-related wellbeing. Results suggest self-care behaviour does not act to mediate the relationships between illness/treatment representations and diabetes-related emotional distress. On the basis of these findings, it is important researchers consider both direct and indirect relationships when examining the connection between representation variables, and illness outcomes.

IMPLICATIONS FOR SELF-REGULATORY THEORY

Findings from the current study contribute to knowledge about the process of diabetes self-regulation. There are also salient implications for self-regulatory theory more broadly. Results show that illness/treatment representations are able to account for variation in key diabetes outcomes (self-care behaviour, physiological wellbeing, emotional adjustment, and quality of life). Findings imply psychosocial and behavioural variables are better at explaining variance in diabetes distress and quality of life, than metabolic control.

Diabetes studies founded on self-regulatory theory have largely focused on the role of illness representations. Findings from the current study show treatment representations play a pertinent role in diabetes self-management, yet few previous studies have examined treatment perceptions. In multivariate analyses, only one of the eight illness representation variables (timeline cyclical) showed a significant association with diabetes self-care behaviour. In contrast, medication necessity showed a significant relationship with dietary self-care, blood glucose testing, and medication use; medication concern also displayed a significant association with medication use. Current results suggest that, in comparison with illness perceptions, treatment representations may play a more important role in diabetes self-care. In order to build

a sound knowledge of the behavioural management process, diabetes researchers should include both illness and treatment representations in future research. It is recommended that treatment representations be explicitly incorporated as a central component within the CSM.

Interpersonal relationships also appear to play a significant role in diabetes management. However, pictorial depiction of the CSM in published literature presents interpersonal relationships as a peripheral component of the theoretical framework (e.g., Lange & Piette, 2006; Leventhal et al., 1992). Findings from the current study challenge the marginalisation of interpersonal variables, suggesting socio-medical relationships can show significant, direct, relationships with behavioural coping. Explanatory theory surrounding the CSM has largely distanced the (individualised) process of illness self-regulation from the ecological context in which it takes place. There has been limited explication of the ways in which social communication might influence illness/treatment perceptions, or acknowledgement that interpersonal relationships may shape coping responses and patterns of appraisal.

Present findings imply there are important relationships between interpersonal factors and core self-regulatory variables (illness/treatment representations and coping behaviour). In order to generate an accurate understanding of illness management, researchers are encouraged to consider inclusion of interpersonal variables in addition to individualised variables shown in the CSM. Although “self-regulation theory offers a framework with which to systematically examine the interactions between persons and contexts – that is, how self-regulation is linked with social relationships” (Cameron & Leventhal, 2003, p. 6), these salient connections have received limited empirical examination in self-regulatory research to date.

Recent self-regulatory literature presents active self-care as a form of ‘problem-focused coping-specific’ (Hagger & Orbell, 2003), and highlights this as an important area for further research. In the present study, active behavioural coping showed significant relationships with illness/treatment representations, and illness outcomes. Illness/treatment representations appear to be more capable of explaining variance in *particular* types of behavioural self-care (e.g., medication use). Findings support a hypothesised mediating relationship indicated within the CSM: specifically, they show that behavioural coping responses mediate the relationship between treatment

representations and physical health among people with type 2 diabetes. This is important because interest in behavioural coping as a type of self-regulatory coping response is only recent, and previous research testing for mediating relationships has been largely unsuccessful in demonstrating evidence for these (Edgar & Skinner, 2003; Kaptein et al., 2006). Results support the addition of active behavioural self-care (as a form of illness-specific coping) to the coping taxonomy associated with self-regulatory theory.

In multivariate analyses, variables displaying significant *Beta* coefficients varied depending on the outcome of interest. It would seem variables that best explain variation in one outcome (e.g., metabolic control) are likely to be different from those explaining variation in a second outcome (e.g., diabetes distress). For example, worry about the use of prescribed medication appears to play a salient role in explaining diabetes-related distress; the perceived consequences of diabetes make an important contribution to explanation of variance in quality of life among people with type 2 diabetes. It is also interesting to examine the collective impact of blocks of variables. The socio-medical context was found to account for variance in diabetes distress and quality of life, but not in metabolic control. Self-care behaviour explained variance in metabolic control, but did not account for differences in emotional wellbeing. Illness/treatment representations explained variation in each of the three main illness outcome variables, suggesting an important connection with both physical and psychological wellbeing.

Similar variability in results emerges when comparing variable blocks employed in self-care regressions. When the collective impact of variables in each block is taken into account, interpersonal relationships seem to be important when explaining differences in lifestyle aspects of self-care; illness/treatment representations appear to be more important in accounting for variance in medical aspects of the treatment regimen (medication use and blood glucose testing).

Current findings emphasise the need to examine *specific* aspects of diabetes self-regulation. Hypotheses that pertain to self-care should consider possible variability in the direction of relationships between individual illness/treatment variables and different aspects of self-care behaviour. For example, in bivariate results, timeline cyclical and consequences showed a positive relationship with blood glucose testing, but a negative

association with medication use and dietary self-care. Research aiming to identify individual illness/treatment variables that play a central role in 'diabetes self-regulation' (that is, both metabolic control and emotional adjustment) may be misconstrued. Generalised hypotheses that span multiple illness outcomes are not recommended.

Findings from the present study provide evidence of both indirect and direct relationships between illness/treatment variables and diabetes outcomes. Results also reveal significant relationships *among* representation variables. Cognitive and emotional perceptions of diabetes are correlated, and there is a strong correlation between emotional perceptions of diabetes and concern about prescribed medication (attesting the important connection between representations of chronic illness *per se*, and of prescribed treatments). Results imply hierarchical associations may be present among representation variables. For example, treatment representations may act to mediate the relationship between illness representations and self-care behaviour (particularly medication use). To date, few studies have explicitly examined mediating relationships among illness/treatment representations. Self-regulatory theory could be strengthened by research that generates a better understanding of such associations.

In the present study there was disparity between bivariate correlations, and relationships displayed in multivariate analyses. This was most notable in the absence of significant findings for hypothesis 6. Results highlight the importance of controlling for relationships *among* illness/treatment representations when investigating the connections between representations to coping. Findings also function to warn researchers against over-interpretation of bivariate associations. When testing key relationship pathways specified in the CSM, multivariate analyses are recommended.

Findings provide preliminary evidence of an emotional pathway in diabetes self-regulation. After controlling for age, ethnicity, and treatment type, variables included in the present study were found to account for an additional 34% of variance in emotional distress about diabetes. Four cognitive variables seem to play important part in the regulation of affect: timeline cyclical, consequences, coherence, and identity. The interaction between cognitive and emotional aspects of diabetes self-regulation is consistent with dual pathways specified in the CSM. Results from the current study identify a possible relationship cluster (connecting emotional illness responses with cyclical symptoms, serious consequences, strong identity, and low coherence). This

highlights a network of variables that might form a core component within the emotional self-regulatory pathway and, as such, is an important theoretical contribution arising from the present study.

In conclusion, results from the current study show self-regulatory variables are capable of demonstrating explanatory power in regard to chronic physical illness. Collectively, findings indicate the common sense model is a useful conceptual framework for research examining self-care and wellbeing among people with diabetes.

CLINICAL IMPLICATIONS

Results from the current study show New Zealanders with type 2 diabetes appear to experience a similar level of physical and psychological wellbeing as people with diabetes in other countries. Many people with diabetes continue to experience good quality of life. However, the majority of people with type 2 diabetes do not achieve good metabolic control (an $HbA_{1c} \leq 7\%$), and average HbA_{1c} is greater than that recommended in New Zealand evidence based guidelines for type 2 diabetes.

Recognition of the Importance of Family in Management of Diabetes

In New Zealand, on the whole, clinical care for people with type 2 diabetes is premised on an individualised, biomedical approach to illness management. Findings from the current study show a significant association between family support/conflict and diabetes self-management. Family relationships appear to be important in shaping lifestyle aspects of diabetes self-care (exercise habits, and diet) and may influence levels of emotional distress about diabetes. Findings encourage clinicians to recognise the role family relationships may play in self-care behaviour, and to consider ways to promote positive family involvement in diabetes care.

As discussed in chapter 1, diabetes rhetoric promotes family participation in diabetes health care. This applies to all people with diabetes, but may be especially salient for certain cultural groups. New Zealand clinical guidelines state that “involving families in diabetes management planning is of particular importance to Māori and Pacific people with diabetes” (New Zealand Guidelines Group, 2003, p. 1). At present, there does not

seem to be a strong sense of how best to achieve this. Additional training for clinicians may be helpful where cultural knowledge and previous experience in building relationships with Māori and Pacific families is limited. Strategic guidance from professional bodies could assist by indicating specific strategies clinicians could employ to encourage family involvement where they believe this might offer benefit for diabetes management.

Findings from the present study highlight the role of family conflict in diabetes self-care and emotional distress; critical reflection implies a need for greater acknowledgement of the impact *negative* family interactions could have on diabetes self-management. Most research to date has focused on the importance of family support in diabetes. There has been limited discussion of the potential tensions diabetes can create among family relationships. While encouragement of family participation may have potential benefits to self-care, clinicians need to ensure both the person with diabetes and family member(s) desire family involvement. Where there is disagreement between these parties, resolution is likely to require an emotionally intelligent approach – such issues could benefit from open discussion among the clinical community.

To summarise, findings from the current study suggest family relationships may play an important role in shaping self-care practices among people with diabetes. Inclusion of family in diabetes-care planning is recommended. However, clinicians should also be aware that conflict over diabetes management is not uncommon, and some people may not wish to be closely involved in the self-care practices of their family members.

Reducing the Emotional Impact of Diabetes

Recent literature arising from the DAWN studies has drawn awareness to the emotional consequences of diabetes (e.g., Peyrot, Rubin, Lauritzen, Snoek et al., 2005). Findings from the present study may be useful for clinicians with an interest in reducing diabetes-related distress among their patients because they highlight particular illness/treatment variables that could form intervention targets. A belief that diabetes symptoms fluctuate in cycles, agreement that diabetes has serious consequences, and strong identification with diabetes appear to be associated with greater distress. High concern about prescribed medication also appears to play an important role in explaining elevated diabetes distress. Interventions that focus on

moderating such perceptions may be effective in decreasing emotional distress about diabetes. As a simple example, clinicians could engage patients in discussion of prescribed medication, seek to elicit any concerns about pharmaceutical treatments, and work towards resolving these.

Findings suggest perceived diabetes consequences play a salient role in explaining quality of life, as well as diabetes distress. Beliefs about consequences could function as an important determinant of emotional adjustment among people with type 2 diabetes. Results imply a need for care when discussing the possible consequences of diabetes in clinical practice. In an attempt to motivate active self-management behaviour, health professionals may emphasise the health complications that can arise from diabetes. Previous diabetes literature suggests this is perceived as a useful clinical tool (Loewe et al., 1998). While certain people may benefit from a discussion that emphasises the seriousness of diabetes complications, for other people this could result in a significant elevation in diabetes-related emotional distress.

Many people with diabetes will be aware of (and often frightened by) the negative health consequences that can accompany diabetes. Clinical styles that strongly emphasise complications may elevate emotional distress to a level that is maladaptive. Excessive emphasis on diabetes complications has the potential to overburden the systems that self-regulate emotional arousal – this is likely to have a negative impact on self-care behaviour (Cameron, 2003; Wiebe & Korbel, 2003), consequently impairing metabolic control. Findings from the present study suggest that when discussing the consequences of diabetes, a carefully balanced, emotionally astute approach is required. The importance of maintaining a positive patient-provider relationship is also emphasised.

On a practical note – where clinicians/researchers are interested in measuring psychological wellbeing among people with diabetes, use of generic and *illness specific* measures is recommended. The SF-12 enables comparison with population norms and international data, and is a useful feature. However, discussion ensuing from the current study implies generic instruments (such as the SF-12/20 MCS) possess limited sensitivity, and may fail to detect variation within an illness group, for example, due to differences in illness severity. Generic measures may also be unable to detect change in illness-related emotional wellbeing over time, and this is an important prerequisite for

research testing the efficacy of interventions aiming to reduce emotional distress among people with type 2 diabetes.

Recognition of Cultural Disparity in Diabetes-related Wellbeing

The current study showed evidence of cultural disparity in emotional wellbeing, metabolic control, concern about diabetes medication, and use of prescribed treatments. Certain subgroups within the diabetes population are more likely to experience poor outcomes. Clinicians need to be aware of this vulnerability and, where feasible, proactive intervention is recommended. Results from the present research imply individuals responsible for designing health policy, or delivering health care, should pay close attention to the needs of Pacific people with diabetes.

In the current study, mean scores on the PAID reveal large variation between New Zealand Europeans ($M = 15.39$, $SD = 15.55$), and Pacific people ($M = 34.15$, $SD = 21.39$). PAID scores (representing emotional distress about diabetes) are more than twice as high for Pacific people as for New Zealand Europeans, and this difference is statistically significant. As discussed previously in chapter 7, chronic elevated emotional distress about diabetes may have a negative impact on self-care behaviour. In order to promote good self-care among Pacific people with diabetes, it may be necessary to address emotional concerns about diabetes. It is useful to bear in mind that, on average, Pacific people are likely to have higher concerns about using prescribed medications in comparison with other cultural groups as shown in Table 11. Post hoc analyses showed Pacific people report greater worry about diabetes medications than those who identify as New Zealand European, or Māori. Attempts to discuss, and resolve, any concerns about the negative impact of pharmaceuticals could be helpful.

Previous literature within health psychology has advocated research that is socially responsive and seeks to activate positive change (Murray, 2005). Pacific people appear to carry the heaviest yoke in response to diabetes in New Zealand, at least according to results from the present study. Current findings intimate a need for efficacious strategies that better enable Pacific people to manage the physiological and emotional consequences of type 2 diabetes.

REFLECTIONS ON RESEARCH METHOD AND CONCEPTUAL APPROACH

Relative Strengths of the Present Research

Comparison with previous research reveals both strengths and weakness within the present study. Small sample sizes (Griva et al., 2000; Hampson et al., 1995; Hampson et al., 1990; Law et al., 2002; Lawson et al., 2004; Skinner & Hampson, 1998, 2001), and low response rates (Garay-Sevilla et al., 1995; Watkins et al., 2000) are present in published diabetes literature. Researchers have not always employed multivariate analyses that enable statistical control for demographic and medical characteristics when examining the relationship between psychological variables and health behaviour/diabetes outcomes (Barnes et al., 2004; Griva et al., 2000). In contrast with some earlier studies, the current study reported a higher response rate (55%), and a relatively large sample broadly representative of the New Zealand diabetes population ($N = 610$). The analytical strategy was carefully designed. All multivariate analyses demonstrated adequate statistical power, and hierarchical regression analyses enabled examination of key variables (e.g., illness/treatment representations) while controlling for other variables (e.g., demographics). Hierarchical entry meant it was also possible to observe the impact of different variable *blocks* (e.g., social context, versus representation). Employment of a priori sub-hypotheses predicting specific directional relationships between individual representation and coping variables is identified as a positive feature within the current research.

The integration of self-report data with medical records is a recommended feature of the current research. This enabled examination of the relationships between psychological variables (e.g., illness/treatment representations) and physiological parameters (e.g., HbA_{1c}). The cultural heterogeneity evident among participants is also an identifiable strength of the current research. Cultural inclusiveness is an important principle per se, but it becomes more significant when taking into account ethnic disparities in diabetes as described in chapter 1. Previous self-regulatory studies have shown limited (Skinner & Hampson, 1998) or absent (Griva et al., 2000; Law et al., 2002; Skinner & Hampson, 2001) cultural variability. Māori and Pacific peoples experience higher prevalence of type 2 diabetes, and worse illness outcomes, than New Zealand Europeans (Foliaki & Pearce, 2003; Simmons, 1999). Both Māori and Pacific groups were well represented in the current sample. The cultural composition

of participants in the current study is very similar to the New Zealand diabetes population.

To summarise, the current study shows identifiable strengths in broader research methods (e.g., participant selection and recruitment, and statistical strategy), as well as specific components within this (e.g., heterogeneity of the sample, integration of self-report data with medical records). In addition, there are recommending features within the conceptual approach employed in the current study. Two examples are highlighted in the following discussion.

Previous literature has noted research and theory in health psychology tends to strip health behaviour of its ecological context (Lyons & Chamberlain, 2006; Murray, 2005). Examination of conceptual frameworks commonly employed in quantitative health psychology reveals support for this critique; individualisation of the illness management process is evident. The label 'social cognition models' (as it is applied within health psychology) may be somewhat misleading. This linguistic terminology implies conceptual frameworks with a sound grounding in *both* social and cognitive dimensions of health and illness behaviour, an implication that is not always substantiated. The current study employed a well-used model of illness management (the CSM), and explicitly sought to integrate the *self*-management process with illness-specific social context. Deliberate examination of the connections between social and individual dimensions of illness has enabled a better understanding of the importance of social relationships in diabetes self-care. For example, findings highlight the significance of family interaction in dietary and exercise choices. Attention to the ecological context surrounding diabetes management is a positive feature of the current study. This has been strongly recommended in previous literature (Dressler & Oths, 1997; Galazka & Eckert, 1984; Jack et al., 1999). The inclusion of social context variables is particularly pertinent, given that the social network has been identified as the "least-studied group of predictors of self-management behavior in type 2 diabetes" (Fisher et al., 1998, p. 600).

Examination of affect can also be identified as a particular strength within the present research. The majority of published research stems from a biomedical view of type 2 diabetes, as a result most studies emphasise that diabetes is a 'physical' illness. Empirical attention to the emotional consequences of diabetes has been sparse,

although this is a dominating theme in patient narratives. In self-regulatory literature, most diabetes studies have focused on examining cognitive illness representations; interest in *emotional* representations of diabetes is less frequently encountered. The present study purposely sought to explore the role of affect in diabetes self-regulation. This is evident at a number of levels: (a) social context variables were focused on the emotional tone of interpersonal interaction (support versus conflict); (b) assessment of illness/treatment representations included measures of diabetes and medication concern; (c) outcome variables included physical wellbeing and emotional adjustment (quality of life, and diabetes-related distress). Results from the present study show self-regulatory variables are able to account for a substantial portion of the variance in quality of life, and diabetes related distress. Findings also highlight useful directions for future research; for example, the potential complexity of associations between affect and self-care behaviour warrants further investigation. Exploration of the emotional consequences of diabetes is identified as a strength within the current study, particularly because this approach contrasts with the emphasis on physical wellbeing and cognition in previous diabetes research.

Limitations of the Present Research

Notwithstanding relative strengths, the current research has some limitations. The primary limitation is employment of cross-sectional data collection. As a result, the current research fails to generate insight into recursive movement between illness/representations, coping, and appraisal, and is unable to examine change in behaviour over time. The decision to use a cross-sectional method of data collection was not the expressed preference of the researcher; this was a response to pragmatic constraints associated with the current study. The most salient implication of cross-sectional data is that it precludes discussion of cause and effect relationships. Assertions of causality have not been attempted in the current research, and the absence of longitudinal data is acknowledged as a weakness.

Other limitations relating to research methods are also evident. The reliance on self-report is one example. Lack of correspondence between reported behaviour and objective diabetes self-care may conceivably have led to an underestimation of the relationship between self-care and metabolic control in hypothesis 1. However, prior self-regulatory literature argues assessment of self-reported behaviour has positive

features (Horne & Weinman, 1999), and research using the MARS has demonstrated similar levels of non-adherence to objective measures of non-adherence among people with asthma (Horne & Weinman, 2002). Operational definition of research constructs relied on completion of a mailed questionnaire survey. This approach to data collection is constrained and structured. Most questions were answerable on a likert response scale; respondents had few opportunities to express idiosyncratic views. In retrospect, some questions may have been unsuitable for this illness group, for example, feedback from participants suggests the IPQ-R item 'my treatment will be effective in curing my illness' may be inappropriate for people with type 2 diabetes.

It is important to emphasise limits in the generalisability of research findings. The present study was focused on people with type 2 diabetes, resident in New Zealand. Analysis of participant characteristics shows broad representation of the national type 2 diabetes population, particularly in reference to cultural composition. Findings were similar to previous New Zealand research, but results from the present study should not be extrapolated to all people with diabetes mellitus. Clinical literature stresses the difference between people with type 1 versus type 2 diabetes. Therefore, application of findings from the present research to the type 1 diabetes population is deemed inappropriate.

A cautious approach to interpretation of research findings is advocated. When a large number of individual tests are conducted, there is increased possibility of reporting a chance association as 'statistically significant'; this can be identified as a potential problem limiting interpretation of bivariate relationships in the present study. Collinearity among illness representations may have adversely affected multivariate analyses. In particular, caution is necessary when interpreting findings from hypothesis 6. Further research is required to clarify relationships between cognitive and emotional representations, and diabetes self-care behaviour. While acknowledging these limitations, extensive use of multivariate analyses and cautious interpretation of bivariate relationships are positive features of the current statistical strategy.

There are other limitations evident within the conceptual approach employed in the present study. For example, as described in the preceding subsection, interest in emotional aspects of diabetes was an important exploratory area in the current study. However, constructs grounded in affect (e.g., diabetes concern, medication concern,

diabetes-related distress) were assessed via questionnaire survey; the assessment of emotional aspects of self-regulation via completion of a cognitive task seems somewhat incongruous.

The common sense model is founded on the belief that people act in a rational way – they are ‘common sense scientists’ (Leventhal et al., 2003). Two important assumptions that accompany this belief are that people are actively *interested* in their personal wellbeing, and *motivated* to reduce health threats (Leventhal et al., 1980). This may not always be true. The possibility that some people with chronic illness are uninterested in their health, and lack motivation to make significant changes to reduce this threat deserves greater discussion in self-regulatory theory. There are also implicit assumptions that accompany assessment choices. For example, where the IPQ-R is used to measure illness representations it is assumed that people are conscious of their own perceptions about diabetes, and are able to represent these linguistically. More fundamentally, this approach presumes that participants do indeed *have* illness representations.

Engagement of critical reflectivity in this area should be encouraged. People who have recently been told they have diabetes may have very poorly developed views about what this means. The CSM implies illness representations are generated over time. This begins with a process of symptom appraisal, from which an embryonic illness schema emerges; this is distilled into coherent views about illness through an extensive and ongoing course of emotional and cognitive processing. Illness representations do not exist inherently; they are generated by self-regulatory processes. To date, there has been little recognition that people may differ in the extent to which tangible illness representations are formed. It could be a misnomer to describe hazy, half-formed cognitions as ‘illness perceptions’ per se. These constitute evidence of a very weak illness-related cognitive schema. In the current research, assessment focused on the *content* of illness representations. No attempt was made to examine the *strength* of representations, or consider the possibility that some people do not have clear perceptions of diabetes.

As described in chapter 1, there are many ways of conceptualising ‘wellbeing’; notable cultural variation is evident. Although the current research acknowledges the importance of culture in determining views about illness, research hypotheses did not

seek to examine cultural differences in views about diabetes, and open exploration of *additional* illness/treatment perceptions that are pertinent to particular groups was not undertaken. This is identified as a useful direction for future research.

Application of a broad perspective identifies another pervasive issue that applies to the chosen theoretical framework as a whole. The present study purposely employed a conceptual model that enabled assessment of variables at multiple levels within the causal pathway determining illness outcomes (e.g., social context, illness/treatment perceptions, and behavioural coping strategies). The choice to pursue a comprehensive explanatory model should be construed as a strength of the present study; for example, it enables a better understanding of the role interpersonal relationships play in diabetes self-regulation. However, the conceptual approach selected in the present study could be criticised for lacking judicious selection of research variables, and possible tautology among these. This issue is discussed further in the following section.

In summary, there are identifiable strengths within both the research methods and conceptual approach employed in the present study. Notwithstanding relative strengths, limitations of the current research are also acknowledged. Most notable amongst these is the absence of longitudinal data.

RECOMMENDATIONS FOR FUTURE RESEARCH

As emphasised in chapter 1, the label 'diabetes mellitus' encompasses a heterogeneous collection of illnesses with some degree similitude, but also many distinguishing features between subgroups. In future research, greater attention should be given to acknowledging differences among the diabetes population, and exploring possible variation in self-regulative processes. For example, discussion with clinicians stresses the difference between people with type 1 versus type 2 diabetes (H. Snell, personal communication, February 16, 2005), and within this latter group the need to make more fine-grained distinctions between (a) those with, and without, complications, and (b) people who do, and do not, require insulin. Significant between-group differences may exist. To date, self-regulatory literature pertaining to diabetes has not often discussed possible differences across sub-groups within this chronic

illness population. To summarise, a sound knowledge of self-regulatory processes will require more detailed examination of variation *within* diabetes – at present this is largely absent.

Findings from the present study indicate the relationship between psychological variables and self-care depends on the precise aspect of self-care behaviour under examination. Results concur with previous literature emphasising that the dimensions of diabetes self-care are distinct; it is not recommended that researchers combine these to create an 'overall self-care' score. To date, most diabetes research stemming from self-regulatory theory has focused on assessment of illness representations. In particular the significance of perceived control and serious consequences has been emphasised. Results from the present study suggest other types of illness perceptions also play a pertinent role in diabetes self-regulation. In future research, assessment of identity and cyclical symptoms is recommended. Current findings also highlight the importance of treatment representations in diabetes self-care behaviour, broad assessment of the illness schema (including both illness and treatment perceptions) is therefore encouraged.

Interpersonal relationships may play a salient role in diabetes self-care behaviour, particularly in relation to diet and exercise. In order to promote a better understanding of the role social context plays in self-regulation, researchers should consider assessment of both supportive interactions, and potential interpersonal conflict over diabetes management (e.g., with family members, or diabetes clinicians). The potential importance of *conflict* in diabetes management requires further investigation.

Recent research by Skinner et al. (in press) has reported evidence of a significant interactive effect involving perceived seriousness and person control. Correlations among illness/treatment representations observed in the present study imply potential for interactive relationships – cognitive and emotional representations may coalesce to produce particular patterns of self-care, or illness outcomes. Further examination of interactive relationships is necessary to build an accurate understanding of diabetes self-regulation. Attention to hierarchical relationships among representation variables is advocated. For example, previous research has shown emotional representation appears to mediate the relationship between cognitive representations (consequences, and coherence) and anxiety among women with an abnormal cervical screening result

(Hagger & Orbell, 2006). Results from the current study imply treatment representations may mediate the relationships between illness perceptions and medication use among people with type 2 diabetes; a proposition consistent with findings from prior self-regulatory research (Horne & Weinman, 2002). The presence of hierarchical 'webs of association' among variables within the illness schema warrants further empirical investigation.

Research examining illness self-regulation is important not only as a source for increasing our knowledge about this process, but also as a guide for action. Medical literature urges researchers to consider the usefulness of lifestyle interventions in diabetes (Heneghan, Thompson, & Perera, 2006). It is necessary to create interventions that work. But perhaps more importantly, researchers need to identify the *mechanisms* through which these interventions are acting. This seminal point has been emphasised by diabetes researchers (Skinner et al., in press), and broader literature within health psychology (Michie & Abraham, 2004). For example, if self-regulatory theory forms the conceptual basis for an intervention aiming to improve self-care behaviour, it is useful to show change in illness/treatment representations is associated with change in self-care behaviour. Researchers testing lifestyle interventions for diabetes are encouraged to measure both (a) outcome variables (e.g., self-care, and metabolic control), and (b) intervening variables (e.g., illness perceptions) that may act as the mechanisms for producing any observed changes.

In a randomised prospective study, interventions founded on self-regulatory theory have shown success in moderating illness representations, and reducing time to return to work among myocardial infarction patients (Petrie et al., 2002). Thus earlier research demonstrates the potential utility of interventions based on self-regulatory principles. However, enthusiastic application of present findings to an intervention context should be tempered by the limited knowledge of diabetes self-regulation afforded by current literature. Historical precedent reveals there is not a strong record of efficacious psychological interventions in diabetes (der Ven et al., 2005; Hampson et al., 2000; Wing, Epstein, Nowalk, & Scott, 1988; Winkley, Landau, Eisler, & Ismail, 2006), particularly interventions that show sustained improvement (Norris, Lau, Smith, Schmid, & Engelgau, 2002). While there are exceptions to this (e.g., Herman et al., 2005), it seems important that researchers avoid making premature recommendations where a sound evidence base is still in the process of becoming established.

At present, empirical exploration of *diabetes* self-regulation is still at an early stage. Until this process has been completed more thoroughly, firm and authoritative recommendations for intervention research are inappropriate. A strong sense of *which* illness representations have the most seminal influence on diabetes self-care behaviour has yet to emerge. However, suggestive possibilities can be identified in regard to emotional distress about diabetes. Tentative research findings indicate that (1) a perception that diabetes symptoms come and go in cycles, and (2) an expectation that diabetes will have serious life consequences, may contribute to elevated levels of diabetes-related emotional distress. Thus findings from the present study identify particular cognitive patterns that could form the targets for psychological interventions aimed at reducing diabetes distress.

As discussed previously in the current chapter, a tension can arise between employment of comprehensive models and a desire for parsimony. Traditionally, quantitative psychology has often aimed to 'explain the most variance with as few variables as possible.' But comprehensive models might be required in order to represent the complexity of diabetes self-regulation and to develop an accurate picture of the many factors that may shape diabetes self-care behaviour and illness outcomes. In exploratory research narrow models may cause researchers to 'miss' key variables and misunderstand those relationships that are present (e.g., unmeasured mediating variables may act as the more proximal determinant of wellbeing). To some extent, excessive focus on illness representations has meant previous diabetes research failed to identify the important role treatment representations play in diabetes self-care.

It is important that future research consider these issues carefully. Striking the right balance might depend on the nature of the study. In exploratory research comprehensive models help to give a broad overview of key variables. Following this, a process of refinement should be engaged, so variables that are least important can be identified and removed from the model. Thus when previous literature is scant, comprehensive models are recommended; where there is already substantive empirical evidence, the need to promote parsimony should become a priority.

In bivariate results a large number of psychological variables showed significant associations with HbA_{1c}; multivariate findings present a very different picture. This highlights the importance of employing robust statistical techniques (for example,

enabling control of demographic characteristics) when evaluating the relationship between variables of interest. This disparity also serves as a warning against over-interpretation of bivariate findings. In future research, use of multivariate analyses is advocated when examining associations between illness/treatment representations and illness outcomes among people with diabetes. Longitudinal research is recommended, so it becomes possible to examine recursive processes within illness self-regulation, and disentangle the causal direction of observed relationships.

PRIORITY TARGETS FOR FURTHER RESEARCH AND CONCEPTUAL DEVELOPMENT

In addition to the broad recommendations outlined thus far, three specific areas are identified as targets for future research.

The Appraisal Process

Published self-regulatory research to date has largely focused on illness/treatment representations and, to a lesser extent, coping strategies. Attention to the appraisal phase, in comparison, has been meagre. However, this is changing, and the role of symptom appraisal can be identified as an important area of recently emerging interest in self-regulatory literature (e.g., Broadbent & Petrie, in press; Moss-Morris, 2005). Findings from hypothesis 2 show symptom appraisal may play a key role in regulation of affect: both diabetes identity and timeline cyclical were related to differences in diabetes-related distress. Further research is needed to explain *why* cyclical symptoms are associated with greater illness-related distress.

For example, it is possible that cyclical symptoms show a direct relationship with emotional distress. An alternative hypothesis suggests cyclical symptoms may be hard to make sense of, and lower coherence is then related to elevated distress. It would be useful for future research to test whether coherence acts to mediate the relationship between timeline cyclical and emotional distress about diabetes. People with diabetes might also find cyclical symptoms hard to control, and this difficulty in controlling symptoms (e.g., blood glucose levels) could lead to distress. Findings from the present study show illness identity is connected with diabetes distress. In future studies using

the IPQ-R, researchers are encouraged to clarify what is being measured in the 'identity' subscale. It is important that operational definitions match research constructs; at present some inconsistency is apparent, as explained in detail in chapter 3.

One important hypothesised outcome from appraisal of illness symptoms is the emergence of illness/treatment representations. Self-regulation of illness does not exist inherently: it is generated by a process of symptom appraisal, which is elaborated over time, developing into a coherent system with multiple interrelated components. Further research is needed to create a better understanding of this temporal development process. It is plausible that some individuals will have elaborate, well-defined and cognitively substantive illness perceptions, while others may have only vague views about their illness. The idea that people may differ in the extent to which they activate 'illness representations' is worth exploration. In particular, this notion may be helpful in explaining the absence of expected relationships between representations and coping/outcomes that are not infrequently encountered in self-regulatory literature. Future research could utilise longitudinal data collection to track the emergence of beliefs about type 2 diabetes over a 12-month period following diagnosis.

The recursive nature of the common sense model gives rise to both primary (symptom-orientated) appraisal, and a process of secondary appraisal; that is, appraisal of coping efforts (Leventhal et al., 1980). One important hypothesised outcome of the appraisal process is affect-based experiences. These can be a positive or negative emotional response, or feelings of confidence or doubt that arise from appraisal of goal directed behaviour. These emotional responses are linked to cognitive variables like hope and purpose, and, as such, can contribute to or detract from the likelihood of engaging in health promoting behaviour in the future (Scheier & Carver, 2003). Secondary appraisal suggests people with diabetes analyse the impact of past self-care efforts, which can produce an emotional response (for example, confidence, or distress). In turn, this emotional response might influence future self-care choices. For example, when active self-care does not produce the desired outcome (improved metabolic control), appraisal of self-care may generate a sense of failure, frustration, and distress; these emotions are likely to reduce motivation for future self-care. The role of affect and diabetes self-management is identified as a pertinent area for further examination; this is discussed in detail in the following sub-section.

The Role of Emotion in Self-regulation of Diabetes

Current findings show evidence of connections between cognition and emotion in chronic illness, and provide embryonic evidence of an emotional pathway in diabetes self-regulation. Results highlight four cognitive variables (timeline cyclical, consequences, coherence, and identity) that seem to play important part in the regulation of affect. This is consistent with the interaction between cognition and affect specified in the CSM. Further research is necessary to replicate results reported in the current study, and expand knowledge of specific components within the self-regulatory process governing affect among those with diabetes.

The relationship between affect and diabetes self-care behaviour is identified as a salient area for additional research. Multivariate findings show (a) greater medication adherence is associated with higher distress about diabetes, and (b) frequent blood glucose testing is related to lower quality of life. In the present study, cross-sectional data collection means it is not possible to determine the direction of causality. This remains an important question for future studies to address. Researchers should also consider the possibility of a non-linear relationship, such that the association between negative affect and diabetes self-care changes depending on the level of affect (low, moderate, high). Longitudinal data collection is advocated so it is possible to examine any interactive relationships between level of affect and duration.

As described previously in the current chapter, it is plausible that chronic illness-related distress may have a very different impact on self-care behaviour than short, infrequent, episodes of elevated affect. Research by Weinger and Jacobson (2001) suggests a short-term elevation in distress about diabetes may help motivate self-care and encourage good metabolic control. However, if coping efforts are unsuccessful (good metabolic control is not achieved) and emotional distress about diabetes remains high, ongoing distress may act as a barrier to good self-care. Further research is required to test whether, as hypothesised, difficulty obtaining good metabolic control (especially after active, effortful, investment in self-care) leads to frustration and, possibly, disengagement from behavioural management of diabetes.

Lawson et al. (2004) assessed three variables that are, arguably, forms of affect (fear, threat, and worries); these variables did not show parallel relationships with health-

related behaviour. Higher perceived threat was associated with less regular participation in diabetes health care; conversely, greater worries showed a positive relationship with health service use. Fear showed no relationship with health service attendance. Results from the present study highlight the salience of negative emotional responses to prescribed treatment(s), suggesting medication concern may play an important role in explaining differences in self-care behaviour, and variation in metabolic control. Collective findings from self-regulatory research to date imply the impact of emotional representation of diabetes on health-related action may vary depending on the specific type of affect (e.g., fear of long-term complications versus worries about day-to-day self-management), and the selected outcome variable (e.g., dietary self-care versus regular attendance at clinical appointments for diabetes). Further study is necessary to clarify the complex relationships between different types of affect and diabetes self-care behaviour.

Although the IPQ-R subscale 'emotional representation' focuses on negative emotional responses to illness, positive affect may also be important in diabetes self-management. In their explication of the self-regulatory process, Scheier and Carver (2003) suggest an optimistic disposition can influence health-related behaviour. Specifically, they propose that positive expectations are associated with persistence and perseverance. Many people with diabetes find the complex and ongoing demands of active self-management burdensome. Optimism appears to fuel positive expectations when faced with health threats, and help to sustain health promoting behaviour among people with long term illnesses. Positive affect is also linked to use of flexible and creative cognitive approaches to managing episodes of illness (Wiebe & Korb, 2003).

Alongside the impact of generalised positive affect, researchers are encouraged to consider the possibility that *illness-specific* forms of positive affect may also exist; and that these could influence diabetes self-care behaviour. For example, research by Paterson et al. (1999) indicates diabetes can generate positive emotional responses including an increased sense of mastery, and a life-affirming belief in 'what you could be', yet such constructs have received little empirical attention in quantitative diabetes research to date. This is identified as a salient direction for future research. To summarise, findings from self-regulatory literature show associations between affect and diabetes self-care behaviour. Present knowledge in this area is limited. Further

empirical investigation is needed to unpack the complex role of affect in diabetes self-management. Attention should be given to both positive and negative emotional responses.

In addition to specific relationships with self-care behaviour, the impact of affect may permutate the self-regulatory system more broadly. For example, negative affect may influence the character of the emergent illness schema. Specifically, high anxiety may produce illness/treatment representations that are robust (firmly held) and resistant to change. Earlier self-regulatory literature proposes that “individuals who experience high anxiety at key points during health threat experiences are likely to develop representations that differ both qualitatively (in terms of contents) and quantitatively (in terms of extensiveness) from those that might have developed under low anxiety arousal” (Cameron, 2003, p. 165). In the present study, emotional distress about diabetes was related to different views of diabetes and perceptions of prescribed treatments, showing that negative affect is associated with variation in the content of illness/treatment representations. High levels of anxiety, resulting in extensive processing, may also impact on the *strength* of resultant illness representations. Emotional distress may produce illness schema that are elaborate and rigid. One possible implication of elaborate and robust illness representations is an ability to counter discordant information and therefore resistance to attitude change (Cameron, 2003). In the context of interventions aimed at altering illness representations, such information may be important. In future research it may be useful to consider the impact of anxiety on both the content and the strength of the illness schema.

An alternative hypothesis could also be considered. There might be some instances where cognitive representation of illness is actively suppressed. For example, employment of emotion-based coping strategies such as denial or avoidance may effectively lead to a ‘shut down’ of the self-regulatory system’s cognitive arm – because such coping strategies are part of an attempt to ignore the illness and its implications. If a person is making purposeful efforts not to engage in the cognitive process of ‘thinking about the symptoms/illness’, this could prevent the formation of concrete illness representations because it is the process of ‘thinking about the illness’ that essentially underlies the production of cognitive illness representations. This description outlines how employment of coping strategies that use disengagement from illness to reduce illness-related distress could, hypothetically, interfere with appraisal

processes that generate elaborate views about illness. This would suggest that emotion-based coping may weaken the cognitive illness schema, rather than strengthen it, as suggested in the preceding paragraph. In future research it would be helpful to determine (a) whether affect may *moderate* the cognitive processes that underpin diabetes self-regulation, and (b), if a moderating relationship is apparent, whether negative affect appears to activate and strengthen cognitive representations of diabetes, or conversely deactivate the cognitive aspects of the illness schema.

In summary, both cognition and affect appear to be important in diabetes self-regulation. Further empirical research is required to provide a clearer understanding of the role emotion plays in diabetes management.

Cultural Variation in Self-regulation of Chronic Illness

The presumption that all people with a given illness *have* measurable illness/treatment perceptions is open to contest as discussed previously in chapter 7. The notion that all people use the *same* schematic framework is also questionable and, perhaps, ethnocentric. Early research using the CSM identified core dimensions within illness/treatment representations. It is argued that this explanatory model is broadly applicable across cultural contexts (Baumann, 2003). Self-regulatory theory claims to present a view of illness that is 'common sense'; but common-sense beliefs about illness and treatment vary substantially according to culture. The question of *whose* 'common sense' has not often been addressed.

The CSM, like all theoretical frameworks, is shaped by the socio-cultural beliefs and values prevalent among (a) researchers who developed this model, (b) those who continue to use it as a research tool, and (c) the particular research populations that dominate within published literature. Most published self-regulatory research has been conducted in Western Europe, America, and Australasia. As a result, it can be argued that our understanding of self-regulation is culturally located; it is founded on an individualistic, 'westernised' view of health and illness that is prevalent in the nations mentioned above.

Kaptein and Broadbent (in press) describe early research assessing illness cognition, and imply that the roots of the CSM are grounded in an anthropological approach.

Recent self-regulatory literature has discussed cultural variability in illness beliefs (Baumann, 2003; Cameron & Moss-Morris, 2004). However, examination of self-regulatory literature published in the last decade reveals the ethnic composition of participants is predominately 'White' or European. Thus our knowledge of illness self-regulation (informed by published research) is strongly influenced by views held by such cultural groups. This is not inherently negative, but does require more explicit recognition.

Research by Barnes (2000) illustrates the potential usefulness of examining cultural variation in illness/treatment perceptions. Compared with New Zealand Europeans, Tongan people with diabetes were more likely to report external factors cause diabetes, believe that diabetes is temporary, report greater emotional distress about diabetes, and show concern about using prescribed medication (Barnes, 2000). These findings provide embryonic evidence of significant cultural variation in views about illness and, potentially, the character of self-regulation. Among certain cultural groups (e.g., Tongans), *affect* might act as the primary driver of coping responses; cognition may play a more subsidiary role in determining coping strategies. Self-regulatory literature "elucidates the potentially disruptive effects of emotional distress on self-control efforts required for sustaining many health behavior changes" (Cameron, 2003, p. 168). This suggests failure to successfully regulate illness-specific affect may lead to compromise in self-care behaviour and metabolic control. This proposition is consistent with research showing Tongan patients have lower dietary self-care, less frequent blood glucose testing, lower reported adherence to prescribed medication, and worse metabolic control, compared with New Zealand Europeans (Barnes, 2000).

Differences in emotional distress about diabetes might be generated through a culture-specific belief in susceptibility. First Nations groups are more likely to get diabetes, and experience worse illness outcomes as a result of diabetes, as outlined in chapter 1. Fear of complications may interact with cultural identity to generate a sense of illness-specific vulnerability; for example, a belief that 'people *like me* often lose a leg when they get diabetes'. Qualitative research suggests *fear* of diabetes complications is an important factor motivating active self-care among indigenous groups that experience a high prevalence of diabetes (Iwasaki, Bartlett, & O'Neil, 2005). This illustrates that culture-specific beliefs about diabetes (I am more vulnerable to complications because I am Samoan/African-American/Aboriginal) could play an important role in determining

coping behaviour among people with chronic illness. To date, self-regulatory literature has not examined the possible existence of culture-specific forms of fear appraisal.

Exploration of illness/treatment perceptions that are pertinent to certain cultural groups is recommended. In particular, it may be useful to identify *additional* illness representations that have received limited attention in self-regulatory research to date. The importance of spiritual beliefs in determining self-care behaviour emerged as a major theme in qualitative research among African-American women with type 2 diabetes (Samuel-Hodge et al., 2000). Illness is often seen to have a spiritual element in Polynesian cultures (Bassett & Holt, 2002; Moata'ane et al., 1996; Simmons & Voyle, 1996). A strong belief that ill health is the result of 'God's will' could be deemed a 'spiritual illness representation'. Spiritually based illness beliefs may influence coping responses, for example, a belief that 'God will take care of my diabetes' might be linked to a passive rather than active approach to diabetes self-care (Simmons & Voyle, 1996). Results from earlier research are consistent with this proposition (Barnes, 2000). Previous diabetes research implies spirituality can also have a positive influence on coping strategies because it provides a source of strength and optimism to help face the daily demands of self-management (Iwasaki et al., 2005; Samuel-Hodge et al., 2000).

Body weight can have different connotations depending on culture. The biomedical view of illness has influenced lay perceptions of wellbeing among most 'western' nations; this emphasises the need to maintain a lean body (low BMI). However, some cultures view weight loss as a sign of reduced vitality, or impending death (Fee, 2006). In Polynesian cultures, high body fat has traditionally signified prestige, and wellbeing (Moata'ane et al., 1996; Simmons & Voyle, 1996). As this discussion illustrates, there may be cultural disparity in views expressing what constitutes a 'healthy body weight' for someone with diabetes (low versus high BMI). Increased body size is perceived as a sign of good health among some groups within the diabetes population (von Hofe et al., 2002).

The preceding discussion implies common operational definitions used in self-regulatory research may not encapsulate illness beliefs that are prevalent among people with diabetes *broadly* (that is, including non-European cultural groups). For example, the IPQ-R contains seven subscales assessing cognitive perceptions of

chronic illness, and one subscale assessing emotional representation of the illness, but there are no subscales assessing spiritual representation of chronic illness (e.g., a belief that 'God will take care of my diabetes'). Perceptions about diabetes that relate to the *physical self* are also absent in the IPQ-R; arguably, beliefs about 'what a person with diabetes should look like' might be an important determinant of behavioural coping (e.g., diet and exercise patterns) among people with diabetes.

As noted in previous literature "culture is central to the ways in which we live, our values, knowledges and subjectivities"; but "the role of culture is often overlooked in models and theories about health behaviours" (Lyons & Chamberlain, 2006, p. 99). To date, few studies have explicitly sought to examine cultural variability in illness self-regulation. This is identified as a salient direction for future research. Studies that examine illness self-regulation in more than one cultural setting are a useful addition to the literature. Such research might help broaden our understanding of illness self-regulation, and potential diversity among subgroups within the global population. Exploratory research (identifying *additional* illness representations) is helpful to ensure researchers do not inadvertently miss a key component of the illness schema specific to certain cultural groups. As Lyons and Chamberlain propose, health psychology will benefit from multicultural (rather than monocultural) views of health and illness. At present the ideological values implicit in self-regulatory theory and research are not often explicitly acknowledged, and greater awareness is recommended.

CONTRIBUTION OF THE PRESENT RESEARCH

Findings from the present study add to accumulating knowledge about illness self-regulation. Contributions of the current research can be measured in regard to conceptual development within self-regulatory theory, and knowledge of diabetes self-management processes.

The present study shows preliminary evidence of an emotional pathway in diabetes self-regulation. After controlling for demographic and medical characteristics, research variables were found to explain 34% of variance in emotional distress about diabetes. Results imply variables labelled as 'cognitive' in previous self-regulatory literature may play an important role in regulation of affect among people with diabetes. Observed

relationships support the proposed interaction between cognition and affect specified in self-regulatory theory.

The identification of a possible relationship cluster connecting emotional illness responses with cyclical symptoms, serious consequences, strong identity, and low coherence, is an important theoretical contribution arising from the present study. Results highlight variables that are important in explaining differences in emotional adjustment among people with diabetes. For example, agreement that diabetes has serious consequences is related to lower quality of life, and higher diabetes-related distress. Findings stress a need for a careful clinical approach when discussing the serious health complications that can accompany type 2 diabetes.

Recent self-regulatory literature has highlighted behavioural coping as a useful direction for future research (Hagger & Orbell, 2003). Results demonstrate that active behavioural self-care is a useful addition to the coping taxonomy associated with self-regulatory theory. The CSM implies coping responses mediate between representations and illness outcomes. Findings from the current study endorse this proposition. Medication use was found to mediate the relationship between concern about prescribed treatments, and HbA_{1c}. The complex relationship between affect and behavioural coping is highlighted as a salient direction for future self-regulatory research.

To date, diabetes studies founded on the CSM have focused on the role of illness perceptions. Present findings highlight the pertinent role treatment representations play in self-management, and accentuate the need to assess both views about diabetes, and perceptions of prescribed treatment(s), when measuring core elements of the illness schema. While current findings draw attention to the importance of interpersonal relationships (particularly within the family) in explaining diet and exercise patterns, in contrast, personal beliefs appear to be important when explaining differences in medication adherence and glucose testing.

To conclude, the current study is premised on a perception that diabetes management is a complex self-regulatory process, with multiple contributory constructs. Findings support this conceptualisation. The common sense model provides a useful theoretical framework for research investigating self-care and wellbeing among people with type 2

diabetes. Self-regulatory variables demonstrate explanatory power in regard to key diabetes outcomes (self-care behaviour, physical wellbeing, and emotional adjustment). Research findings contribute to conceptual development within self-regulatory theory and increase knowledge of diabetes self-management processes.

REFERENCES

- Abel, S., & Iles, M. (2006, May). *Process evaluation of Ngati and Healthy Prevent Diabetes Project*. Paper presented at the 30th Annual Scientific Meeting of the New Zealand Society for the Study of Diabetes, Palmerston North, New Zealand.
- Abraham, C., & Sheeran, P. (2005). The Health Belief Model. In M. Conner & P. Norman (Eds.), *Predicting health behaviour* (2nd ed., pp. 29-80). New York: Open University Press.
- Aikens, J. E., Bingham, R., & Piette, J. D. (2005). Patient-provider communication and self-care behavior among type 2 diabetes patients. *The Diabetes Educator, 31*(5), 681-690.
- Ajzen, I. (1991). The Theory of Planned Behavior. *Organizational Behavior and Human Decision Processes, 50*, 179-211.
- Ajzen, I., & Fishbein, M. (1980). *Understanding attitudes and predicting social behavior*. Englewood Cliffs, NJ: Prentice-Hall.
- Albright, T. L., Parchman, M., & Burge, S. K. (2001). Predictors of self-care behavior in adults with type 2 diabetes: An RRNeST study. *Family Medicine, 33*(5), 354-360.
- Allen, N. A. (2004). Social Cognitive Theory in diabetes exercise research: An integrative literature review. *The Diabetes Educator, 30*(5), 805-819.
- Anderson, B., Funnell, M. M., Carlson, A., Seleh-Statin, N., Craddock, S., & Skinner, T. C. (2000). Facilitating self-care through empowerment. In F. J. Snoek & T. C. Skinner (Eds.), *Psychology in diabetes care* (pp. 69-97). Chichester, UK: John Wiley.
- Anderson, R. M., & Funnell, M. M. (2005). Patient empowerment: Reflections on the challenge of fostering the adoption of a new paradigm. *Patient Education and Counseling, 57*(2), 153-157.
- Antoni, M. H., Lehman, J. M., Kilbourn, K. M., Boyers, A. E., Culver, J. L., Alferi, S. M., et al. (2001). Cognitive-behavioral stress management intervention decreases the prevalence of depression and enhances benefit finding among women under treatment for early-stage breast cancer. *Health Psychology, 20*(1), 20-32.
- Apfel, J. (1995). What do patients really want to say to us, the health care workers? Some possible answers from a lay association. *Patient Education and Counseling, 26*, 273-276.
- Armitage, C. J., & Conner, M. (2000). Social cognition models and health behaviour: A structured review. *Psychology and Health, 15*(2), 173-189.
- Australian Centre for Diabetes Strategies. (2004). *Diabetes attitudes, wishes and needs: The Australian experience*. New South Wales, Australia: Author.
- Bandura, A. (1986). *Social foundations of thought and action: A social cognitive theory*. Englewood Cliffs, NJ: Prentice-Hall.
- Bandura, A. (2005, September). The growing centrality of self-regulation in health promotion and disease prevention. *The European Health Psychologist, 1*(1). Retrieved October 5, 2005, from http://www.ehps.net/new/news_2005-09.pdf

- Barnes, L. C. (2000). *Cultural perceptions of diabetes mellitus*. Unpublished master's thesis, University of Auckland, Auckland, New Zealand.
- Barnes, L. C., Moss-Morris, R., & Kaufusi, M. (2004). Illness beliefs and adherence in diabetes mellitus: A comparison between Tongan and European patients. *New Zealand Medical Journal*, 117, 743-751.
- Barnett, J. R., Pearce, J., & Howes, P. (2006). 'Help, educate, encourage?': Geographical variations in the provision and utilisation of diabetes education in New Zealand. *Social Science & Medicine*, 63(5), 1328-1343.
- Baron, R. M., & Kenny, D. A. (1986). The moderator-mediator variable distinction in social psychological research: Conceptual, strategic, and statistical considerations. *Journal of Personality and Social Psychology*, 51(6), 1173-1182.
- Bassett, S. F., & Holt, E. A. L. (2002). New Zealand resident Tongan peoples' health and illness beliefs and utilisation of the health care system. *Pacific Health Dialog*, 9(1), 40-47.
- Baumann, L. C. (2003). Culture and illness representation. In L. D. Cameron & H. Leventhal (Eds.), *The self-regulation of health and illness behaviour* (pp. 242-253). London: Routledge.
- Baumann, L. J., & Leventhal, H. (1985). "I can tell when my blood pressure is up, can't I?" *Health Psychology*, 4(3), 203-218.
- Bergental, R. M., & Gavin, J. R. (2005). The role of self-monitoring of blood glucose in the care of people with diabetes: Report of a global consensus conference. *The American Journal of Medicine*, 118(Suppl. 9A), 1-6.
- Bradley, C., & Speight, J. (2002). Patient perceptions of diabetes and diabetes therapy: Assessing quality of life. *Diabetes/Metabolism Research and Reviews*, 18(Suppl. 3), 64-69.
- Bradley, C., Todd, C., Gorton, T., Symonds, E., Martin, A., & Plowright, R. (1999). The development of an individualized questionnaire measure of perceived impact of diabetes on quality of life: The ADDQoL. *Quality of Life Research*, 8, 79-91.
- Broadbent, E., & Petrie, K. J. (in press). Symptom perception. In A. Baum & S. Newman (Eds.), *Cambridge handbook of psychology, health and medicine* (2nd ed.). UK: Cambridge University Press.
- Broadbent, E., Petrie, K. J., Ellis, C. J., Ying, J., & Gamble, G. (2004). A picture of health - myocardial infarction patients' drawings of their hearts and subsequent disability: A longitudinal study. *Journal of Psychosomatic Research*, 57, 583-587.
- Broadbent, E., Petrie, K. J., Main, J., & Weinman, J. (2006). The Brief Illness Perception Questionnaire. *Journal of Psychosomatic Research*, 60(6), 631-637.
- Broom, D., & Whittaker, A. (2004). Controlling diabetes, controlling diabetics: Moral language in the management of diabetes type 2. *Social Science & Medicine*, 58(11), 2371-2382.

- Brown, S. A., Garcia, A. A., Kouzekanani, K., & Hanis, C. L. (2002). Culturally competent diabetes self-management education for Mexican Americans: The Starr County Border Health Initiative. *Diabetes Care*, 25(2), 259-268.
- Byrne, M., Walsh, J., & Murphy, A. W. (2005). Secondary prevention of coronary heart disease: Patient beliefs and health-related behaviour. *Journal of Psychosomatic Research*, 58(5), 403-415.
- Cameron, L. D. (2003). Anxiety, cognition, and responses to health threats. In L. D. Cameron & H. Leventhal (Eds.), *The self-regulation of health and illness behaviour* (pp. 157-183). London: Routledge.
- Cameron, L. D., & Leventhal, H. (2003). Self-regulation, health, and illness: An overview. In L. D. Cameron & H. Leventhal (Eds.), *The self-regulation of health and illness behaviour* (pp. 1-13). London: Routledge.
- Cameron, L. D., & Moss-Morris, R. (2004). Illness-related cognition and behaviour. In A. A. Kaptein & J. Weinman (Eds.), *Health psychology* (pp. 84-110). Cornwall, UK: Blackwell.
- Cameron, L. D., & Reeve, J. (2006). Risk perceptions, worry, and attitudes about genetic testing for breast cancer susceptibility. *Psychology and Health*, 21(2), 211-230.
- Campbell, C. (2001). Social capital and health: Contextualising health promotion within local community networks. In S. Baron, J. Field & T. Schuller (Eds.), *Social capital: Critical perspectives* (pp. 182-196). UK: Oxford University Press.
- Campbell, R., Pound, P., Pope, C., Britten, N., Pill, R., Morgan, M., et al. (2003). Evaluating meta-ethnography: A synthesis of qualitative research on lay experiences of diabetes and diabetes care. *Social Science & Medicine*, 56(4), 671-684.
- Carver, C. S., Scheier, M. F., & Weintraub, J. K. (1989). Assessing coping strategies: A theoretically based approach. *Journal of Personality and Social Psychology*, 56(2), 267-283.
- Chun, K. M., & Chesla, C. A. (2004). Cultural issues in disease management for Chinese Americans with type 2 diabetes. *Psychology and Health*, 19(6), 767-785.
- Ciechanowski, P. S., Katon, W. J., & Hirsch, I. B. (2002). Interpersonal predictors of HbA_{1c} in patients with type 1 diabetes. *Diabetes Care*, 25(4), 731-736.
- Clark, M., & Asimakopoulou, K. (2005). Diabetes in older adults. In F. J. Snoek & T. C. Skinner (Eds.), *Psychology in diabetes care* (2nd ed., pp. 61-93). Chichester, UK: John Wiley.
- Clark, M., Avery, L., & Hampson, S. E. (2006). Beliefs about medicines and personal models of diabetes in relation to adherence to medication in patients with type 2 diabetes. *Diabetic Medicine*, 2, 27-28.
- Colagiuri, R., & Peyrot, M. (2006, April). *World status on implementation of the DAWN call to action and patient-centred initiatives in diabetes: Introduction*. Paper presented at the 3rd International DAWN Summit, Florence, Italy.

- Conner, M., & Norman, P. (2005). Predicting health behaviour: A social cognition approach. In M. Conner & P. Norman (Eds.), *Predicting health behaviour* (2nd ed., pp. 1-27). New York: Open University Press.
- Conner, M., & Sparks, P. (2005). Theory of Planned Behaviour and health behaviour. In M. Conner & P. Norman (Eds.), *Predicting health behaviour* (2nd ed., pp. 170-222). New York: Open University Press.
- Coulter, A. (2002). After Bristol: Putting patients at the centre. *British Medical Journal*, *324*(7338), 648-651.
- Coulter, A., & Magee, H. (2003). *The European patient of the future*. Berkshire, UK: Open University Press.
- DAFNE Study Group. (2002). Training in flexible, intensive insulin management to enable dietary freedom in people with type 1 diabetes: Dose Adjustment For Normal Eating (DAFNE) randomised controlled trial. *British Medical Journal*, *325*(7367), 746-751.
- Davidson, M. B. (2003). Effect of nurse-directed diabetes care in a minority population. *Diabetes Care*, *26*(8), 228-287.
- Davidson, M. B. (2005). SF-36 and diabetes outcome measures. *Diabetes Care*, *28*(6), 1536-1537.
- Davis, M., Hart, G., Bolding, G., Sherr, L., & Elford, J. (2006). E-dating, identity and HIV prevention: Theorising sexualities, risk and network society. *Sociology of Health and Illness*, *28*(4), 457-478.
- Davis, S. (2006). The patient's journey: Living with diabetes. *British Medical Journal*, *332*(7548), 1018-1020.
- Dawson, S. (2003, August). *The New Zealand experience*. Paper presented at the Annual Scientific Meeting of the Australian Diabetes Society & New Zealand Society for the Study of Diabetes, Melbourne, Australia.
- Delamater, A. M. (2006). Improving patient adherence. *Clinical Diabetes*, *24*(2), 71-77.
- der Ven, N. C. W., Hogenelst, M. H. E., Tromp-Wever, A. M. E., Twisk, J. W. R., der Ploeg, H. M., Heine, R. J., et al. (2005). Short-term effects of cognitive behavioural group training (CBGT) in adult type 1 diabetes patients in prolonged poor glycaemic control. A randomized controlled trial. *Diabetic Medicine*, *22*(11), 1619-1623.
- DiClemente, C. C., Prochaska, J. O., Fairhurst, S. K., Velicer, W. F., Velasquez, M. M., & Rossi, J. S. (1991). The process of smoking cessation: An analysis of precontemplation, contemplation, and preparation stages of change. *Journal of Consulting and Clinical Psychology*, *59*, 295-304.
- DiMatteo, M. R., Sherbourne, C. D., Hays, R. D., Ordway, L., Kravitz, R. L., McGlynn, E. A., et al. (1993). Physicians' characteristics influence patients' adherence to medical treatment: Results from the Medical Outcomes Study. *Health Psychology*, *12*(2), 93-102.

- DiNicola, D. D., & DiMatteo, M. R. (1984). Practitioners, patients, and compliance with medical regimens: A social psychological perspective. In A. Baum, S. E. Taylor & J. E. Singer (Eds.), *Handbook of psychology and health* (Vol. IV Social psychological aspects of health, pp. 55-84). Hillsdale, NJ: Lawrence Erlbaum.
- Dressler, W. W., & Oths, K. S. (1997). Cultural determinants of health behavior. In D. S. Gochman (Ed.), *Handbook of health behavior research* (Vol. I Personal and social determinants, pp. 359-377). New York: Plenum Press.
- Du Pasquier-Fediaevsky, L., Chwalow, A. J., & Tubiana-Rufi, N. (2005). Is the relationship between adherence behaviours and glycaemic control bi-directional at adolescence? A longitudinal cohort study. *Diabetic Medicine*, 22(4), 427-433.
- Dunn, S. M. (2006, April). *Psychosocial care as an integral part of chronic disease management: Lessons from diabetes and cancer*. Paper presented at the 3rd International DAWN Summit, Florence, Italy.
- Durie, M. (1997). Whanau, whanaungatanga and healthy Maori development. In P. Te Whaiti, M. McCarthy & A. Durie (Eds.), *Mai i rangiatea* (pp. 1-24). New Zealand: Auckland University Press.
- Durie, M. (1998). Tirohanga Maori: Maori health perspectives. In *Whaiora: Maori health development* (2nd ed., pp. 66-80). Auckland, New Zealand: Oxford University Press.
- Durie, M. (2000). Maori health: Key determinants for the next twenty-five years. *Pacific Health Dialog*, 7(1), 6-11.
- Durie, M. (2001). *Mauri ora: The dynamics of Maori health*. Auckland, New Zealand: Oxford University Press.
- Durie, M. (2003). A strategic framework for addressing the impact of diabetes on indigenous peoples. In *Nga kahui pou - Launching Maori futures* (pp. 182-195). Wellington, New Zealand: Huia.
- Edelman, D., Olsen, M. K., Dudley, T. K., Harris, A. C., & Oddone, E. Z. (2002). Impact of diabetes screening on quality of life. *Diabetes Care*, 25(6), 1022-1026.
- Edelwich, J., & Brodsky, R. A. (1986). *Diabetes: Caring for your emotions as well as your health*. New York: Perseus Books.
- Edelwich, J., & Brodsky, R. A. (1998). *Diabetes: Caring for your emotions as well as your health* (Rev. ed.). New York: Perseus Books.
- Edgar, K. A., & Skinner, T. C. (2003). Illness representations and coping as predictors of emotional well-being in adolescents with type 1 diabetes. *Journal of Pediatric Psychology*, 28(7), 485-493.
- Eiser, J. R., Riazi, A., Eiser, C., Hammersley, S., & Tooke, J. E. (2001). Predictors of psychological well-being in types 1 and 2 diabetes. *Psychology and Health*, 16(1), 99-110.
- Farmer, L., Pearson, S., & Strong, A. (2004). *Type 2 diabetes - and how to live with it*. Wellington, New Zealand: Massey University.

- Fawzy, F. I., Fawzy, N. W., Hyun, C. S., Elashoff, R., Guthrie, D., Fahey, J. L., et al. (1993). Malignant melanoma: Effects of an early structured psychiatric intervention, coping, and affective state on recurrence and survival 6 years later. *Archives of General Psychiatry*, *50*(9), 681-689.
- Fee, M. (2006). Racializing narratives: Obesity, diabetes and the "Aboriginal" thrifty genotype. *Social Science & Medicine*, *62*(12), 2988-2997.
- Feldman, S. S., & Weinberger, D. A. (1994). Self-restraint as a mediator of family influences on boys' delinquent behaviour: A longitudinal study. *Child Development*, *65*, 195-211.
- Ferrencia, R. (2001). Diffusion theory and drug use. *Addiction*, *96*(1), 165-173.
- Fisher, E. B., Brownson, C. A., O'Toole, M. L., Shetty, G., Anwuri, V. V., & Glasgow, R. E. (2005). Ecological approaches to self-management: The case of diabetes. *American Journal of Public Health*, *95*(9), 1523-1535.
- Fisher, E. B., La Greca, A. M., Greco, P., Arfken, C., & Schneiderman, N. (1997). Directive and nondirective social support in diabetes management. *International Journal of Behavioral Medicine*, *4*(2), 131-144.
- Fisher, K. L. (2006). Assessing psychosocial variables: A tool for diabetes educators. *The Diabetes Educator*, *32*(1), 51-58.
- Fisher, L., Chesla, C. A., Bartz, R. J., Gilliss, C., Skaff, M. M., Sabogal, R. A., et al. (1998). The family and type 2 diabetes: A framework for intervention. *The Diabetes Educator*, *24*(5), 599-607.
- Fisher, L., Chesla, C. A., Skaff, M. M., Gilliss, C., Mullan, J. T., Bartz, R. J., et al. (2000). The family and disease management in Hispanic and European-American patients with type 2 diabetes. *Diabetes Care*, *23*(3), 267-272.
- Foliaki, S., & Pearce, N. (2003). Prevention and control of diabetes in Pacific people. *British Medical Journal*, *327*(7412), 437-439.
- Fortune, D. G., Richards, H. L., Griffiths, C. E. M., & Main, C. J. (2002). Psychological stress, distress and disability in patients with psoriasis: Consensus and variation in the contribution of illness perceptions, coping and alexithymia. *British Journal of Clinical Psychology*, *41*(2), 157-174.
- Fox, C., & Kilvert, A. (2003). Intensive education for lifestyle change in diabetes. *British Medical Journal*, *327*(7424), 1120-1121.
- Funnell, M. M., & Anderson, R. M. (2005). Patient empowerment. In F. J. Snoek & T. C. Skinner (Eds.), *Psychology in diabetes care* (2nd ed., pp. 94-108). Chichester, UK: John Wiley.
- Galazka, S. S., & Eckert, J. K. (1984). Diabetes mellitus from the inside out: Ecological perspectives on a chronic disease. *Family Systems Medicine*, *2*(1), 28-33.
- Garay-Sevilla, M. E., Malacara, J. M., Gutierrez-Roa, A., & Gonzalez, E. (1999). Denial of disease in type 2 diabetes mellitus: Its influence on metabolic control and associated factors. *British Diabetic Association*, *16*, 238-244.

- Garay-Sevilla, M. E., Nava, L. E., Malacara, J. M., Huerta, R., de Leon, J. D., Mena, A., et al. (1995). Adherence to treatment and social support in patients with non-insulin dependent diabetes mellitus. *Journal of Diabetes and Its Complications*, 9, 81-86.
- Gentili, P., Maldonado, A., Grieco, R., & Santini, A. (2001). Influence of patients' representations and beliefs about diabetes and its treatment on their adherence to therapy. *Diabetes, Nutrition and Metabolism*, 14(3), 140-152.
- Gerich, J. E. (2005). The importance of tight glycemic control. *The American Journal of Medicine*, 118(Suppl. 9A), 7-11.
- Gillespie, C. R., & Bradley, C. (1988). Causal attributions of doctor and patients in a diabetes clinic. *British Journal of Clinical Psychology*, 27, 67-76.
- Glasgow, R. E. (1994). Social-environmental factors in diabetes: Barriers to diabetes self-care. In C. Bradley (Ed.), *Handbook of psychology and diabetes* (pp. 335-349). Chur, Switzerland: Harwood Academic.
- Glasgow, R. E. (2005). Medical office-based interventions. In F. J. Snoek & T. C. Skinner (Eds.), *Psychology in diabetes care* (2nd ed., pp. 110-139). Chichester, UK: John Wiley.
- Glasgow, R. E., Hampson, S. E., Strycker, L. A., & Ruggiero, L. (1997). Personal-model beliefs and social-environmental barriers related to diabetes self-management. *Diabetes Care*, 20(4), 556-561.
- Glasgow, R. E., Hiss, R. G., Anderson, R. M., Friedman, N. M., Hayward, R. A., Marrero, D. G., et al. (2001). Report of the Health Care Delivery Work Group - behavioral research related to the establishment of a chronic disease model for diabetes care. *Diabetes Care*, 24(1), 124-130.
- Glasgow, R. E., & Toobert, D. J. (1988). Social environment and regimen adherence among type II diabetic patients. *Diabetes Care*, 11(5), 377-386.
- Glover, M. (2002). *A literature review and commentary of the use of a kaupapa Maori approach within a doctoral study of Maori smoking cessation*. Auckland, New Zealand: The University of Auckland.
- Gochman, D. S. (1997). Provider determinants of health behavior: An integration. In D. S. Gochman (Ed.), *Handbook of health behaviour research* (Vol. II Provider determinants, pp. 397-419). New York: Plenum Press.
- Godin, G., & Kok, G. (1996). The Theory of Planned Behavior: A review of its applications to health-related behaviors. *American Journal of Health Promotion*, 11, 87-98.
- Goldney, R. D., Phillips, P. J., Fisher, L. J., & Wilson, D. H. (2004). Diabetes, depression, and quality of life: A population study. *Diabetes Care*, 27(5), 1066-1070.
- Gordon, D., Fisher, S. O., Wilson, M., Fergus, E., Paterson, O. R., & Semple, C. G. (1993). Psychological factors and their relationship to diabetes control. *Diabetic Medicine*, 10, 530-534.

- Griva, K., Myers, L. B., & Newman, S. (2000). Illness perceptions and self efficacy beliefs in adolescents and young adults with insulin dependent diabetes mellitus. *Psychology and Health, 15*(6), 733-750.
- Groarke, A., Curtis, R., Coughlan, R., & Gsel, A. (2005). The impact of illness representations and disease activity on adjustment in women with rheumatoid arthritis: A longitudinal study. *Psychology and Health, 20*(5), 597-613.
- Hagger, M. S., & Orbell, S. (2003). A meta-analytic review of the Common-Sense Model of illness representations. *Psychology and Health, 18*(2), 141-184.
- Hagger, M. S., & Orbell, S. (2005). A confirmatory factor analysis of the revised Illness Perception Questionnaire (IPQ-R) in a cervical screening context. *Psychology and Health, 20*(2), 161-173.
- Hagger, M. S., & Orbell, S. (2006). Illness representations and emotion in people with abnormal screening results. *Psychology and Health, 21*(2), 183-209.
- Haidet, P., Dains, J. E., Paterniti, D. A., Hechtel, L., Chang, T., Tseng, E., et al. (2002). Medical student attitudes toward the doctor-patient relationship. *Medical Education, 36*(6), 568-574.
- Hampson, S. E. (1997). Illness representations and the self-management of diabetes. In K. J. Petrie & J. Weinman (Eds.), *Perceptions of health and illness: Current research and applications* (pp. 323-347). Amsterdam: Harwood Academic.
- Hampson, S. E., Glasgow, R. E., & Foster, B. A. (1995). Personal models of diabetes among older adults: Relationship to self-management and other variables. *The Diabetes Educator, 21*(4), 300-307.
- Hampson, S. E., Glasgow, R. E., & Strycker, L. A. (2000). Beliefs versus feelings: A comparison of personal models and depression for predicting multiple outcomes in diabetes. *British Journal of Health Psychology, 5*, 27-40.
- Hampson, S. E., Glasgow, R. E., & Toobert, D. (1990). Personal models of diabetes and their relations to self-care activities. *Health Psychology, 9*(5), 632-646.
- Harmel, A. P., & Mathur, R. (2004). *Davidson's diabetes mellitus: Diagnosis and treatment* (5th ed.). Philadelphia: Elsevier.
- Harris, M., Klein, R., Welborn, T., & Knudman, M. (1992). Onset of NIDDM occurs at least 4-7 yr before clinical diagnosis. *Diabetes Care, 15*(7), 815-819.
- Hayes, R. P., Bernard, A. M., Slocum, W., El-Kebbi, I., Ziemer, D., Gallina, D., et al. (2000). Diabetes in urban African Americans: Assessment of diabetes-specific locus of control in patients with type 2 diabetes. *The Diabetes Educator, 26*(1), 121-128.
- Heijmans, M. (1998). Coping and adaptive outcome in chronic fatigue syndrome: Importance of illness cognitions. *Journal of Psychosomatic Research, 45*(1), 39-51.
- Heijmans, M. (1999). The role of patients' illness representations in coping and functioning with Addison's disease. *British Journal of Health Psychology, 4*(2), 137-149.

- Heijmans, M., & de Ridder, D. (1998). Assessing illness representations of chronic illness: Explorations of their disease-specific nature. *Journal of Behavioral Medicine, 21*(5), 485-503.
- Heller, S. (2005). Forward. In T. C. Skinner & F. J. Snoek (Eds.), *Psychology in diabetes care* (2nd ed., pp. xv-xvi). Chichester, UK: John Wiley.
- Heneghan, C., Thompson, M., & Perera, R. (2006). Prevention of diabetes. *British Medical Journal, 333*(7572), 764-765.
- Herman, W. H., Hoerger, T. J., Brandle, M., Hicks, K., Sorensen, S., Zhang, P., et al. (2005). The cost-effectiveness of lifestyle modification or metformin in preventing type 2 diabetes in adults with impaired glucose tolerance. *Annals of Internal Medicine, 142*(5), 323-332.
- Hill-Briggs, F., Gary, T. L., Baptiste-Roberts, K., & Brancati, F. L. (2005). Thirty-six-item Short-Form outcomes following a randomized controlled trial in type 2 diabetes. *Diabetes Care, 28*(2), 443-444.
- Holmbeck, G. N. (1997). Toward terminological, conceptual, and statistical clarity in the study of mediators and moderators: Examples from the child-clinical and pediatric psychology literatures. *Journal of Consulting and Clinical Psychology, 65*(4), 599-610.
- Horne, R. (1997). Representations of medication and treatment: Advances in theory and measurement. In K. J. Petrie & J. A. Weinman (Eds.), *Perceptions of health and illness: Current research and applications* (pp. 155-188). Amsterdam: Harwood Academic.
- Horne, R. (1999). Patients' beliefs about treatment: The hidden determinant of treatment outcome? *Journal of Psychosomatic Research, 47*(6), 491-495.
- Horne, R. (2003). Treatment perceptions and self-regulation. In L. D. Cameron & H. Leventhal (Eds.), *The self-regulation of health and illness behaviour* (pp. 138-153). London: Routledge.
- Horne, R., Petrie, K. J., Davis, C., Diefenbach, M., Leventhal, H., & Leventhal, E. A. (2004, August). *The Sensitive Soma Assessment Scale (SSAS)*. Paper presented at the Eighth International Congress of Behavioral Medicine, Mainz, Germany.
- Horne, R., & Weinman, J. (1999). Patients' beliefs about prescribed medicines and their role in adherence to treatment in chronic physical illness. *Journal of Psychosomatic Research, 47*(6), 555-567.
- Horne, R., & Weinman, J. (2002). Self-regulation and self-management in asthma: Exploring the role of illness perceptions and treatment beliefs in explaining non-adherence to preventer medication. *Psychology and Health, 17*(1), 17-32.
- Horne, R., Weinman, J., & Hankins, M. (1999). The Beliefs about Medicines Questionnaire: The development and evaluation of a new method for assessing the cognitive representation of medication. *Psychology and Health, 14*(1), 1-24.
- Hornsten, A., Sandstrom, H., & Lundman, B. (2004). Personal understandings of illness among people with type 2 diabetes. *Journal of Advanced Nursing, 47*(2), 174-182.

- Hughes, E. (2006, April). *World status on implementation of the DAWN call to action and patient-centred initiatives in diabetes: Europe*. Paper presented at the 3rd International DAWN Summit, Florence, Italy.
- Hurley, A. C. (1990). The Health Belief Model: Evaluation of a diabetes scale. *The Diabetes Educator, 16*(1), 44-48.
- Hurley, A. C., & Shea, C. A. (1992). Self-efficacy: Strategy for enhancing diabetes self-care. *The Diabetes Educator, 18*(2), 146-150.
- Hyoty, H., Hiltunen, M., Knip, M., Laakkonen, M., Vahasalo, P., Karjalainen, J., et al. (1995). A prospective study of the role of coxsackie B and other enterovirus infections in the pathogenesis of IDDM. Childhood Diabetes in Finland (DiMe) Study Group. *Diabetes, 44*(6), 652-657.
- International Diabetes Federation. (2006a). *Diabetes atlas*. Retrieved July 8, 2006, from <http://www.eatlas.idf.org/>
- International Diabetes Federation. (2006b). *Diabetes atlas: Executive summary*. Retrieved July 7, 2006, from <http://www.eatlas.idf.org/webdata/docs/Atlas%202003-Summary.pdf>
- International Diabetes Federation Clinical Guidelines Task Force. (2006). Global guideline for type 2 diabetes: Recommendations for standard, comprehensive, and minimal care. *Diabetic Medicine, 23*, 579-593.
- Iwasaki, Y., Bartlett, J., & O'Neil, J. (2005). Coping with stress among Aboriginal women and men with diabetes in Winnipeg, Canada. *Social Science & Medicine, 60*(5), 977-988.
- Jack, L., Jr, Liburd, L., Vinicor, F., Brody, G., & Murry, V. M. (1999). Influence of the environmental context on diabetes self-management: A rationale for developing a new research paradigm in diabetes education. *The Diabetes Educator, 25*(5), 775-790.
- Jenkins, C. (2003). Self-management in diabetes: The dynamics of behaviour change. *Journal of Diabetes Nursing, 7*(6), 225-227.
- Jessop, D. C., & Rutter, D. R. (2003). Adherence to asthma medication: The role of illness representations. *Psychology and Health, 18*(5), 595-612.
- Johnston, M. (1994). Current trends in health psychology. *The Psychologist, 7*, 114-118.
- Johnston, M. (2005, September). Means and meanings in health psychology. *The European Health Psychologist, 1*(1). Retrieved October 5, 2005, from http://www.ehps.net/new/news_2005-09.pdf
- Kaptein, A. A., & Broadbent, E. (in press). Illness cognition assessment. In A. Baum & S. Newman (Eds.), *Cambridge handbook of psychology, health and medicine* (2nd ed.). UK: Cambridge University Press.
- Kaptein, A. A., Helder, D. I., Scharloo, M., Van Kempen, M., Weinman, J., Van Houwelingen, H. J. C., et al. (2006). Illness perceptions and coping explain well-being in patients with Huntington's disease. *Psychology and Health, 21*(4), 431-446.

- Katsilambros, N., & Tentolouris, N. (2003). Type 2 diabetes: An overview. In J. C. Pickup & G. Williams (Eds.), *Textbook of diabetes* (Vol. 1, Section 1, pp. 4.1 - 4.19). Boston: Blackwell Science.
- Keers, J. C., Links, T. P., Bouma, J., Sluiter, W. J., Sanderman, R., & Wolffenbuttel, B. H. (2006, April). *Diabetes-related coping as a determinant of success in diabetes rehabilitation*. Paper presented at the 3rd International DAWN Summit, Florence, Italy.
- Kelleher, D. (1988). *Diabetes*. London: Routledge.
- Kemp, S., Morley, S., & Anderson, E. (1999). Coping with epilepsy: Do illness representations play a role? *British Journal of Clinical Psychology, 38*, 43-58.
- King, H., Aubert, R., & Herman, W. (1998). Global burden of diabetes, 1995-2025: Prevalence, numerical estimates, and projections. *Diabetes Care, 21*(9), 1414-1431.
- Kruger, D. F., Martin, C. L., & Sadler, C. E. (2006). New insights into glucose regulation. *The Diabetes Educator, 32*(2), 221-228.
- Lange, L., & Piette, J. (2006). Personal models for diabetes in context and patients' health status. *Journal of Behavioral Medicine, 29*(3), 239-253.
- Larme, A. C., & Pugh, J. A. (2001). Evidence-based guidelines meet the real world: The case of diabetes care. *Diabetes Care, 24*(10), 1728-1733.
- Law, G. U., Kelly, T. P., Huey, D., & Summerbell, C. (2002). Self-management and well-being in adolescents with diabetes mellitus: Do illness representations play a regulatory role? *Journal of Adolescent Health, 31*(4), 381-385.
- Lawson, V. L., Bundy, C., Lyne, P. A., & Harvey, J. N. (2004). Using the IPQ and PMDI to predict regular diabetes care-seeking among patients with type 1 diabetes. *British Journal of Health Psychology, 9*, 241-252.
- Leventhal, H. (2005). Health psychology: Past, present and future. *The European Health Psychologist, 1*(1). Retrieved October 5, 2005, from http://www.ehps.net/new/news_2005-09.pdf
- Leventhal, H., Brissette, I., & Leventhal, E. A. (2003). The Common-Sense Model of self-regulation of health and illness. In L. D. Cameron & H. Leventhal (Eds.), *The self-regulation of health and illness behaviour* (pp. 42-65). London: Routledge.
- Leventhal, H., Diefenbach, M., & Leventhal, E. A. (1992). Illness cognition: Using common sense to understand treatment adherence and affect cognition interactions. *Cognitive Therapy and Research, 16*(2), 143-163.
- Leventhal, H., Meyer, D., & Nerenz, D. (1980). The common sense representation of illness danger. In S. Rachman (Ed.), *Contributions to medical psychology* (Vol. 2, pp. 7-30). Oxford, UK: Pergamon Press.
- Leventhal, H., Nerenz, D. R., & Steele, D. J. (1984). Illness representations and coping with health threats. In A. Baum, S. E. Taylor & J. E. Singer (Eds.), *Handbook of psychology and health* (Vol. IV Social psychological aspects of health, pp. 219-252). Hillsdale, NJ: Lawrence Erlbaum.

- Lewis, K. S., & Bradley, C. (1994). Measures of diabetes-specific health beliefs. In C. Bradley (Ed.), *Handbook of psychology and diabetes* (pp. 247-289). Chur, Switzerland: Harwood Academic.
- Little, P., Everitt, H., Williamson, I., Warner, G., Moore, M., Gould, C., et al. (2001a). Observational study of effect of patient centredness and positive approach on outcomes of general practice consultations. *British Medical Journal*, *323*(7318), 908-911.
- Little, P., Everitt, H., Williamson, I., Warner, G., Moore, M., Gould, C., et al. (2001b). Preferences of patients for patient centred approach to consultation in primary care: Observational study. *British Medical Journal*, *322*(7284), 1-7.
- Lo, R. (1999). Correlates of expected success at adherence to health regimen of people with IDDM. *Journal of Advanced Nursing*, *30*(2), 418-424.
- Loewe, R., Schwartzman, J., Freeman, J., Quinn, L., & Zuckerman, S. (1998). Doctor talk and diabetes: Towards an analysis of the clinical construction of chronic illness. *Social Science & Medicine*, *47*(9), 1267-1276.
- Luszczynska, A., & Schwarzer, R. (2005). Social cognitive theory. In M. Conner & P. Norman (Eds.), *Predicting health behaviour* (2nd ed., pp. 127-169). New York: Open University Press.
- Lyons, A. C., & Chamberlain, K. (2006). *Health psychology: A critical introduction*. New York: Cambridge University Press.
- Macdonald, N. (2006a, May 10). Battling the bulge for a better future. *The Dominion Post*, p. A10.
- Macdonald, N. (2006b, May 10). Goodbye greasy chips, hello greens. *The Dominion Post*, p. A10.
- Macdonald, N. (2006c, May 10). Price of avoiding the doctor. *The Dominion Post*, p. A10.
- Manwatu Horowhenua and Tararua Diabetes Trust. (2003). *Annual Report*. Palmerston North, New Zealand: Manwatu Horowhenua and Tararua Diabetes Trust.
- Marks, D. F., Murray, M., Evans, B., & Willig, C. (2000). *Health psychology: Theory, research and practice*. London: Sage Publications.
- Matthews, D., & Lloyd, H. (2005). *Diabetes stories: Personal tales of diabetes through the decades*. Retrieved April 3, 2006, from <http://www.diabetes-stories.com>
- Mau, M. K., Glanz, K., Severino, R., Grove, J. S., Johnson, B., & Curb, J. D. (2001). Mediators of lifestyle behavior change in native Hawaiians. *Diabetes Care*, *24*(10), 1770-1775.
- McCaul, K. D., Glasgow, R. E., & Schafer, L. C. (1987). Diabetes regimen behaviors: Predicting adherence. *Medical Care*, *25*(9), 868-881.
- McCord, E. C., & Brandenburg, C. (1995). Beliefs and attitudes of persons with diabetes. *Family Medicine*, *27*(4), 267-271.

- McDonald, R. (2004). Individual identity and organisational control: Empowerment and modernisation in a primary care trust. *Sociology of Health and Illness*, 26(7), 925-950.
- Metzger, B., Cho, N., Roston, S., & Radvany, R. (1993). Prepregnancy weight and antepartum insulin secretion predict glucose tolerance five years after gestational diabetes mellitus. *Diabetes Care*, 16(12), 1598-1605.
- Michie, S., & Abraham, C. (2004). Interventions to change health behaviours: Evidence-based or evidence-inspired? *Psychology and Health*, 19(1), 29-49.
- Michie, S., Johnston, M., Abraham, C., Lawton, R., Parker, D., & Walker, A. (2005). Making psychological theory useful for implementing evidence based practice: A consensus approach. *Quality in Health Care*, 14, 26-33.
- Michie, S., Miles, J., & Weinman, J. (2003). Patient-centredness in chronic illness: What is it and does it matter? *Patient Education and Counseling*, 51(3), 197-206.
- MidCentral District Health Board. (2005). *Diabetes Service Plan July 2005*. Palmerston North, New Zealand: Author.
- Ministry of Health. (1999). *Taking the Pulse: The 1996-1997 New Zealand Health Survey*. Wellington, New Zealand: Author.
- Ministry of Health. (2002). *Modelling Diabetes: A summary*. Wellington, New Zealand: Author.
- Ministry of Health. (2004). *A Portrait of Health: Key results of the 2002/03 New Zealand Health Survey*. Wellington, New Zealand: Author.
- Moata'ane, L. M., Muimui-Heata, S., & Guthrie, B. E. (1996). Tongan perceptions of diet and diabetes mellitus. *Journal of the New Zealand Dietetic Association*, 50(2), 52-56.
- Monash University. (n.d.). *Multicollinearity*. Retrieved September 28, 2005, from <http://www.med.monash.edu.au/spppm/research/rda/Multi-collinearity.htm>
- Montez, J. K., & Karner, T. X. (2005). Understanding the diabetic body-self. *Qualitative Health Research*, 15(8), 1086-1104.
- Moss-Morris, R. (2005). Symptom perceptions, illness beliefs and coping in chronic fatigue syndrome. *Journal of Mental Health*, 14(3), 223-235.
- Moss-Morris, R., Petrie, K. J., & Weinman, J. (1996). Functioning in chronic fatigue syndrome: Do illness representations play a regulatory role? *British Journal of Health Psychology*, 1, 15-25.
- Moss-Morris, R., Weinman, J., Petrie, K. J., Horne, R., Cameron, L. D., & Buick, D. (2002). The revised Illness Perception Questionnaire (IPQ-R). *Psychology and Health*, 17(1), 1-16.
- Murphy, E., & Kinmonth, A. L. (1995). No symptoms, no problem? Patients' understandings of non-insulin dependent diabetes. *Family Practice*, 12(2), 184-192.

- Murray, M. (2005). Challenges and prospects for a socially activist health psychology. *The European Health Psychologist*, (1). Retrieved October 5, 2005, from http://www.ehps.net/new/news_2005-09.pdf
- Nakahara, R., Yoshiuchi, K., Kumano, H., Hara, Y., Suematsu, H., & Kuboki, T. (2006). Prospective study on influence of psychosocial factors on glycemic control in Japanese patients with type 2 diabetes. *Psychosomatics*, 47(3), 240-246.
- National Advisory Committee on Health and Disability. (2005). *National Health Committee Annual Report*. Wellington, New Zealand: National Health Committee.
- Nelson, R., Gohdes, D., Everhart, J., Hartner, J., Zwemer, F., Pettitt, D., et al. (1988). Lower-extremity amputations in NIDDM. 12-yr follow-up study in Pima Indians. *Diabetes Care*, 11(1), 8-16.
- New Zealand Guidelines Group. (2003). *Best practice evidence-based guideline: Management of type 2 diabetes*. Retrieved February 1, 2005, from http://www.nzgg.org.nz/guidelines/0036/Diabetes_full_text.pdf
- Nichols, G. A., & Brown, J. B. (2004). Functional status before and after diagnosis of type 2 diabetes. *Diabetic Medicine*, 21(7), 793-797.
- Norris, S. L., Lau, J., Smith, S. J., Schmid, C. H., & Engelgau, M. M. (2002). Self-management education for adults with type 2 diabetes: A meta-analysis of the effect on glycemic control. *Diabetes Care*, 25(7), 1159-1171.
- Novo Nordisk Pharmaceuticals. (2004). *News from the 2nd International DAWN Summit*. Bagsvaerd, Denmark: Author.
- Ogden, J. (2000). *Health psychology: A textbook* (2nd ed.). London: Open University Press.
- Oomen, J. S., Owen, L. J., & Suggs, L. S. (1999). Culture counts: Why current treatment models fail Hispanic women with type 2 diabetes. *The Diabetes Educator*, 25(2), 220-225.
- Opie, A. (1998). "Nobody's asked me for my view": Users' empowerment by multidisciplinary health teams. *Qualitative Health Research*, 8(2), 188-206.
- Orbell, S., Hodgkins, S., & Sheeran, P. (1997). Implementation intentions and the theory of planned behavior. *Personality and Social Psychology Bulletin*, 23, 945-954.
- Paddison, C. A. M. (2004). *Diabetes education among Maori in MidCentral: A discussion document for the MidCentral District Health Board diabetes care review*. Palmerston North, New Zealand: Massey University, School of Psychology.
- Paschalides, C., Wearden, A. J., Dunkerley, R., Bundy, C., Davies, R., & Dickens, C. M. (2004). The associations of anxiety, depression and personal illness representations with glycaemic control and health-related quality of life in patients with type 2 diabetes mellitus. *Journal of Psychosomatic Research*, 57(6), 557-564.
- Paterson, B. (2001). Myth of empowerment in chronic illness. *Journal of Advanced Nursing*, 34(5), 574-581.

- Paterson, B., Thorne, S., Crawford, J., & Tarko, M. (1999). Living with diabetes as a transformational experience. *Qualitative Health Research, 9*(6), 786-802.
- Paterson, B. L., Russell, C., & Thorne, S. (2001). Critical analysis of everyday self-care decision making in chronic illness. *Journal of Advanced Nursing, 35*(3), 335-341.
- Pennings-Van der Eerden, L. J. M. (1990). Psychological determinants of diabetic self-care: The role of knowledge, beliefs and intentions. In L. R. Schmidt, P. Schwenkmezger, J. Weinman & S. Maes (Eds.), *Theoretical and applied aspects of health psychology* (pp. 353-359). London: Harwood Academic.
- Pescosolido, B. A. (1992). Beyond rational choice: The social dynamics of how people seek help. *American Journal of Sociology, 97*(4), 1096-1138.
- Petrie, K. J., Broadbent, E., & Meechan, G. (2003). Self-regulatory interventions for improving the management of chronic illness. In L. D. Cameron & H. Leventhal (Eds.), *The self-regulation of health and illness behaviour* (pp. 257-296). London: Routledge.
- Petrie, K. J., Cameron, L. D., Ellis, C. J., Buick, D., & Weinman, J. (2002). Changing illness perceptions after myocardial infarction: An early intervention randomized controlled trial. *Psychosomatic Medicine, 64*(4), 580-586.
- Petrie, K. J., Weinman, J., Sharpe, N., & Buckley, J. (1996). Role of patients' view of their illness in predicting return to work and functioning after myocardial infarction: Longitudinal study. *British Medical Journal, 312*(7040), 1191-1194.
- Peyrot, M., Rubin, R. R., Lauritzen, T., Skovlund, S. E., Snoek, F. J., Matthews, D. R., et al. (2005). Resistance to insulin therapy among patients and providers: Results of the cross-national Diabetes Attitudes, Wishes, and Needs (DAWN) study. *Diabetes Care, 28*(11), 2673-2679.
- Peyrot, M., Rubin, R. R., Lauritzen, T., Snoek, F. J., Matthews, D. R., & Skovlund, S. E. (2005). Psychosocial problems and barriers to improved diabetes management: Results of the cross-national Diabetes Attitudes, Wishes and Needs (DAWN) Study. *Diabetic Medicine, 22*(10), 1379-1385.
- Picker Institute. (2003). *Eight dimensions of patient-centred care*. Retrieved April 18, 2003, from <http://nrcpicker.com/Default.aspx?DN=112,22,2,1,Documents>
- Plumridge, E., & Chetwynd, J. (1999). Identity and the social construction of risk: Injecting drug use. *Sociology of Health and Illness, 21*(3), 329-343.
- Polonsky, W. H., Fisher, L., Earles, J., Dudl, R. J., Lees, J., Mullan, J., et al. (2005). Assessing psychosocial distress in diabetes: Development of the Diabetes Distress Scale. *Diabetes Care, 28*(3), 626-631.
- Pooley, C. G., Gerrard, C., Hollis, S., Morton, S., & Astbury, J. (2001). 'Oh it's a wonderful practice ... you can talk to them': A qualitative study of patients' and health professionals' views on the management of type 2 diabetes. *Health and Social Care in the Community, 9*(5), 318-326.

- Pouwer, F., Beekman, A. T. F., Lubach, C., & Snoek, F. J. (2006). Nurses' recognition and registration of depression, anxiety and diabetes-specific emotional problems in outpatients with diabetes mellitus. *Patient Education and Counseling, 60*(2), 235-240.
- Pouwer, F., Skinner, T. C., Pibernik-Okanovic, M., Beekman, A. T. F., Craddock, S., Szabo, S., et al. (2005). Serious diabetes-specific emotional problems and depression in a Croatian-Dutch-English Survey from the European Depression in Diabetes (EDID) Research Consortium. *Diabetes Research and Clinical Practice, 70*(2), 166-173.
- Powell, S., Vulikh, E., Jones, M., & Schroen, L. (2003, August). *Diabetes education for people from non-English speaking backgrounds: A needs assessment of a Russian speaking community*. Paper presented at the Annual Scientific Meeting of the Australian Diabetes Society & New Zealand Society for the Study of Diabetes, Melbourne, Australia.
- Pratt, H. L., & Jackson, L. J. (2003, August). *Individualising a diabetes education programme for Samoan people*. Paper presented at the Annual Scientific Meeting of the Australian Diabetes Society & New Zealand Society for the Study of Diabetes, Melbourne, Australia.
- PricewaterhouseCoopers. (2001). *Type 2 diabetes: Managing for better health outcomes*. Wellington, New Zealand: Author.
- Prochaska, J. O., & DiClemente, C. C. (1984). *The transtheoretical approach: Crossing traditional boundaries of therapy*. Homewood, IL: Dow Jones Irwin.
- Ramachandran, S. (2006, April). *World status on implimentation of the DAWN call to action and patient-centred initiatives in diabetes: India*. Paper presented at the 3rd International DAWN Summit, Florence, Italy.
- Rhodes, T. (1997). Risk theory in epidemic times: Sex, drugs and the social organisation of 'risk behaviour'. *Sociology of Health and Illness, 19*(2), 227.
- Roglic, G., Unwin, N., Bennett, P. H., Mathers, C., Tuomilehto, J., Nag, S., et al. (2005). The burden of mortality attributable to diabetes: Realistic estimates for the year 2000. *Diabetes Care, 28*(9), 2130-2135.
- Rose, M., Fliege, H., Hildebrandt, M., Schirop, T., & Klapp, B. F. (2002). The network of psychological variables in patients with diabetes and their importance for quality of life and metabolic control. *Diabetes Care, 25*(1), 35-42.
- Rotter, R. B. (1966). Generalized expectancies for internal and external control of reinforcement. *Psychological Monographs: General and Applied, 80*, 1-28.
- Rubin, R. R. (2005). Counselling and psychotherapy in diabetes mellitus. In F. J. Snoek & T. C. Skinner (Eds.), *Psychology in diabetes care* (2nd ed., pp. 171-193). Chichester, UK: John Wiley.
- Samuel-Hodge, C. D., Headen, S. W., Skelly, A. H., Ingram, A. F., Keyserling, T. C., Jackson, E. J., et al. (2000). Influences on day-to-day self-management of type 2 diabetes among African-American women - Spirituality, the multi-caregiver role, and other social context factors. *Diabetes Care, 23*(7), 928-933.

- Schaefer-Graf, U. M., Buchanan, T. A., Xiang, A. H., Peters, R. K., & Kjos, S. L. (2002). Clinical predictors for a high risk for the development of diabetes mellitus in the early puerperium in women with recent gestational diabetes mellitus. *American Journal of Obstetrics and Gynecology*, *186*(4), 751-756.
- Schafer, L. C., McCaul, K. D., & Glasgow, R. E. (1986). Supportive and nonsupportive family behaviors: Relationships to adherence and metabolic control in persons with type 1 diabetes. *Diabetes Care*, *9*(2), 179-185.
- Scharloo, M., Kaptein, A., Weinman, J., Hazes, J., Breedveld, F., & Rooijmans, H. (1999). Predicting functional status in patients with rheumatoid arthritis. *The Journal of Rheumatology*, *26*(8), 1686-1693.
- Scharloo, M., Kaptein, A. A., Weinman, J., Hazes, J. M., Willems, L. N. A., Bergman, W., et al. (1998). Illness perceptions, coping and functioning in patients with rheumatoid arthritis, chronic obstructive pulmonary disease and psoriasis. *Journal of Psychosomatic Research*, *44*(5), 573-585.
- Schattner, A. (2003). The emotional dimension and the biological paradigm of illness: Time for a change. *QJM*, *96*(9), 617-621.
- Schechtman, J. M., Nadkarni, M. M., & Voss, J. D. (2002). The association between diabetes metabolic control and drug adherence in an indigent population. *Diabetes Care*, *25*(6), 1015-1021.
- Scheier, M. F., & Carver, C. S. (2003). Goals and confidence as self-regulatory elements underlying health and illness behavior. In L. D. Cameron & H. Leventhal (Eds.), *The self-regulation of health and illness behaviour* (pp. 17-41). London: Routledge.
- Schwarzer, R. (1999). Self-regulatory processes in the adoption and maintenance of health behaviors. *Journal of Health Psychology*, *4*(2), 115-127.
- Scott, D., & Brown, E. P. (1989). *Stories of life with diabetes*. Palmerston North, New Zealand: Dunmore Press.
- Scott, K. M., Tobias, M. I., Sarfati, D., & Haslett, S. (1999). SF-36 health survey reliability, validity and norms for New Zealand. *Australian and New Zealand Journal of Public Health*, *23*(4), 401-406.
- Sheeran, P., & Abraham, C. (1996). The Health Belief Model. In M. Conner & P. Norman (Eds.), *Predicting health behaviour* (pp. 23-61). Buckingham, UK: Open University Press.
- Sheeran, P., & Orbell, S. (1998). Do intentions predict condom use? Meta-analysis and examination of six moderator variables. *British Journal of Social Psychology*, *37*, 231-250.
- Sherbourne, C. D., & Stewart, A. L. (1991). The MOS social support survey. *Social Science & Medicine*, *32*(6), 705-714.
- Simmons, D. (1996). Diabetes and its complications in New Zealand: An epidemiological perspective. *New Zealand Medical Journal*, *109*(1025), 245-247.

- Simmons, D. (1997). Diabetes and its complications among Pacific people in New Zealand. *Pacific Health Dialog*, 4(2), 75-79.
- Simmons, D. (1999). Diabetes in Maori and Pacific Islands People. *New Ethicals Journal*, 2(2), 45-49.
- Simmons, D., Shaw, L., Kenealy, T., Scott, D., & Scragg, R. (1994). Ethnic differences in diabetes knowledge and education - The South Auckland Diabetes Survey. *New Zealand Medical Journal*, 107(978), 197-200.
- Simmons, D., & Voyle, J. A. (1996). Psychosocial and behavioural aspects of NIDDM among Pacific Islanders in South Auckland. *Pacific Health Dialog*, 3(1), 100-106.
- Simmons, D., Voyle, J. A., Fou, F., Feo, S., & Leakehe, L. (2004). Tale of two churches: Differential impact of a church-based diabetes control programme among Pacific Islands people in New Zealand. *Diabetic Medicine*, 21, 122-128.
- Skinner, E. A., Edge, K., Altman, J., & Sherwood, H. (2003). Searching for the structure of coping: A review and critique of category systems for classifying ways of coping. *Psychological Bulletin*, 129(2), 216-269.
- Skinner, T. C., Carey, M. E., Cradock, S., Daly, H., Davies, M. J., Doherty, Y., et al. (in press). Diabetes education and self-management for ongoing and newly diagnosed (DESMOND): Process modelling of pilot study. *Patient Education and Counselling*.
- Skinner, T. C., & Hampson, S. E. (1998). Social support and personal models of diabetes in relation to self-care and well-being in adolescents with type I diabetes mellitus. *Journal of Adolescence*, 21(6), 703-715.
- Skinner, T. C., & Hampson, S. E. (2001). Personal models of diabetes in relation to self-care, well-being, and glycemic control. *Diabetes Care*, 24(5).
- Skinner, T. C., Hampson, S. E., & Fife-Schaw, C. (2002). Personality, personal model beliefs, and self-care in adolescents and young adults with type 1 diabetes. *Health Psychology*, 21(1), 61-70.
- Skinner, T. C., Howells, L., Greene, S., Edgar, K., McEvilly, A., & Johansson, A. (2003). Development, reliability and validity of the Diabetes Illness Representations Questionnaire: four studies with adolescents. *Diabetic Medicine*, 20(4), 283-289.
- Skovlund, S. E., Peyrot, M., & on behalf of the DAWN International Advisory Panel. (2005). The Diabetes Attitudes, Wishes, and Needs (DAWN) program: A new approach to improving outcomes of diabetes care. *Diabetes Spectrum*, 18(3), 136-142.
- Slama, G. (2003). Type 1 diabetes: An overview. In J. C. Pickup & G. Williams (Eds.), *Textbook of diabetes* (3rd ed., Vol. 1, Section 1, pp. 3.1 - 3.17). Boston: Blackwell Science.
- Snoek, F., Pouwer, F., Welch, G., & Polonsky, W. (2000). Diabetes-related emotional distress in Dutch and U.S. diabetic patients: Cross-cultural validity of the Problem Areas In Diabetes scale. *Diabetes Care*, 23(9), 1305-1309.
- Snoek, F. J. (2006, April). *Efficacy of psychological interventions in people with diabetes*. Paper presented at the 3rd International DAWN Summit, Florence, Italy.

- Snoek, F. J., & Visser, A. (2003). Improving quality of life in diabetes: How effective is education? *Patient Education and Counseling*, 51(1), 1-3.
- Spicer, J. (2005). *Making sense of multivariate data analysis*. Thousand Oaks, CA: Sage Publications.
- Steed, L., Newman, S. P., & Hardman, S. M. C. (1999). An examination of the self-regulation model in atrial fibrillation. *British Journal of Health Psychology*, 4, 337-347.
- Stephens, A., & Wardle, J. (2004). Health-related behaviour: Prevalence and links with disease. In A. A. Kaptein & J. Weinman (Eds.), *Health psychology* (1st ed., pp. 21-51). Cornwall, UK: Blackwell Publishing.
- Stewart, M. (2001). Towards a global definition of patient centred care. *British Medical Journal*, 322(7284), 444-445.
- Stewart, T. (1997). Historical interfaces between Maori and psychology. In P. Te Whaiti, M. McCarthy & A. Durie (Eds.), *Mai i rangiatea* (pp. 75-95). New Zealand: Auckland University Press.
- Sutton, S. (2005). Stage theories of health behaviour. In M. Conner & P. Norman (Eds.), *Predicting health behaviour* (2nd ed., pp. 223-275). New York: Open University Press.
- Tabachnick, B. G., & Fidell, L. S. (2001). *Using Multivariate Statistics* (4th ed.). Boston: Allyn & Bacon.
- Talbot, F., & Nouwen, A. (2000). A review of the relationship between depression and diabetes in adults: Is there a link? *Diabetes Care*, 23(10), 1556-1562.
- Taylor, S. (1990). Health psychology: The science and the field. *American Psychologist*, 45, 40-50.
- Terry, D. J., & O'Leary, J. E. (1995). The Theory of Planned Behaviour: The effects of perceived behavioural control and self-efficacy. *British Journal of Social Psychology*, 34, 199-220.
- The Diabetes Control and Complications Trial Research Group. (1993). The effect of intensive treatment of diabetes on the development and progression of long-term complications in insulin-dependent diabetes mellitus. *New England Journal of Medicine*, 329(14), 977-986.
- The Diabetes Prevention Program Research Group. (2002). The Diabetes Prevention Program (DPP): Description of lifestyle intervention. *Diabetes Care*, 25(12), 2165-2171.
- Thompson, S. J., & Gifford, S. M. (2000). Trying to keep a balance: The meaning of health and diabetes in an urban Aboriginal community. *Social Science and Medicine*, 51, 1457-1472.
- Thorne, S., Paterson, B., & Russell, C. (2003). The structure of everyday self-care decision making in chronic illness. *Qualitative Health Research*, 13(10), 1337-1352.
- Tibbetts, C. (2003). Case study: Care coordination and case finding of undetected depression in a 72-year-old man with type 2 diabetes. *Clinical Diabetes*, 21(4), 188-190.

- Tilden, B., Charman, D., Sharples, J., & Fosbury, J. (2005). Identity and adherence in a diabetes patient: Transformations in psychotherapy. *Qualitative Health Research, 15*(3), 312-324.
- Tillotson, L. M., & Smith, M. S. (1996). Locus of control, social support, and adherence to the diabetes regimen. *The Diabetes Educator, 22*(2), 133-139.
- Toijamo, M., & Hentinen, M. (2001). Adherence to self-care and social support. *Journal of Clinical Nursing, 10*(5), 618-627.
- Toobert, D. J., Hampson, S. E., & Glasgow, R. E. (2000). The Summary of Diabetes Self-care Activities measure - Results from 7 studies and a revised scale. *Diabetes Care, 23*(7), 943-950.
- Turner, R., Cull, C., & Holman, R. (1996). United Kingdom Prospective Diabetes Study 17: A 9-year update of a randomized, controlled trial on the effect of improved metabolic control on complications in non-insulin-dependent diabetes mellitus. *Annals of Internal Medicine, 124*, 136-145.
- UK Prospective Diabetes Study (UKPDS) Group. (1998a). Effect of intensive blood-glucose control with metformin on complications in overweight patients with type 2 diabetes (UKPDS 34). *The Lancet, 352*(9131), 854-865.
- UK Prospective Diabetes Study (UKPDS) Group. (1998b). Intensive blood-glucose control with sulphonylureas or insulin compared with conventional treatment and risk of complications in patients with type 2 diabetes (UKPDS 33). *The Lancet, 352*(9131), 837-853.
- Vijan, S., Hayward, R. A., Ronis, D. L., & Hofer, T. P. (2005). Brief report: The burden of diabetes therapy. Implications for the design of effective patient-centered treatment regimens. *Journal of General Internal Medicine, 20*(5), 479-482.
- Vinacor, F. (2005). Time for "drilling down". *Journal of General Internal Medicine, 20*(5), 483-484.
- von Hofe, B., Thomas, M., & Colagiuri, R. (2002). *A systematic review of issues impacting on health care for culturally diverse groups using diabetes as the model*. Sydney, Australia: Australian Centre for Diabetes Strategies & Multicultural Health Unit.
- Walker, A., Grimshaw, J., Johnston, M., Pitts, N., Steen, N., & Eccles, M. (2003). PRIME - PProcess modelling in ImpleMEntation research: Selecting a theoretical basis for interventions to change clinical practice. *BMC Health Services Research, 3*(1), 22.
- Wang, C., & Fenske, M. M. (1996). Self-care of adults with non-insulin-dependent diabetes mellitus: Influence of family and friends. *The Diabetes Educator, 22*(5), 465-470.
- Ware, J. E., Kosinski, M., & Keller, S. D. (1998). *SF12: How to Score the SF-12 Physical and Mental Health Summary Scales*. (3rd ed.). Lincoln, RI: QualityMetric.
- Watkins, K., Connell, C., Fitzgerald, J., Klem, L., Hickey, T., & Ingersoll-Dayton, B. (2000). Effect of adults' self-regulation of diabetes on quality-of-life outcomes. *Diabetes Care, 23*(10), 1511-1515.

- Wearden, A. J., Paschalides, C., Dunkerley, R., Dickens, C., Bundy, C., & Davies, R. (2005). *Illness representations and well-being in recently-diagnosed and long-standing patients with type 2 diabetes*. Unpublished manuscript.
- Weinger, K., & Jacobson, A. M. (2001). Psychosocial and quality of life correlates of glycemic control during intensive treatment of type 1 diabetes. *Patient Education and Counseling*, 42(2), 123-131.
- Weinman, J., & Petrie, K. J. (1997). Illness perceptions: A new paradigm for psychosomatics. *Journal of Psychosomatic Research*, 42(2), 113-116.
- Weinman, J., Petrie, K. J., Moss-Morris, R., & Horne, R. (1996). The Illness Perception Questionnaire: A new method for assessing the cognitive representation of illness. *Psychology and Health*, 11, 431-445.
- Weinman, J., Petrie, K. J., Sharpe, N., & Walker, S. (2000). Causal attributions in patients and spouses following first-time myocardial infarction and subsequent lifestyle change. *British Journal of Health Psychology*, 5, 265-273.
- Weiss, M. (2006, April). *The patient perspective: The psychosocial implications of living with a chronic disease*. Paper presented at the 3rd International DAWN Summit, Florence, Italy.
- Welch, G., Weinger, K., Anderson, B., & Polonsky, W. H. (2003). Responsiveness of the Problem Areas In Diabetes (PAID) questionnaire. *Diabetic Medicine*, 20(1), 69-72.
- Wen, L. K., Shepherd, M. D., & Parchman, M. L. (2004). Family support, diet, and exercise among older Mexican Americans with type 2 diabetes. *The Diabetes Educator*, 30(6), 980-993.
- Wensing, M., Jung, H. P., Mainz, J., Olesen, F., & Grol, R. (1998). A systematic review of the literature on patient priorities for general practice care. Part 1: Description of the research domain. *Social Science & Medicine*, 47(10), 1573-1588.
- WHO Regional Office for Europe and International Diabetes Federation. (1989). *Diabetes care and research in Europe: The St Vincent declaration*. Retrieved 8 June, 2002, from <http://www.idf.org/webdata/docs/SVD%20and%20Istanbul%20Commitment.pdf>
- Wiebe, D. J., & Korbel, C. (2003). Defensive denial, affect, and the self-regulation of health threats. In L. D. Cameron & H. Levevthal (Eds.), *The self-regulation of health and illness behaviour* (pp. 184-203). London: Routledge.
- Williams, K. E., & Bond, M. J. (2002). The roles of self-efficacy, outcome expectancies and social support in the self-care behaviours of diabetics. *Psychology, Health & Medicine*, 7(2), 127-141.
- Williams, M. H., Oehley, M., Rush, E., & Simmons, D. (2006, May). *Mapping the availability and accessibility of healthy food within the Waikato and lakes district health regions: Te Wai o Rona diabetes prevention strategy*. Paper presented at the 30th Annual Scientific Meeting of the New Zealand Society for the Study of Diabetes, Palmerston North, New Zealand.

- Williams, M. H., Simmons, D., Henry, J., Corrigan, C., McLennan, S., & Wilkinson, G. (2006, May). *Te Wai o Rona diabetes prevention strategy: The use of a modified green prescription*. Paper presented at the 30th Annual Scientific Meeting of the New Zealand Society for the Study of Diabetes, Palmerston North, New Zealand.
- Wing, R. R., Epstein, L. H., Nowalk, M. P., & Scott, N. (1988). Self-regulation in the treatment of type II diabetes. *Behavior Therapy, 19*, 11-23.
- Winkley, K., Landau, S., Eisler, I., & Ismail, K. (2006). Psychological interventions to improve glycaemic control in patients with type 1 diabetes: Systematic review and meta-analysis of randomised controlled trials. *British Medical Journal, 333*(7558), 65-70.
- Wittlin, S. D. (2006). Treating the spectrum of type 2 diabetes: Emphasis on insulin pump therapy. *The Diabetes Educator, 32*(Suppl. 1), 39-46.
- Wolpert, H. A., & Anderson, B. J. (2001). Management of diabetes: Are doctors framing the benefits from the wrong perspective? *British Medical Journal, 323*(7319), 994-996.
- Woodcock, A. J., Julious, S. A., Kinmonth, A. L., & Campbell, M. J. (2001). Problems with the performance of the SF-36 among people with type 2 diabetes in general practice. *Quality of Life Research, 10*, 661-670.
- Woodcock, A. J., & Kinmonth, A. L. (2001). Patient concerns in their first year with type 2 diabetes: Patient and practice nurse views. *Patient Education and Counseling, 42*, 257-270.
- Woodcock, A. J., Kinmonth, A. L., Campbell, M. J., Griffin, S. J., & Spiegel, N. M. (1999). Diabetes care from diagnosis: Effects of training in patient-centred care on beliefs, attitudes and behaviour of primary care professionals. *Patient Education and Counseling, 37*(1), 65-79.
- Young, J. T. (2004). Illness behaviour: A selective review and synthesis. *Sociology of Health and Illness, 26*(1), 1-31.
- Zoffmann, V., & Kirkevold, M. (2005). Life versus disease in difficult diabetes care: Conflicting perspectives disempower patients and professionals in problem solving. *Qualitative Health Research, 15*(6), 750-765.
- Zwier, G., & Clarke, D. (2005). *How well do we monitor patient satisfaction? Problems with the nation-wide patient survey*. Retrieved September 30, 2005, from http://www/hscr.co.nz/pdf/how_well_do_we_monitor_patient_satisfaction.pdf

Appendix A
PILOT STUDIES

Overview

Before the main study a series of pilot studies was used to generate an informed understanding of the research area, and test methods of data collection. This process helped develop new measures where current published measures did not meet the requirements of the present study. It was also instrumental in ensuring a system of unique identifiers worked to preserve patient confidentiality, while allowing successful merger of self-report data (collected via mailed questionnaire survey) with clinical information (collated from medical records).

Pilot Study 1

The aim of the first pilot project was to supplement knowledge gleaned through review of relevant literature with experiences reported by people living with diabetes in the *New Zealand context*, and the views of health professionals who work closely with the local diabetes community. Expert advice from patient/consumer representatives, and health professionals (diabetes physicians, dieticians, and diabetes nurse specialists), was sought both in regional meetings (Diabetes Manawatu, and Manawatu, Horowhenua, Tararua Diabetes Trust) and in eight personal interviews.

At the invitation of Diabetes Manawatu, a public seminar was held to discuss the research with the local (Palmerston North) community. Twenty-seven people with diabetes attended; this provided the researcher with a rich opportunity to explore views about diabetes within an informal, highly personal context. A small, mailed questionnaire survey was also undertaken. This contained two instruments intended for use in the main study (IPQ-R and PAID). Participants were recruited through advertisements placed in the Manawatu Diabetes Society newsletter. On making contact with the researcher, potential participants were given a verbal outline of the project, and explanation of the procedure for data collection. Thirty-six people contacted the researcher to volunteer as participants for this study. From this group, 22 questionnaires were returned to the researcher. Respondents were invited to complete the questionnaire, and give feedback to the researcher regarding any items they found difficult, or problems they perceived within the questionnaire. Ethical

approval for the mailed questionnaire survey was obtained from the Massey University Human Ethics Committee.

Results from Pilot Study 1 helped identify where modification of existing measures was appropriate. For example, following advice from people with diabetes, the IPQ-R identity subscale was amended. One item in the IPQ-R (weight change) was separated into two symptoms: weight gain, and weight loss. One new symptom (mood swings) was added. Advice from dieticians highlighted the incongruity between dietary recommendations in the SDSCA, and contemporary New Zealand recommendations for people with diabetes; appropriate changes were made. Feedback from participants in the mailed survey showed the questionnaire had face validity.

Pilot Study 2

The second pilot study comprised four small projects aimed at exploring views about diabetes, and experiences with diabetes health services among Māori and Pacific people with diabetes. The item wording and research methods were developed in collaboration with post-graduate students as part of four New Zealand Health Research Council Summer Studentships. The contributions of Kanita Nikora (Māori), Joanna Hoera (Māori), Fiasili Vae'au (Samoan) and Mandy Faimaile (Samoan) are gratefully acknowledged. The four summer studentships were grouped into two clusters that effectively produced two studies. These studies were titled (a) Te Mate Huka me te Māori (Diabetes Among Māori), and (b) O le silafia po'o le malamalamaaga o tagata Samoa o lo'o gasegase I le Ma'l o le Suka (Living with Diabetes: The Samoan Experience). Ethical approval was sought and obtained from the Massey University Human Ethics Committee.

In reference to the current thesis, the main aims were to examine the role of (a) family relationships, and (b) patient-provider relationships, in supporting diabetes management, and generate items for use in future research. Informal discussion with whānau/aiga (family members) and personal networks was combined with formal review of Māori and Polynesian models of health and illness. The advice of senior cultural advisors was sought (Rebecca Tuli'toa (Fale Pacifica); Kirsty Maxwell-Crawford

(Te Putahi-a-Toi); and Professor Chris Cunningham (Massey University)) and integrated into the project.

In order to support the Māori project, relationships were established with regional health care providers (Whakapai Hauora, Te Waka Huia). Key contacts (Gill George (diabetes nurse specialist), and Virginia Jones (health services manager)) facilitated access to research participants for the two Māori studies; in reciprocity support was provided to assist both Gill and Virginia with completion of their Masterate qualifications. Regular bimonthly meetings were held across a 2-year period. The Samoan project was supported by Pacific health workers in the North Island (Porirua, Lower Hutt, Kapiti Coast).

Data for all four projects in Pilot Study 2 were collected through semi-structured interviews; these were used to complete an English language questionnaire survey. Inclusion criteria were (a) self-identify as Māori or Samoan, (b) diagnosed with type 2 diabetes, and (c) aged over 18. Participant recruitment was undertaken using a community network approach, with assistance from Māori and Samoan community health networks in the middle and lower North Island of New Zealand. Potential participants were contacted by a Māori/Pacific health care provider representative, given information about this project, and invited to take part in this study. To supplement this, an information sheet providing culturally appropriate information was offered (for example, in the Māori studies, this contained a mihi introducing the researchers and their iwi/hapu affiliations). A verbal and written summary of the study was provided in both Māori and English. All participation in this study was voluntary.

In the Māori study, a 60% response rate provided 41 participants. The Samoan study included 70 participants (and a response rate of 65%). All participants were presented with a copy of the questionnaire and given the option of (a) completing it on their own, or (b) with the assistance of the researcher, Māori/Pacific health care provider, and/or other support persons of their choice including whānau and kaumātua. Further detail regarding participant characteristics and explanation of the data collection process is available in published literature (Faimalie, 2003; Hoera, 2003; Nikora, 2003). At the conclusion of the projects, a hui (meeting) was held to provide feedback to the research participants in person, and disseminate research findings to health professionals with an interest in diabetes among Māori and Pacific groups. Findings

have also been presented at national (Paddison, Flett, Alpass, & Stephens, 2004; Paddison, Vae'au, & Flett, 2004b) and international conferences (Paddison, Flett et al., 2004; Paddison, Vae'au, & Flett, 2004a).

Pilot Study 3

The third pilot was primarily a feasibility study to ensure the process outlined in a memorandum of understanding with the Wellington Regional Diabetes Trust (WRDT) would work successfully. As secondary goals, participant responses were analysed to determine whether the response burden imposed by the current 24-page questionnaire was excessive (that is, large blocks left uncompleted), and psychometric properties of main measures (e.g., IPQ-R and PAID) were examined. The research protocol was approved by the Massey University Human Ethics Committee.

Participants for Pilot Study 3 were randomly selected from a medical database held in by the WRDT (database $N = 5,312$). Inclusion criteria were: diagnosis of type 2 diabetes; aged over 18. A mailed questionnaire survey was the primary mode of data collection. Three hundred questionnaires were mailed, and a total of 113 completed questionnaires were returned, providing a 33% response rate. Fifty-one percent of participants were male, mean age 62 ($SD = 9.2$). The average time since diagnosis was 7.7 years. Eighty-six percent of respondents were of New Zealand European ethnicity (Caucasian); the remainder identified as Māori (indigenous to New Zealand) (2%), Chinese (2%), Indian (3%), or European (7%). Clinical data collected by diabetes health professionals were obtained from medical notes, with participants' permission. The mean HbA_{1c} among participants in this study was 7.2% ($SD = 1.4$).

The mail out procedure was deemed to be successful. A system of unique identifiers allowed the researcher to randomly select the sample (while maintaining patient confidentiality), and then to merge medical data with self-report information provided by the mailed survey. The WRDT had previously expressed concerns (and obtained legal advice) regarding the privacy of medical data. The success of the pilot study assisted in allaying these fears, and building a good relationship with stakeholders in the research. Analysis of missing data indicated participants completed most questions, although respondents expressed frustration at items that were perceived to be repetitious (e.g., in the patient-provider relationship measure), and some individuals

found the length of the questionnaire longer than they had expected on the basis of the information sheet accompanying the questionnaire. In response to this feedback, guidelines regarding expected length of time to complete the questionnaire were changed from 20 minutes to 25 minutes. Most measurement instruments showed acceptable internal reliability, although one subscale in the IPQ-R showed low internal consistency (treatment control Cronbach's Alpha = .52). Research findings from Pilot Study 3 have been disseminated to professional peers. Further information can be found in published literature (Paddison, Alpass, & Stephens, in press).

Conclusions

The pilot studies were successful in generating a more informed understanding of the research area (particularly in relation to an appreciation of Māori and Pacific views about diabetes), and testing methods of data collection before beginning the main study.

The *process* of piloting enabled (a) exploration of cultural diversity in views about diabetes, (b) identification of unsuitable items (e.g., relating to dietary recommendations in the SDSCA), and integration of feedback from people with diabetes to improve the questionnaire content and format. The Māori and Samoan studies were instrumental in encouraging research attention to the importance of social context as a determinant of self-care behaviour. In particular, findings from Pilot Study 2 emphasised the significance of family relationships.

The main *outcomes* arising from the pilot studies were (a) generation of items for two new measures, and (b) development of a successful data collection protocol. The first main outcome from the piloting process was identification of potential items for two new measures assessing the family context, and patient-provider relationship. In the main study, a principal component analysis was used to refine item content further, and develop summary scores that could be used to assess two dimensions (support and conflict) of the patient-provider relationship, and diabetes-related family context. The second main outcome from piloting was confirmation that the collaborative mail-out worked, and verification that the system of unique identifiers was able successfully to merge self-report and clinical data from medical records.

REFERENCES

- Faimalie, M. (2003). *Living with Diabetes: The Samoan Experience - Report to the New Zealand Health Research Council*. Palmerston North, New Zealand: Massey University, School of Psychology.
- Hoera, J. (2003). *Type 2 Diabetes Among Māori: Psychosocial determinants of Self-care - Report to the New Zealand Health Research Council*. Palmerston North, New Zealand: Massey University, School of Psychology.
- Nikora, K. (2003). *Te Mate Huka me te Māori: Diabetes among Māori - Report to the New Zealand Health Research Council*. Palmerston North, New Zealand: Massey University, School of Psychology.
- Paddison, C. A. M., Alpass, F. M., & Stephens, C. V. (in press). Deconstructing distress among people with type 2 diabetes. *European Diabetes Nursing*.
- Paddison, C. A. M., Flett, R. A., Alpass, F. M., & Stephens, C. V. (2004, September). *Promoting healthy populations: The importance of understanding socio-cultural context*. Poster session presented at the Satellite meeting to the Eighth International Congress of Behavioural Medicine, Budapest, Hungary.
- Paddison, C. A. M., Vae'au, F., & Flett, R. A. (2004a). Promoting physical and psychological wellbeing among Samoan people with diabetes in New Zealand: Does a good doctor make a difference (Abstract). *Proceedings of the Eighth International Congress of Behavioural Medicine, Mainz, Germany, 11 (Suppl.)*, 280
- Paddison, C. A. M., Vae'au, F., & Flett, R. A. (2004b, February). *The role of family context in managing chronic illness: Are there cultural differences?* Poster session presented at the Australasian Society for Behavioural Health and Medicine Conference, Christchurch, New Zealand.

Appendix B
LETTER OF INTRODUCTION



Wellington Regional Diabetes Trust

May 10, 2004

Study on personal experiences of Diabetes Letter of Invitation

Dear

Who is this letter from?

My name is Robert Smith and I am the Chairperson of the Wellington Regional Diabetes Trust. This is a community trust, set up for people with diabetes in the lower North Island region.

What is this letter about?

The Wellington Regional Diabetes Trust would like to invite you to be part of a research project to learn more about people's experiences with diabetes. This project is being run with Charlotte Paddison and Dr. Fiona Alpass from Massey University. This is a letter to invite you to be part of this study. We have made every effort to ensure our records are accurate. If we've sent this to you in error we apologise sincerely, please phone free on 0800 743 788 and let us know if we have made a mistake. We will take you off our research database records immediately, and we will not contact you again.

What will I be asked to do?

If you choose to take part in the research we would ask you to fill out the questionnaire in this envelope. This should take about 25 minutes. All information you give is **completely confidential**. For more detail about the research study please read the information sheet on the following pages.

How will this research be useful to people with diabetes?

We need to learn more about the experiences of people who live with diabetes on a daily basis. This includes things like how people take care of themselves and how you feel about the health services available for people with diabetes. If you choose to take part in this project the information you give will be used to help design better diabetes health policy and community programs, and to improve health services for people with diabetes now and in the future. A copy of research results will be made available to all people who take part in this study.

The Wellington Regional Diabetes Trust sees this research project as a useful and important study. We support this project, and believe it will have useful benefits for people with diabetes.

Robert Smith
Chairperson of the Wellington Regional Diabetes Trust

Appendix C
INFORMATION SHEET



**Study about
Your personal experiences with Diabetes
INFORMATION SHEET**

You are invited to take part in a research study that aims to find out more about people's experiences with Diabetes. If you choose to take part, we would ask you to complete the questionnaire enclosed with this letter and send it back to us in the freepost envelope provided (no stamp required). This should take about 25 minutes. Your participation is entirely voluntary (your choice). You do not have to take part in this study, and if you choose not to take part this will not affect your future care or treatment in any way.

Thank you for taking the time to read this information and consider our request for your help in this study. We really appreciate it.

Yours sincerely

Charlotte Paddison
PhD student
Massey University

Dr. Fiona Alpass
Senior Lecturer
Massey University

What is this study about and who is doing it?

My name is Charlotte Paddison, and I am the principal investigator in this research project. This study is part of my PhD, and is supervised by Dr. Fiona Alpass in the School of Psychology, Massey University. We welcome any questions you may have about this study and you can find our contact details on the following page.

In this project, we are interested in understanding people's views about Diabetes, and their experiences in living with Diabetes. The purpose of this research is to develop a better understanding of Diabetes from the perspective of people who live with it on a daily basis.

This study is being conducted in co-operation with the Wellington Regional Diabetes Trust. The Trust holds information collected by G.P.'s around New Zealand from people with Diabetes as part of the national "Get Checked" programme. Members of this Trust have randomly identified 2000 people from the lower North Island with Type 2 Diabetes, who indicated they would be interested in receiving information from the Wellington Regional Diabetes Trust in the past. You have been chosen as part of this group. No personal contact details (names or addresses) have been given to the researchers, this invitation has been mailed to you by the Wellington Diabetes Trust. We would like to invite you to complete our questionnaire.

What will I be asked to do?

Your participation in this research, should you choose to take part, would involve filling out the questionnaire in this envelope. Please also remember to fill in the consent form if you are willing to allow the researcher access to clinical data about your diabetes held by the Wellington Regional Diabetes Trust. The questionnaire is estimated to take about 25 minutes to complete, although it may be longer for some people. Completion and return of this questionnaire implies consent. Please note that all information that you give is **completely confidential**, and will be used only for the purposes of this study. Nobody else will be able to see your questionnaire, this includes your doctor, nurse or family members. It will not be possible to identify individuals in any reports of the results. You can return the questionnaire in the freepost envelope supplied (no stamp needed). If you do not want to take part in this study and do not want to receive a reminder, simply return your questionnaire uncompleted and I will delete your name from the list.

What are my rights as a participant in this study?

As someone invited to take part in this project you have the right to:

- **Ask questions** about the study at any time
- **Decline** to take part, refuse to answer any questions(s), or withdraw from the study at any time without giving any reason. This will not affect your future health care in any way.
- **Provide information** on the understanding that it is **completely confidential** to the researchers, to be used only for the purposes of the study.
- **Receive a summary** of the findings from the study when it is completed.

Answers to some common questions about this study:

Confidentiality

Will my doctor be told I am in this study?

No. All information you provide is totally confidential, including your participation in this study.

Will anybody be able to see my questionnaire (other than the research team members)?

No. Your questionnaire will be kept in a locked cabinet, and will only be seen by the main researcher (Charlotte Paddison). After 5 years the questionnaires will be destroyed to ensure confidentiality.

Will people be able to identify me when the results of this study are presented?

No, absolutely not. All results will be presented in a way that ensures individual participants can not be identified. No material that could personally identify you will be used in any reports on this study.

Results

Where can I get a copy of the results of this study?

All people who take part in this study can request a copy of results by ticking a box on the lower part of the consent form. There may be a delay of some months between data collection and results publication.

Statement of Ethical Approval

This study has been reviewed and approved by the Massey University Human Ethics Committee, PN Protocol 02/140. If you have any concerns about the conduct of this research, please contact Professor Sylvia Rumball, Chair, Massey University Campus Human Ethics Committee: Palmerston North, telephone 06 350 5249, email S.V.Rumball@massey.ac.nz.

Who can I contact if I have further questions about this study?

Principal Researcher:

Charlotte Paddison

School of Psychology
Massey University
Private Bag 11-222
Palmerston North
Email: C.A.Paddison@massey.ac.nz
Ph: (06) 350-5799 ext 2049 Ph: (06) 350-5799 ext 2081
Phone **FREE** on 0800 743 788

Academic Supervisor:

Dr. Fiona Alpass

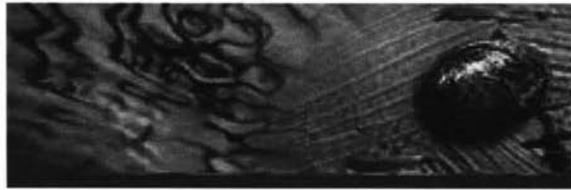
School of Psychology
Massey University
Private Bag 11-222
Palmerston North
Email: F.M.Alpass@massey.ac.nz

Thank you for taking the time to read this information and consider our request for your help in this study. We really appreciate it.

Appendix D
QUESTIONNAIRE



Massey University



Living with
Diabetes:
A New Zealand
study





STUDY ON PERSONAL EXPERIENCES OF DIABETES

What this questionnaire is about

This questionnaire will help us to find out more about what you think about diabetes, and your experiences in managing diabetes.

Once you have completed the questionnaire, please put it in the free-post self addressed envelope provided, and send it to us as soon as you have completed it.

Thank you for taking the time to fill this out. We really appreciate your help.

Instructions for completing this questionnaire:

- We would **appreciate** it if you could answer every question. If you get stuck on a question just give the best answer you can, and move on to the next one.
- It is important to say there are **no right or wrong answers** to the questions.
- Remember your answers to this questionnaire are **completely confidential**.

This project has been reviewed and approved by the Massey University Human Ethics Committee, PN protocol 01/142. If you have any concerns about the conduct of this research, please contact Professor Sylvia V Rumball, Assistant to the Vice-Chancellor (Equity & Ethics), telephone 06 3505249, email S.V.Rumball@massey.ac.nz.

1) About your diabetes

First we would like to ask some questions about your diabetes

a. How long is it since you were first diagnosed with diabetes? _____ years or _____ months

b. Which type of diabetes do you have? (please tick)

- Type 1 diabetes Type 2 diabetes I am not sure

2) Quality of Life

The following questions ask about your quality of life and the effects of your diabetes on your quality of life. Your quality of life is how good or bad you feel your life to be. Please tick the box that best indicates the way you feel. There are no right or wrong answers; we just want to know how you feel about your life right now.

a. In general, my present quality of life is: (please tick)

- Excellent Very good Good Neither good or bad Bad Very bad Extremely bad

For the next statement please think about the effects of your diabetes, it's management and any complications you may have.

b. If I did not have diabetes, my quality of life would be: (please tick)

- Very much better Much better A little better The same A little worse Much worse Very much worse

3) **Causes of your diabetes**

We are interested in what YOU consider may have been the cause of your diabetes. As people are very different, there is no correct answer for this question. We are most interested in your own views about the factors that caused your diabetes rather than what others including doctors or family may have suggested to you. Below is a list of possible causes for your diabetes. Please indicate how much you agree or disagree that they were causes for you by ticking one box for each line.

Possible causes of my diabetes	Strongly Disagree ▼	Disagree ▼	Neither agree nor disagree ▼	Agree ▼	Strongly Agree ▼
Stress or worry	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Hereditary – it runs in my family	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
A germ or virus	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Diet or eating habits	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Chance or bad luck	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Poor medical care in my past	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
Pollution in the environment	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
My own behaviour	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
My mental attitude e.g. thinking about life negatively	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Family problems or worries	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Overwork	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
My emotional state e.g. feeling down, lonely, anxious, empty	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Ageing	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Alcohol or smoking	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Spiritual or emotional worries	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
God's will	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Accident or injury	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
My personality	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Altered immunity	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

In the spaces below, please list in rank-order the **three most important** factors that you now believe caused **your diabetes**. You may use any of the items from the box above, or you may have additional ideas of your own. The most important causes for me are:

1. _____ 2. _____ 3. _____

4) **Views about your diabetes**

We are interested in your own personal views of how you now see your current diabetes. Please indicate how much you agree or disagree with each of the following statements about your diabetes by ticking one box for each line.

	Strongly Disagree ▼	Disagree ▼	Neither agree nor disagree ▼	Agree ▼	Strongly Agree ▼
My diabetes will last a short time	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
My diabetes has major consequences on my life	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
What I do can determine whether my diabetes gets better or worse	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
My diabetes is likely to be permanent rather than temporary	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
My diabetes does <u>not</u> have much effect on my life	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
My diabetes causes difficulties for those who are close to me	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
My diabetes is a serious condition	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
My diabetes will last for a long time	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
The course of my diabetes depends on me	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
My diabetes strongly affects the way others see me	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
My diabetes has serious financial consequences	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
This diabetes will pass quickly	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
There is a lot which I can do to control my symptoms	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>
I expect to have this diabetes for the rest of my life	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Nothing I do will affect my diabetes	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I have a clear picture or understanding of my condition	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>
My diabetes will improve in time	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
My actions will have no affect on the outcome of my diabetes	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
The negative effects of my diabetes can be prevented (avoided) by my treatment	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
There is very little that can be done to improve my diabetes	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
My diabetes makes me feel angry	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
My symptoms come and go in cycles	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Having this diabetes makes me feel anxious	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

5) Views about your diabetes (continued)

Please indicate how much you agree or disagree with the following statements about your diabetes by ticking one box.

	Strongly Disagree ▼	Disagree ▼	Neither agree nor disagree ▼	Agree ▼	Strongly Agree ▼
I don't understand my diabetes	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
There is nothing which can help my condition	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
The symptoms of my condition are puzzling to me	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I have the power to influence my diabetes	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
My diabetes doesn't make any sense to me	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
My treatment can control my diabetes	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
The symptoms of my diabetes change a great deal from day to day	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
When I think about my diabetes I get upset	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
My diabetes makes me feel afraid	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
My diabetes is very unpredictable	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I go through cycles in which my diabetes gets better and worse	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I get depressed when I think about my diabetes	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
My treatment will be effective in curing my diabetes	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
My diabetes does not worry me	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
My diabetes is a mystery to me	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>

6) Other symptoms

Listed below are a number of symptoms that you may or may not have experienced since your diabetes. Please indicate by ticking YES or NO, whether you have experienced any of these symptoms since your diabetes was diagnosed, and whether you believe that these symptoms are related to your diabetes.

	I have experienced this symptom since my diabetes			This symptom is related to my diabetes	
	▼			▼	
Pain	<input type="checkbox"/> Yes	<input type="checkbox"/> No	_____	<input type="checkbox"/> Yes	<input type="checkbox"/> No
Sore throat	<input type="checkbox"/> Yes	<input type="checkbox"/> No	_____	<input type="checkbox"/> Yes	<input type="checkbox"/> No
Nausea	<input type="checkbox"/> Yes	<input type="checkbox"/> No	_____	<input type="checkbox"/> Yes	<input type="checkbox"/> No
Breathlessness	<input type="checkbox"/> Yes	<input type="checkbox"/> No	_____	<input type="checkbox"/> Yes	<input type="checkbox"/> No
Weight loss	<input type="checkbox"/> Yes	<input checked="" type="checkbox"/> No	_____	<input type="checkbox"/> Yes	<input type="checkbox"/> No
Fatigue	<input type="checkbox"/> Yes	<input type="checkbox"/> No	_____	<input type="checkbox"/> Yes	<input type="checkbox"/> No
Stiff joints	<input type="checkbox"/> Yes	<input type="checkbox"/> No	_____	<input type="checkbox"/> Yes	<input type="checkbox"/> No
Sore eyes	<input checked="" type="checkbox"/> Yes	<input type="checkbox"/> No	_____	<input type="checkbox"/> Yes	<input type="checkbox"/> No
Wheeziness	<input type="checkbox"/> Yes	<input type="checkbox"/> No	_____	<input type="checkbox"/> Yes	<input type="checkbox"/> No
Headaches	<input checked="" type="checkbox"/> Yes	<input type="checkbox"/> No	_____	<input type="checkbox"/> Yes	<input type="checkbox"/> No
Upset stomach	<input checked="" type="checkbox"/> Yes	<input type="checkbox"/> No	_____	<input type="checkbox"/> Yes	<input type="checkbox"/> No
Sleep difficulties	<input type="checkbox"/> Yes	<input type="checkbox"/> No	_____	<input type="checkbox"/> Yes	<input type="checkbox"/> No
Dizziness	<input type="checkbox"/> Yes	<input type="checkbox"/> No	_____	<input type="checkbox"/> Yes	<input type="checkbox"/> No
Loss of strength	<input type="checkbox"/> Yes	<input type="checkbox"/> No	_____	<input type="checkbox"/> Yes	<input type="checkbox"/> No
Weight gain	<input checked="" type="checkbox"/> Yes	<input type="checkbox"/> No	_____	<input type="checkbox"/> Yes	<input type="checkbox"/> No
Mood Swings.....	<input type="checkbox"/> Yes	<input type="checkbox"/> No	_____	<input type="checkbox"/> Yes	<input type="checkbox"/> No

7) *Diabetes and your family*

The next set of questions asks about family. By family we mean anyone who you consider to be part of your immediate or extended family (this can include your spouse, partner, son/daughter, son/daughter-in-law, niece, nephew or grandchild). If you do not have any contact with your family, please move on to question 8, otherwise answer the questions below.

- a. Please think about your family and answer the questions below. It is important to note there are no right or wrong answers to these questions.

	Yes, always ▼	Yes, often ▼	Sometimes ▼	No, not usually ▼	No, never ▼
I feel my family <u>understand</u> why <u>diet</u> is important to people with diabetes	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
My family <u>nag me</u> about taking my diabetes medications	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
My family <u>complain</u> about eating the kinds of foods that are good for people with diabetes	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
My family <u>encourage</u> me to get exercise and keep active	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
My family <u>argue</u> with me about how I choose to take care of my diabetes	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
My family <u>encourage</u> me to eat foods that are healthy for my diabetes	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I feel my family <u>understand</u> why <u>exercise</u> is important to people with diabetes	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
My family <u>hassle me</u> about getting more exercise	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I feel my family <u>understand</u> why my diabetes <u>medicines</u> are important	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
My family seem <u>embarrassed</u> about my diabetes	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
My family <u>support me emotionally</u> if I feel frustrated or down about my diabetes	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

8) Your experience with diabetes health services

The next questions ask about your experiences with diabetes health services. There are no right or wrong answers, we are just interested in your own experiences. All answers remain **strictly confidential**. This means your answers will only be seen by the researcher (Charlotte Paddison), and will **not** be seen by your doctor, nurse or any other health professionals.

a. Please think about the health services you have received for your diabetes and answer the questions below.

	Yes, definitely ▼	Yes, sort of ▼	No, not really ▼	No, not at all ▼
The diabetes health services I have used are located in a <u>place</u> that is <u>easy</u> for me to get to	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>
When I needed to see a diabetes <u>specialist</u> (for example dietician, podiatrist, ophthalmologist) it was easy to get an appointment	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Sometimes important information can <u>get lost between</u> doctors/nurses at the <u>hospital</u> and doctors/nurses in the <u>community</u> . This happened to me	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Sometimes one doctor or nurse will say one thing, and another will say something <u>quite different</u> . This happened to me	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I am <u>able to pay</u> for my diabetes care without a problem (e.g. doctor visits)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>
I am <u>able to pay</u> for my diabetes <u>medication</u> without a problem	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
When I was sick and had an important diabetes question I found it <u>difficult</u> to contact a doctor or nurse that I could talk to	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
It is <u>hard</u> to find a diabetes doctor or nurse who understands my personal or cultural background	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>
When I go back to the same diabetes service more than once I get to see the <u>same doctor/nurse</u> each time	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Sometimes <u>communication gaps</u> between different <u>health services</u> mean my diabetes care is not properly co-ordinated	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I found it <u>difficult</u> to see a doctor/nurse about my diabetes because of cost	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I <u>worry</u> about having to pay for my diabetes care (for example health visits or medication)	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>
Sometimes I <u>go without</u> the diabetes care I need (doctors visits or medication) because it is too expensive	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
It is <u>easy</u> to find diabetes health services that fit with <u>my personal</u> or <u>cultural values</u>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>

Your experience with diabetes health services (continued)

Please think about the health services you have received for your diabetes and answer the questions below.

	Yes, definitely ▼	Yes, sort of ▼	No, not really ▼	No, not at all ▼
The doctors/nurses <u>gave me clear information on how to access</u> other diabetes services (e.g. dietician, podiatrist, or community diabetes groups)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>
It was <u>difficult</u> to see a specialist about my diabetes (e.g. dietician, podiatrist, ophthalmologist) because of long waiting times	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
It is <u>hard</u> to find a diabetes doctor or nurse who speaks the same language as me	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>
The different doctors and nurses <u>work as a team</u> to make sure my diabetes care is properly co-ordinated	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
The different diabetes health professionals involved in my care <u>share information</u> and <u>keep up to date with changes</u> in my diabetes	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
When I had an <u>urgent question</u> with my diabetes, I was able to find a doctor or nurse that I could talk to <u>quickly and easily</u>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

b. Who is your preferred main provider of care for your diabetes? Please tick one box only.

(By preferred main provider we mean the health professional **you would choose** as the person who provided the main part of your diabetes care, and co-ordinated access to other services, if you were given a choice in the future).

<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
Doctor in community (G.P.)	Doctor's Practice Nurse	Diabetes Specialist (Doctor at hospital)	Diabetes Nurse Specialist	Diabetes Educator	Māori or Pacific Health Worker (Doctor, Nurse or Educator)
<input type="checkbox"/> Other (please specify) _____					

9) Your experience with your main diabetes care provider

The next set of questions ask about your experience with the one health professional you see most often about your diabetes. There are no right or wrong answers to these questions. All responses remain **strictly confidential**. This means your answers will only be seen by the researcher (Charlotte Paddison), and will **not** be seen by your doctor, nurse or any other health professionals.

a. Think of the **one health professional** that you **see most often** about your diabetes? This person can be a doctor, nurse, educator or any other diabetes health professional. Please **choose one person** only. Which health professional group does this person belong to?

<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Doctor in community (G.P.)	Doctor's Practice Nurse	Diabetes Specialist (Doctor at hospital)	Diabetes Nurse Specialist	Diabetes Educator	Māori or Pacific Health Worker (Doctor, Nurse or Educator)	I am not sure

b. Please think about the **person you choose** above in **question 9) a.** and answer the questions below while thinking about this person. All responses are strictly confidential.

	Yes, definitely ▼	Yes, sort of ▼	No, not really ▼	No, not at all ▼
When talking with this person I feel -				
He/she <u>involves me in decisions</u> about my diabetes care, we make the choices together	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
He/she has explained how I should <u>take care of my feet</u> in a way I <u>can understand</u>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
He/she has explained how <u>what I eat</u> can affect my diabetes in a way I <u>can understand</u>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>
He/she has <u>shown me clearly</u> how to use a blood glucose metre and read my results	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Sometimes he/she <u>ignores</u> what I have to say	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>
At times he/she talks in front of me <u>as if I wasn't there</u>	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
He/she asks about my family, social and financial <u>commitments</u> when making suggestions about how I should take care of my diabetes	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
He/she offers information about diabetes for me to <u>give to family/close friends</u>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
This person is <u>helpful and friendly</u> to me	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
He/she seems to <u>care about me</u> as a person, not just my diabetes	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>
I could <u>trust</u> this person with personal information about me or my family	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>

Your experience with your main diabetes care provider (continued)

Please think about the **person you choose in question 9) a.**, and answer the questions below. All responses are strictly confidential.

	Yes, definitely ▼	Yes, sort of ▼	No, not really ▼	No, not at all ▼
When talking with this person I feel -				
I have been <u>involved in decisions</u> about my diabetes care as much as I have wanted to	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
He/she helps me feel encouraged and <u>motivated</u> to <u>take action</u> to care for my own diabetes	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
He/she shows <u>respect for my choices</u> about how much I want my family to know or be involved in my diabetes care	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
He/she uses too many <u>long medical words</u> and <u>technical terms</u> when explaining what diabetes is	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
It is <u>hard</u> to get clear information on what things people with diabetes should eat	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>
He/she gives advice about how to <u>prevent</u> my diabetes from becoming worse	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
He/she gives advice on how to control my diabetes and <u>stay healthy</u> in the future	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>
He/she shows <u>respect for my own personal</u> or <u>cultural</u> beliefs and values	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>
He/she <u>asks if</u> I have any questions or <u>worries</u> about the <u>financial cost</u> of diabetes (e.g. medicines or visits to specialists)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
He/she <u>asks if</u> I have any questions or <u>worries</u> about the effect diabetes might have on <u>my body</u> (e.g. eyes or feet)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
He/she <u>asks if</u> I have any questions or <u>worries</u> about the effect of diabetes on my <u>family life</u> or relationships	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
When planning diet or exercise changes, he/she sets goals that are <u>realistic for me</u>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Sometimes I feel he/she <u>ignores</u> the effect diabetes can have on your moods and feelings	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>
Sometimes I feel he/she <u>ignores</u> the effect diabetes can have on your family life and relationships	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
When I have important questions about diabetes, it is <u>hard</u> to get answers that <u>I can understand</u>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Sometimes my family are <u>left out</u> of important diabetes decisions when I would want them to be involved	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Sometimes I feel I am <u>left out</u> of important decisions about my diabetes care	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Language barriers make it <u>difficult</u> for this person and I to understand each other	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
When planning diet or exercise changes he/she set goals that are just <u>too hard</u> for me	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Your experience with your main diabetes care provider (continued)

Please think about the **person you choose in question 9) a.**, and answer the questions below. All responses are strictly confidential.

	Yes, definitely ▼	Yes, sort of ▼	No, not really ▼	No, not at all ▼
When talking with this person I feel -				
He/she shows <u>respect for my own choices</u> about how I manage my diabetes	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>
He/she has told me about the <u>free 'diabetes check'</u> I can have each year	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>
He/she has told me <u>how often</u> I should get my <u>eyes checked</u>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
He/she has <u>explained clearly what to do</u> about my diabetes medications if I get sick and can't eat	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
At times he/she is <u>too busy</u> to listen properly to what I have to say	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>
At times he/she <u>ignores my opinions</u> about what works best to manage my own diabetes	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
When I have tests for my diabetes, he/she explains the results in a way that is <u>easy to understand</u>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
He/she gives me <u>enough time</u> to say everything I want to, and ask all my questions	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Overall, are you <u>satisfied</u> with the diabetes care this person provides?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>
Would you <u>come back</u> to see this health professional about your diabetes in the future?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>
Would you <u>recommend</u> this person to a friend who had your type of diabetes?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Think about the **person you choose in question 9) a.**, then answer the questions below.

c. How **many times** have you seen this person for something to do with your diabetes in the **last 12 months?** (please tick)

- Never
 1-2 times
 3-4 times
 More than 5 times

d. How **long** have you been seeing this health professional about your diabetes? (please tick)

- Less than 1 year
 1-2 years
 3-4 years
 More than 5 years

10) Your contact with Health Professionals

Think about the care you have had from different health professionals in the last 12 months for your diabetes. How satisfied are you with the care or service you received from the following people? (Please tick)

	Extremely Satisfied +2 ▼	Mostly Satisfied +1 ▼	Not very Satisfied -1 ▼	Not at all Satisfied -2 ▼	OR I have had no contact with this person/group in the last 12 months ▼
Doctor in community (G.P.)	<input type="checkbox"/>				
Diabetes Specialist (Doctor at hospital)	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Diabetes Nurse Specialist or Educator	<input type="checkbox"/>				
Doctor's practice nurse	<input type="checkbox"/>				
District or public health nurse	<input type="checkbox"/>				
Māori DSM Nurse	<input type="checkbox"/>				
Community-based Diabetes Centre	<input type="checkbox"/>				
Pharmacist or Chemist	<input type="checkbox"/>				
Foot Specialist (Podiatrist or Chiropodist)	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>
Eye Specialist (Ophthalmologist, Optician or Optometrist)	<input type="checkbox"/>				
Dietician or Nutritionist	<input type="checkbox"/>				
Social worker, psychologist or counsellor	<input type="checkbox"/>				
Naturopath, homeopath, iridologist or acupuncturist	<input type="checkbox"/>				
Traditional healer (e.g. tohunga or fofo)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>
Iwi based health care provider or Pacific community health centre	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>
Māori or Pacific community health worker	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>

11) **Your satisfaction with diabetes health services**

Think about the diabetes health services you have used in the last 12 months. Please tell us how satisfied you are with the care or service you received. Tick one box for each line.

	Extremely Satisfied +2 ▼	Mostly Satisfied +1 ▼	Not very Satisfied -1 ▼	Not at all Satisfied -2 ▼
How <u>easy it is</u> to get to see a diabetes doctor or nurse in the community	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
How <u>easy it is</u> to get an appointment with a diabetes specialist (for example dietician, podiatrist, ophthalmologist)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
The <u>cost</u> of visits to diabetes health services	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
The <u>continuity</u> of your care (for example, being able to see the <u>same</u> doctor or nurse each time you visit)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
How <u>easy</u> it is to find diabetes health services that <u>fit with</u> your personal or cultural values	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
The <u>co-ordination</u> of your diabetes care (for example, the way different doctors/nurses/organisations <u>work together</u>)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
The <u>cost</u> of diabetes medications	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
How <u>easy</u> it is to find diabetes health professionals who <u>understand</u> your personal or cultural background	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
The <u>respect</u> health professionals show for your own choices about your diabetes care	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
The <u>information</u> health professionals give about how to take care of your diabetes	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
The <u>information</u> health professionals give about how to stay well in the future	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
How <u>clearly</u> health professionals explain things to you	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
How much advice and encouragement health professionals give for <u>self-care</u> (to help you take care of your own diabetes)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
The <u>respect</u> health professionals show for your <u>personal or cultural</u> beliefs	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
How much you have <u>been involved</u> in decisions about your diabetes care	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
The way diabetes health professionals <u>treat you</u> (e.g. making you feel welcome, valued and respected)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
The <u>support</u> health professionals give for dealing with the effect diabetes can have on emotions and feelings	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
The way health professionals involved in your diabetes care treat your <u>family/close friends</u>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Overall, how satisfied are you with the diabetes health services you have received?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

12) *Your experience with diabetes health services*

Please make any comments you feel are important to you in answering the following questions. Remember that all responses remain strictly confidential.

What is the one thing you have found best about your diabetes care so far?

What is the one thing you have found worst about your diabetes care so far?

Are there any changes you would like to see made to existing health services to better support people with diabetes?

13) Your Diabetes Self-Care

Self-care is a major part of living with diabetes. We would like to ask you some questions about your diet, exercise, glucose testing, and medication. It is very important to us to know what you really think. Your answers are completely confidential.

a) Eating patterns:

These questions ask you about your **eating patterns** over the **last week**. If you were sick during the past 7 days, please think back to the last 7 days that you were not sick. Please tick one box for each question.

How many of the last SEVEN DAYS have you followed a healthful eating plan?

0 days
 1 day
 2 days
 3 days
 4 days
 5 days
 6 days
 7 days

On average, over the past month, how many DAYS PER WEEK did you follow the diet or eating plan recommended by your doctor/nurse/dietician?

0 days
 1 day
 2 days
 3 days
 4 days
 5 days
 6 days
 7 days

On how many of the last SEVEN DAYS did you eat five or more servings of fruit and vegetables each day? (note that one serving is about the size of the palm of your hand).

0 days
 1 day
 2 days
 3 days
 4 days
 5 days
 6 days
 7 days

On how many of the last SEVEN DAYS did your meals for that day include high fat foods like chocolate, icecream, cakes, cream, lard, fat on meat, skin on chicken, fried foods including fried takeaways?

0 days
 1 day
 2 days
 3 days
 4 days
 5 days
 6 days
 7 days

b) Exercise:

These questions ask you about your **exercise patterns** over the **last week**.

On how many of the last SEVEN DAYS did you do at least 30 minutes of physical activity? (Total minutes of accumulative activity - including walking, gardening, climbing stairs, housework etc). Please tick one box.

0 days
 1 day
 2 days
 3 days
 4 days
 5 days
 6 days
 7 days

On how many of the last SEVEN DAYS did you take part in a specific exercise session (such as swimming, walking, biking, gym session, bowls, golf) other than what you do around the house or as part of your work? Please tick one box.

0 days
 1 day
 2 days
 3 days
 4 days
 5 days
 6 days
 7 days

c) Blood sugar testing:

These questions ask you about your **blood sugar testing** over the **last week**. If you do not test your blood sugar level go to question d), otherwise please answer the questions below.

On how many of the last SEVEN DAYS did you test your blood sugar? Please tick one box.

0 days
 1 day
 2 days
 3 days
 4 days
 5 days
 6 days
 7 days

On how many of the last SEVEN DAYS did you test your blood sugar the number of times (or more) recommended by your doctor/nurse? Please tick one box.

0 days
 1 day
 2 days
 3 days
 4 days
 5 days
 6 days
 7 days

d) Foot Care:

On how many of the last SEVEN DAYS did you check your feet? Please tick one box.

0 days
 1 day
 2 days
 3 days
 4 days
 5 days
 6 days
 7 days

On how many of the last SEVEN DAYS did you inspect the inside of your shoes? Please tick one box.

0 days
 1 day
 2 days
 3 days
 4 days
 5 days
 6 days
 7 days

e) Smoking:

Have you smoked a cigarette – even one puff – during the past SEVEN DAYS?

No Yes

If yes, how many cigarettes do you smoke on an average day? : _____ number of cigarettes

14) We would like to ask you about your personal views about the diabetes medications and treatments prescribed for you.

a. What treatment(s) do you now have for your diabetes? Please tick the boxes that apply to you. You may tick more than one box.

- | | |
|--|--|
| <input type="checkbox"/> No treatment | <input type="checkbox"/> Tablets or capsules |
| <input type="checkbox"/> Diet | <input type="checkbox"/> Insulin injections |
| <input type="checkbox"/> Exercise | <input type="checkbox"/> Insulin pump |
| <input type="checkbox"/> Other - please specify: _____ | |

If you do **not** use any medications (tablets and/or insulin injections) for your diabetes, please move onto question 15 now. Otherwise, please carry on with the questions below.

b. Many people find a way of using their medicines in a way that suits them. This may differ from the instructions on the label or from what their doctor has said. We would like to ask you a few questions about how you use your diabetes medicines (by 'diabetes medicines' we mean tablets and/or Insulin).

Please tick one box for each line. Remember your answers are completely confidential.

	Always ▼	Often ▼	Sometimes ▼	Rarely ▼	Never ▼
I use my diabetes medicines <u>only</u> when I need to	<input type="checkbox"/>				
I use my diabetes medicines regularly every day	<input type="checkbox"/>				
I avoid using my diabetes medicines if I can	<input type="checkbox"/>				
I forget to take my diabetes medicines	<input type="checkbox"/>				
I stop taking my diabetes medicines for a while	<input type="checkbox"/>				
I decide to miss out a dose	<input type="checkbox"/>				
I take more than instructed	<input type="checkbox"/>				
I take less than instructed	<input type="checkbox"/>				

c. Here are some statements that other people have made about medicines prescribed for their diabetes (by **diabetes medicines** we mean **tablets and/or insulin**). Please show how much you agree or disagree with them by ticking one box for each line.

	Strongly agree ▼	Agree ▼	Uncertain ▼	Disagree ▼	Strongly Disagree ▼
My health at present depends on my diabetes medicines	<input type="checkbox"/>				
Having to take my diabetes medicines worries me	<input type="checkbox"/>				
My life would be impossible without my diabetes medicine	<input type="checkbox"/>				
I sometimes worry about the long-term effects of my diabetes medicines	<input type="checkbox"/>				
Without my diabetes medicines I would be very ill	<input type="checkbox"/>				
My diabetes medicines are a mystery to me	<input type="checkbox"/>				
My health in the future will depend on my diabetes medicines	<input type="checkbox"/>				
My diabetes medicines disrupt my life	<input type="checkbox"/>				
I sometimes worry about becoming too dependent on my diabetes medicines	<input type="checkbox"/>				
My diabetes medicines protect me from becoming worse	<input type="checkbox"/>				
These diabetes medicines give me unpleasant side effects	<input type="checkbox"/>				

d. The following questions ask about your diabetes self-care and diabetes treatments. By **self-care** we mean the things you do to take care of your own diabetes (for example testing blood sugar levels, or exercising). By **diabetes treatments** we mean things your doctor has recommended like tablets and/or insulin. Please think about your experiences over the last 12 months and answer each question.

	Extremely Satisfied +2 ▼	Mostly Satisfied +1 ▼	Not very Satisfied -1 ▼	Not at all Satisfied -2 ▼
Overall, how satisfied are you with -				
How well your diabetes <u>self-care</u> is working to control your diabetes	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
The amount of <u>time</u> your diabetes <u>self-care</u> takes	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
The amount of <u>energy</u> your diabetes <u>self-care</u> takes	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
How well the diabetes <u>treatment</u> your doctor prescribes (tablets and/or insulin) is working to control your blood sugar levels	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
How <u>flexible</u> your diabetes treatment is	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
How <u>convenient</u> your diabetes treatment is	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
How well your diabetes treatment is working to <u>prevent</u> your diabetes becoming worse	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

15) Your General Health

The next set of questions asks you about your health in general and how this affects your daily activities. Please answer every question by marking one box. If you are unsure about how to answer, please give the best answer you can.

a. In general would you say your health is (please tick one box)

Excellent	Very good	Good	Fair	Poor
<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>

b. The following 2 items are about activities you might do in a typical day. Does your health now limit you in these activities? If so, how much?

	Yes, Limited <u>a lot</u>	Yes, Limited <u>a little</u>	No, <u>not</u> limited at all
	▼	▼	▼
<u>Moderate activities</u> (such as moving a table, pushing a vacuum cleaner, bowling or playing golf)	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>
<u>Vigorous activities</u> (such as climbing several flights of stairs)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

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

<u>Accomplished less</u> than you would like	<input type="checkbox"/>	Yes	<input checked="" type="checkbox"/>	No
Were limited in the <u>kind</u> of work or other activities	<input type="checkbox"/>	Yes	<input type="checkbox"/>	No

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

<u>Accomplished less</u> than you would like	<input type="checkbox"/>	Yes	<input type="checkbox"/>	No
Didn't do work or other activities as <u>carefully</u> as usual	<input type="checkbox"/>	Yes	<input type="checkbox"/>	No

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

f. During the past 4 weeks how much did pain interfere with your normal work (including both work

	All of the time	Most of the time	A good bit of the time	Some of the time	A little of the time	None of the time
	▼	▼	▼	▼	▼	▼
Have you felt calm and peaceful?	<input type="checkbox"/>	<input type="checkbox"/>				
Did you have a lot of energy?	<input type="checkbox"/>	<input type="checkbox"/>				
Have you felt downhearted and blue? outside the home and housework)?	<input checked="" type="checkbox"/>	<input type="checkbox"/>				

Not at all A little bit Moderately Quite a bit Extremely

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

All of the time Most of the time Some of the time A little of the time None of the time

16) *Health complications related to diabetes*

The following are a list of health complications sometimes experienced by people with diabetes.

a. Have any of the health problems below affected you in the **last 2 years?** (please tick)

Sores, ulcers or black areas on your feet	<input type="checkbox"/> Yes	<input type="checkbox"/> No
Loss of feeling, numbness or tingling in your feet or legs	<input checked="" type="checkbox"/> Yes	<input type="checkbox"/> No
Eye problems: e.g. cataracts, glaucoma, detached retina, retinopathy, blindness, or poor vision	<input type="checkbox"/> Yes	<input type="checkbox"/> No
Kidney problems: e.g. kidney or bladder infections, kidney failure, protein in your urine	<input type="checkbox"/> Yes	<input type="checkbox"/> No
Heart problems: e.g. heart attack, heart failure, angina, stroke	<input checked="" type="checkbox"/> Yes	<input checked="" type="checkbox"/> No

b. Have you ever had any of the following operations or procedures?

Cataract surgery or laser treatment on your eyes	<input checked="" type="checkbox"/> Yes	<input checked="" type="checkbox"/> No
Amputation of a toe, foot or part of leg for a poorly healing sore or poor circulation? (that is, not due to injury or accident)	<input type="checkbox"/> Yes	<input type="checkbox"/> No
Heart surgery: e.g. Coronary artery bypass surgery, coronary angioplasty ("balloon" heart procedure) or heart catheterisation	<input type="checkbox"/> Yes	<input type="checkbox"/> No
Renal CAPD Dialysis, Hemo CAPD Dialysis, or Renal transplantation	<input type="checkbox"/> Yes	<input type="checkbox"/> No

c. Have you ever been diagnosed with any of the following health problems?
Please tick as many boxes as apply to you.

Stroke Cancer Memory loss

High blood pressure Arthritis/Rheumatism Depression

Heart attack Breathing problems Fits/seizures

17) Your experience in living with diabetes

Past research studies in other places have found that many people with diabetes experience similar problems. Below is a list of common issues that people with diabetes may face. Please tick one box for each line to indicate how much each of these diabetes issues are currently a problem for you. Remember that all responses remain strictly confidential.

<i>How much of a problem is this for you?</i>	Not at all ▼	Minor ▼	Moderate ▼	Some what serious ▼	Serious ▼
Not having clear goals for your diabetes care	<input type="checkbox"/>				
Feeling discouraged with your diabetes treatment plan	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Feeling scared when you think about living with diabetes	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
Uncomfortable social situations related to your diabetes care (e.g. people telling you what to eat)	<input type="checkbox"/>				
Feelings of deprivation regarding food and meals	<input type="checkbox"/>				
Feeling depressed when you think about living with diabetes	<input type="checkbox"/>				
Not knowing if your mood or feelings are related to your diabetes	<input type="checkbox"/>				
Feeling overwhelmed by your diabetes	<input type="checkbox"/>				
Worrying about low blood sugar reactions	<input type="checkbox"/>				
Feeling angry when you think about living with diabetes	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
Feeling constantly concerned about food and eating	<input type="checkbox"/>				
Worrying about the future and possibility of serious complications	<input type="checkbox"/>				
Feelings of guilt or anxiety when you get off track with your diabetes management	<input type="checkbox"/>				
Not "accepting" your diabetes	<input type="checkbox"/>				
Feeling unsatisfied with your diabetes doctor/nurse	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>
Feeling that diabetes is taking up too much of your mental and physical energy every day	<input type="checkbox"/>				
Feeling alone with your diabetes	<input type="checkbox"/>				
Feeling that your friends and family are not supportive of your diabetes management efforts	<input type="checkbox"/>				
Coping with the complications of diabetes	<input type="checkbox"/>				
Feeling "burned out" by the constant effort needed to manage diabetes	<input type="checkbox"/>				

18) About yourself

Lastly, so that we can be sure we have a good cross section of people in the survey, would you please answer the following questions about yourself. Remember that all responses remain strictly confidential.

- a. What is your current age? ____ years
- b. What is your gender? Male Female
- c. Are you currently living with (please tick)
- Spouse/partner
- Extended family or relatives
- Friends
- I live alone
- d. Which ethnic group/s do you belong to? Tick the box or boxes that apply to you.
- | | |
|---|---|
| <input type="checkbox"/> New Zealand European | <input type="checkbox"/> Niuean |
| <input type="checkbox"/> Māori | <input checked="" type="checkbox"/> Indian |
| <input checked="" type="checkbox"/> Samoan | <input type="checkbox"/> Chinese |
| <input checked="" type="checkbox"/> Tongan | <input checked="" type="checkbox"/> Other (e.g. Dutch, Japanese, Tokelauan)
please specify:
_____ |
- e. What is your highest educational qualification?
- | | |
|---|--|
| <input checked="" type="checkbox"/> No school qualification | <input checked="" type="checkbox"/> Trade certificate, Professional diploma |
| <input type="checkbox"/> School certificate passes | <input checked="" type="checkbox"/> University degree, diploma, or certificate |
| <input checked="" type="checkbox"/> Higher school qualifications,
e.g. University entrance | <input checked="" type="checkbox"/> University post graduate qualification |
| <input checked="" type="checkbox"/> Other (please specify) _____ | |
- f. Do you have medical or health insurance? Yes No
- g. Do you have a community services card? Yes No

Date of return	

DIABETES STUDY CONSENT FORM

Participant's Declaration

I have read through the study information sheet, and this has explained the details of the research project to me. If I had any questions about this study I have been able to contact the researchers and had them answered to my satisfaction. I understand that taking part in this study is voluntary (my choice) and that I may withdraw from this project at any time and this will not affect my future health care in any way. I agree to provide information to the researchers on the understanding that my name will not be used in any publications. I also agree to allow the research team access, for the purposes of this project only, to the records related to my Diabetes held by the Wellington Regional Diabetes Trust. I agree to participate in this study under the conditions set out in the Information Sheet.

Date: _____ Signed: _____

Full name and title (please print):

Mr./Mrs./Ms/Miss _____

Address: _____

Would you like to receive a summary of the results of this research at the completion of the study? If yes, we will post you a summary of the research findings. Please tick one box.

Yes, I would like to receive a summary of the results of this research at the completion of the study.

No, I do not wish to receive a summary of the results of this study

**Thank you for your time in completing this questionnaire.
We really appreciate your help.**

Appendix E
FOLLOW UP LETTER



Study on personal experiences of Diabetes
Follow up letter of Invitation

24 May 2004

Greetings Mrs. X

About 2 weeks ago I sent you a copy of our research questionnaire, and asked if you would like to take part in our project. This questionnaire is part of an important study on people's experiences with diabetes. The Wellington Diabetes Trust has mailed this follow up letter to you on my behalf.

If you have **already returned** the questionnaire, I would like to thank you very much for your help. If you have not returned the questionnaire, I would like you to know that I am still keen to receive your reply.

What should I do if I need another copy of the questionnaire?

If you did not receive a questionnaire, or it is lost, please telephone us free on 0800 743 788 and I can send you another one in the mail today.

What if I do not want to be part of this project?

That is ok too. If you do not want to be part of this project you can send the questionnaire back uncompleted (not filled out) using the free-post envelope we sent you - no stamp needed. We will then take your name off the mailing list, and will not send any more information about this study to you.

Thank you for taking the time to think about this.

Charlotte Paddison
PhD Student
Massey University

Dr. Fiona Alpass
Senior Lecturer
Massey University